

DOCUMENT RESUME

ED 227 610

EC 151 051

**AUTHOR** Stein, Laszlo; Pien, Diana  
**TITLE** A Model Program for Hearing-Handicapped Infants Providing Medical, Academic, and Psychological Services (HI-MAPS). Final Report, July 1979-June 1982.

**INSTITUTION** Michael Reese Hospital and Medical Center, Chicago, Ill.

**SPONS AGENCY** Special Education Programs (ED/OSERS), Washington, DC. Handicapped Children's Early Education Program.

**PUB DATE** 30 Sep 82

**GRANT** G007900505

**NOTE** 228p.; The document was prepared through David T. Siegel Institute for Communicative Disorders.

**PUB TYPE** Reports - Descriptive (141) -- Reports - Evaluative/Feasibility (142) -- Tests/Evaluation Instruments (160)

**EDRS PRICE** MF01/PC10 Plus Postage.

**DESCRIPTORS** Academic Achievement; Counseling; \*Delivery Systems; \*Demonstration Programs; \*Hearing Impairments; Interdisciplinary Approach; \*Intervention; Medical Services; \*Parent Education; Preschool Education; Program Descriptions; Sign Language

ABSTRACT

The document contains the final report of the HI-MAPS project, designed to develop a model program that would meet the medical, academic, and psychological needs of young hearing handicapped children, birth to 3 years, and their families in Chicago. An introductory section reviews project rationale, project philosophy, and overall project goals. Section II describes the following HI-MAPS services: educational services, sign language/communication classes for families, parent counseling, and medical and audiological services/consultation. A third section outlines characteristics of the population served. Section IV discusses other services, such as the provision of educational lectures and written materials, referral, follow-up, and special activities. Among conclusions noted from child evaluation (Section V) is that children have made progress in developing effective communication systems including a formal linguistic system based on sign language. Section VI mentions demonstration and dissemination activities; Section VII outlines program development and administration. Conclusions are reviewed briefly in the final section. Appendixes include sample forms, information sheets, and evaluation instruments. (SW)

\*\*\*\*\*  
 \* Reproductions supplied by EDRS are the best that can be made \*  
 \* from the original document. \*  
 \*\*\*\*\*

FINAL REPORT: HI-MAPS PROJECT  
July 1979 - June 1982

GRANT NO. G007900505

PROJECT NO. 444 AH 90198

Title: A Model Program for Hearing-Handicapped  
Infants Providing Medical, Academic, and  
Psychological Services (HI-MAPS)

Submitted to: Handicapped Children's Early Education Program  
Special Education Programs  
U.S. Department of Education  
400 Maryland Avenue, S.W.  
Washington, D.C. 20202

Grantee: David T. Siegel Institute for Communicative  
Disorders  
Michael Reese Hospital and Medical Center  
3033 South Cottage Grove Avenue  
Chicago, ILL 60616

Co-Principal Investigator: Laszlo Stein, Ph.D., Director  
David T. Siegel Institute for Communicative  
Disorders  
Phone: 312/791-2910

Co-Principal Investigator: Diana Pien, Ph.D.  
David T. Siegel Institute for Communicative  
Disorders  
Phone: 312/791-2900

Date Submitted: September 30, 1982

U.S. DEPARTMENT OF EDUCATION  
NATIONAL INSTITUTE OF EDUCATION  
EDUCATIONAL RESOURCES INFORMATION  
CENTER (ERIC)

This document has been reproduced as  
received from the person or organization  
originating it.  
Minor changes have been made to improve  
reproduction quality.

• Points of view or opinions stated in this docu-  
ment do not necessarily represent official NIE  
policy.

150151651

ED227610

## TABLE OF CONTENTS

I. INTRODUCTION	
A. Project Rationale	1
B. Project Philosophy	3
C. Overall Project Goals	8
II. BASIC DESCRIPTION OF THE COMPREHENSIVE SERVICES	9
A. Referral and Criteria for Program Entry	11
B. Intake	12
C. Parent Orientation	13
D. Education Sessions	18
E. Sign Language/Communication Skills Classes	39
F. Parent Counseling Groups	52
G. Audiological Services	56
H. Medical Services	62
I. Interrelationship Among Staff	65
III. CHARACTERISTICS OF THE POPULATION SERVED	68
A. Referral Sources	68
B. Demographic Characteristics of the Population	69
C. Special Problems of an Urban Population	76
D. Adaptation of HI-MAPS to Special Needs	82
E. Number of Children Served and Program Participation	86
F. Increasing Commitment of Parents to the Program	89
IV. OTHER SERVICES	92
A. Factual Information: Educational Lectures and Written Materials	92
B. School Referral	96
C. Follow-Up Services	98
D. Special Activities for Children and Families	101
E. Referral of Children to Other Agencies	102
V. EVALUATION OF CHILD PROGRESS	103
A. HI-MAPS Sample	104
B. Procedure	106
C. Results and Discussion	111
D. Conclusions	122
VI. DEMONSTRATION AND DISSEMINATION ACTIVITIES	123
A. Increasing General Awareness	123
B. Information to Professionals in the Area of Deafness and/or Early Childhood Education	125
C. Information to Medical Professionals	127

VII. PROGRAM DEVELOPMENT AND ADMINISTRATION	128
A. Staff Development	128
B. Budget/Fiscal Management	141
C. Inter-Agency Cooperation	142
D. HI-MAPS Advisory Council	144
E. Program Networks	145

VIII. CONCLUSIONS	147
-------------------	-----

APPENDICES

1. Data Base Form
2. Demographic Form
3. Questions Parents Ask
4. Brochure Given to Parents
5. Fact Sheets on Audiological and Medical Tests
6. Child Development Bibliography
7. Babysitting Pamphlet
8. Report on Workshop for Parents
9. In-service Sessions Provided by HI-MAPS Staff
10. Presentations at Conferences
11. Conferences Attended
12. In-service Training for HI-MAPS Staff
13. Student Training Program

THE HI-MAPS PROJECT

A MODEL PROGRAM FOR HEARING-HANDICAPPED  
INFANTS PROVIDING MEDICAL, ACADEMIC, AND  
PSYCHOLOGICAL SERVICES

"Hearing is the basic sensory avenue for the learning of a child's first language and all related communication systems and ... the invisible handicap of hearing impairment can cause serious damage of these learning processes in children. The severity and scope of this damage is little recognized or understood either by the public or many professionals."

- Hazel Bothwell

Council for Exceptional Children

1976 Monograph

## I. INTRODUCTION

### A. PROJECT RATIONALE

The aim of the HI-MAPS Project was to develop a model program that would meet the medical, academic and psychological needs of young hearing-handicapped children, birth to 3, and their families. Central to the HI-MAPS Project was the emphasis on the importance of a healthy, positive parent-infant relationship. The HI-MAPS Model was developed with a multi-focused approach aimed at benefitting the whole child.

Three key elements for successful intervention included:

- 1) Early medical identification and audiological intervention
- 2) Educational services based on total communication, child development principles and active parental participation.
- 3) Parent counseling using psychotherapeutic approaches aimed at strengthening the parent-infant relationship.

The HI-MAPS Project was sponsored by the David T. Siegel Institute for Communicative Disorders, Michael Reese Hospital and Medical Center, Chicago, Illinois. The Siegel Institute is a multidisciplinary diagnostic and treatment center for children and adults with communicative disorders. The provision of diagnostic, medical, educational, psychological, and psychiatric services to deaf adults and children has been one of the principle functions of Siegel Institute for nearly thirty years. Since its founding by Dr. Robert Henner shortly after World War II, Siegel Institute has maintained a team or multi-disciplinary approach to the problem of hearing impairment.

Siegel Institute started a parent-infant nursery program for hearing-handicapped children in the mid-1960's. In the late 1960's, Siegel participated with the Psychiatric and Psychosomatic Institute of Michael Reese.

in a research and development project on the psychiatric needs of deaf adults and children. As an outgrowth of this project, the Institute received a community service grant in 1973 from the Illinois Department of Mental Health and Developmental Disabilities designating the Siegel Institute as the state center for the psychiatric evaluation and treatment of deaf adults and children. In addition, the Institute has functioned as the state center for medical and psychoeducational evaluation of all suspected deaf-blind children in the State of Illinois.

In 1974 Siegel Institute began clinical studies with Brainstem Evoked Response (BSER) audiometry, a computerized electrophysiological test of hearing for infants and otherwise untestable young children. The Electrophysiological Laboratory of Siegel Institute was the first facility in the state of Illinois to offer BSER testing as a clinical procedure. Over the years the Institute has been active in using this technique for both clinical and research purposes. The technique, renamed the Auditory Brainstem Response (ABR) test, has been used to identify hearing impairment in high-risk infants from the Special Care Nursery at Michael Reese as well as in infants and young children referred by physicians, hospitals, parents, organizations and agencies. The value of the experience and research of the Electrophysiology Laboratory has been recognized throughout the country and by the many facilities in the Chicago area that refer children to the Siegel Institute for ABR testing and management of hearing impairment.

The history of Siegel Institute reveals a strong commitment to many disciplines working together to serve the hearing-handicapped person. It was in this spirit that the HI-MAPS Project was conceived and developed. To diagnose children at an early age, to provide services that would facilitate cognitive and emotional growth, and to provide a strong support system for parents to optimize the parent-child relationship were goals at the heart of the HI-MAPS Project.

## B. PROJECT PHILOSOPHY

Understanding the relationship of language deficits to social, emotional and cognitive growth was critical in developing a curriculum designed to meet the needs of the whole child. In the past, deaf educators had focused on use of promoting the auditory and speech skills of deaf children while often disregarding the functional use of language and the child's motor, cognitive, and social development. The intent of the HI-MAPS Project was to incorporate the child's strengths and weaknesses, deficits and skills into the ongoing activities and services. In addition, facilitating the parents' realistic understanding of their child's development was vital in each aspect of the delivery of services.

Using a child development perspective, the program worked with the parents around the problems characteristic of each developmental phase. One of the goals for HI-MAPS children and their parents was that they successfully negotiate and resolve early conflicts in development in order that the children could become fully functioning, independent adults. For the deaf infants the difficulties of each of the developmental phases were compounded by the auditory deficit that prevented the spontaneous growth of speech and oral language skills. The lack of language and reciprocal communication in the early years of a child's life has been cited as a critical factor resulting in later emotional disturbance in deaf adults and children (Grinker, 1969). In The Magic Years (1959), p. 118, Selma Fraiberg stated:

"...All those qualities that we call human derive from the possibility within every human being of acquiring control over the instinctual self and of modifying his character and his circumstances through an intelligence that has a large degree of independence from the primary human drives. We have excellent reasons to believe that these uniquely human achievements are not alone the product of a superior mental apparatus, but that the apparatus itself acquires the

possibility of controlling this vast and intricate organization of the human personality through language!"

Most of the children served by the HI-MAPS Project were diagnosed and participated in the program during the phase that Erikson called Autonomy versus Doubt and Shame. During this time, generally eighteen months to three years, the child makes attempts to become an independent being and have greater control over his/her environment. Language plays a critical role. It allows the child to control his impulses, to effectively communicate with others, and to manipulate and organize his/her world. The child begins to form symbols to represent absent objects or events. Language is one of the most powerful systems of symbolic representation, allowing two people to more easily share their symbolic representations of the world. Without a formal language system, the child may have more difficulty in what Mahler calls separation/individuation. The child may be unable to comfortably separate from mother or other familiar people. Physically, the child is walking more steadily month by month, but from a psychological perspective, may still be unable to separate with ease. Many later social and emotional difficulties of the deaf child can be traced to inadequacies in the normal development of the child's autonomy (see Litoff and Feldman, 1981).

One of the primary goals of the Direct Services Component of the HI-MAPS Project was to facilitate the development of language and communication through parent-infant interaction. HI-MAPS staff focused on the parents as the primary caretakers of the children. For young deaf children and their parents, the attempts to negotiate conflicts around autonomy were most often limited to non-verbal, informal cues. This reciprocal inability to communicate effectively resulted in frustration and anger for many of the parents as well as the children. Work with parents focused on internal

feeling states as well as on external realities. The parents' feelings of self-esteem and worth were shaken as they attempted to come to grips with the loss of their hoped-for normal child. Educational sessions were individualized to take into account the parent-child interaction as it was being influenced by the parent's internal issues.

In the HI-MAPS Project, play provided the vehicle through which spontaneous language, social relationships, curiosity, and exploration developed. Through play, the children learned about people, things, space, and time. Formal language was attached to activities of interest to each child. As the child manipulated objects, he/she began to form object concepts such as a cookie, dog, car as well as action concepts such as open, pop, and up. The teacher attached signs and words to label these concepts. The child began to generalize his/her understanding of the language to a variety of settings. For example, the child learned about "up and down" as he/she toddled up and down the stairs or when mother lifted him into the air. The teacher utilized many situations to promote generalization of labels. All types of trucks were labeled—a puzzle piece shaped like trucks, a picture of trucks, toy trucks that the child pushed, large toy trucks that the child could ride on. The child's play provided the forum for diverse language experiences.

The most appropriate method of teaching deaf children has been a matter of controversy for decades. The controversy has centered around the issue of whether sign language should be used as opposed to an oral-only approach. The approach used by HI-MAPS was a Total Communication approach. The basic premise of this approach was to use every and all means available to communicate. Total Communication incorporated the use of hearing aid(s), speech, lipreading, the language of signs, gestures, facial expression,

fingerspelling, and body language. Total Communication provided a spontaneous means of communication between the deaf child and his/her family, teacher and peers. Since the language of signs is easier to learn than an oral language for both hearing and hearing-handicapped infants, the primary mode of formal communication for the hearing-handicapped infant/toddler tended to be the language of signs combined with vocalizations. The child's development of formal intelligible speech was usually facilitated by the child's ability to manually express a formal word or thought.

The use of a Total Communication approach with young hearing-handicapped children was consonant with a child development focus. When manual symbols (i.e. signs) were associated to the children's feeling, and needs, in their natural play environment, children were able to become effective communicative partners with their parents. Parents felt excited that their children could express themselves, that they did have ideas and thoughts, that they were not "deaf and dumb." Parents realized that their children were able to communicate through signs, gestures, vocalizations, and facial expression. As two-way communication progressed, parents began to understand the child's development from a more realistic standpoint. With language parents and children began to progress more comfortably through the normal developmental phases of early childhood.

HI-MAPS staff viewed the interactions between parents and children from a psycho-social perspective. As staff members came to better understand parents' cultural and familial styles and patterns of child-rearing, it was frequently easier to acknowledge the origin of their fears, their anger, their hopes, and their dreams. For example, one family feared that their infant daughter would be unable to read because of her handicap. In talking with the family, it was learned that the parents both had dropped out of

school and had limited reading ability. Many years later, they deeply regretted their decision. Their daughter was their hope for the future. The parents' hope for their child was supported by HI-MAPS staff. Educational and communication sessions focused on the young child's developing ability to express herself through gestures and vocalizations as a basis of language growth. Counseling sessions gave the parents the opportunity to reflect on their own needs in relation to their daughter. The valued child was reintroduced to the parents.

In order to assess and serve the varying needs of the child and family, HI-MAPS staff members functioned as a multidisciplinary team. Staff from the fields of deafness, communication disorders, child development, speech and language, social work, psychology and audiology met regularly to plan and implement child and family services. In addition assessment included medical tests and information from medical records. This multi-focused view of families provided an integrated approach to serving the whole child and was consistent with the child development perspective of the project.

C. OVERALL PROJECT GOALS

The overall goal of the HI-MAPS Project was to develop a model program that would demonstrate effective techniques for diagnosing and serving hearing-handicapped infants and their families. This goal was to be achieved through the development of a program of direct services, through the demonstration of this program to a variety of audiences (physicians, parents, schools, etc.), and through the dissemination of materials and information that would give others the opportunity to examine the effectiveness of such a program.

The following report describes the HI-MAPS Project as services were developed over the three-year funding cycle. With the history of Siegel Institute as solidly committed to the needs of young hearing-handicapped children and their families, with strong support from the United States Department of Education, with a dedicated staff of individuals working on the HI-MAPS Project, and with the courageous input of HI-MAPS parents, an effective model demonstration program was developed to serve young hearing-handicapped children in the years to come. The generous support of the Foundation for Hearing and Speech Rehabilitation has ensured that the HI-MAPS Project will continue for the fiscal year 1982-1983.



## II. BASIC DESCRIPTION OF THE COMPREHENSIVE SERVICES

This section gives a basic description of the HI-MAPS services as originally planned in the areas of 1) educational services; 2) sign language/ communication classes for families; 3) parent counseling; and 4) medical and audiological services/consultation. All of these services were made available to children with severe and profound hearing losses and their families; however, not all families were able to participate fully in the program. Factors which hindered regular attendance and participation are discussed in this section and in section III. Modifications of the program to serve hard-of-hearing children and their families and to fit the needs of families with special problems are described in section III part D.

As originally planned, if the deaf child and family met the criteria for program entry, the child and parent both participated in weekly individual sessions with one teacher, and simultaneously the parent received orientation counseling from the parent counselor. After approximately four to six weeks of regular participation in these sessions, the parent and child were then asked to join a weekly nursery group attended by several children and their families. Optimally child and parent attended the center twice a week-- once for an individual session and once a week for the group. During part of the nursery group time period, the parents left the nursery room to attend a sign language/communication skills class and also a parent counseling group.

Two full-time teachers were responsible for implementing the educational sessions for the deaf children. The head teacher also served as the

A. REFERRAL AND CRITERIA FOR PROGRAM ENTRY

There were two procedures for referral to the HI-MAPS Project. The majority of referrals were made by the Audiology Department of the Siegel Institute after testing here. The second source of referrals was from outside audiologists. In these cases, the Siegel chief audiologist reviewed the test results. The criteria for acceptance into the program were:

- 1) Hearing handicap of at least severe to profound degree (see description of Hard-of-hearing Program for criteria for children with less severe losses, Section III Part D).
- 2) Child's age less than 36 months.
- 3) Ability of the parent, relative or babysitter to bring the child between 9 a.m. and 4 p.m. weekdays.
- 4) Ability of the program to meet the child's needs.

The chief audiologist presented information regarding newly diagnosed or referred children at the weekly HI-MAPS staff meeting. Parents were then contacted to arrange an intake appointment.

## B. INTAKE

The head teacher and parent counselor met with the parents for the Intake Session. The head teacher used this session to obtain diagnostic information for program planning. This was done by observing and interacting with the child and by observing the child and family interacting together. She noted the types of materials and activities that were of interest to the child as well as the child's fine and gross motor skills. The child's reactions to a new environment and to unfamiliar people were also observed. The family's methods of communicating with each other and playing together and the parents' understanding of the nature of their child's handicap were of special interest.

The primary objective of the parent counselor in the intake session was to give the parents an opportunity to discuss their feelings about the diagnosis. Many parents were exhausted by their long search for help. Their anger at the medical system and grief about the diagnosis needed to be expressed so that they could move forward to make plans for their child's participation in the program.\* Asking them questions about the pregnancy, the birth, the child's medical history and their efforts to obtain services provided a structure that helped them focus their thoughts and express their feelings.

At the same time most parents also had many questions about deafness and their child's prognosis for speech. Some parents needed detailed information about the philosophy and format of the HI-MAPS program in order to make a decision about participation. Another topic discussed in the intake session was funding for obtaining a hearing aid. It was necessary to prepare parents for a complex, lengthy process of obtaining financial assistance from the Division of Services for Crippled Children.

### C. PARENT ORIENTATION

At the end of the intake session, appointments were made for weekly individual educational sessions with a teacher and weekly orientation sessions with the parent counselor. It worked best when the parents could attend the orientation sessions without the child. If this was not possible, the parent counselor met with the parents during the hour immediately following the educational session.

One of the major goals of the parent orientation was to gather information that would enable the staff to relate to the uniqueness of each individual family and child. Two forms were developed in order to systematically collect this information: The Data Base Form and The Family History Outline.

The Data Base Form (See Appendix) recorded demographic information, the medical history and a developmental profile. The medical history was the foundation for the search for the cause of deafness. This was of great importance to the parents as they struggled with the issue of blame. It was also important if another pregnancy was being considered and if there were other conditions which could complicate the handicap of deafness.

As they answered the questions in the Data Base Form, parents continued to describe their frustrations as in the intake session. As they talked about delays in obtaining referrals for testing and finding information about services, the parent counselor supported their efforts to become effective advocates for their child. Apathy, delays, denial or over-compliance and a tendency to idealize helping persons were also sometimes evident. Other questions in the Data Base Form covered changes in the

relationship with the child since the diagnosis and the parents' hopes for the program.

The second form used during the parent orientation was the Family History Outline (see Table 1). Its purpose was to gather information about the family's values, educational experiences and ethnic and cultural background. This outline was designed specifically for the HI-MAPS program with the aim of assessing family patterns and issues in the context of the sociology of deafness. It was helpful to try to understand experiences of migration, emigration or changes in socio-economic status, since many parents related their own experiences of not belonging to the child's future entry into the deaf community and separation from them. On the other hand, a stable sense of cultural identity could be supportive for the parents. In that case, the parents often wondered if the deaf child would be acceptable to their group.

As the parents discussed their own educational experiences, they were able to articulate their aspirations for the child. Some parents had hoped that the child would achieve more than they had. Their child's deafness raised the question of future dependency for them. A few parents were adult students or were still in high school. The increased demands for educating a deaf child from infancy posed a threat to their own educational goals.

Another important topic in the Family History was family structure. It was essential to understand the roles of all persons who carried out parenting functions, whether or not they lived with or were related to the child. The parenting functions which were important for the HI-MAPS program were attachment, management, and play. Often babysitters, friends, siblings and grandmothers as well as biological parents carried out these functions. If so, the program attempted to involve them.

The topic of support from relatives was an important theme in the parent orientation. Many young parents were ashamed about needing extra help from relatives and saddened by their lack of acceptance of the child's deafness.

At the end of the four to six week orientation, the staff evaluated the readiness of the child for a group experience. The parents usually wished to begin interacting with other parents about this time. (See section II Part F for a discussion of the Parent Counseling Groups).

TABLE 1

Family History Outline

- I. Ethnic and Cultural Background Before the Birth of the Child's Mother and father
  - A. Reasons for migration and emigration
  - B. Conflicts between various branches of the families or between the families of the mother and father
  - C. Changes from generation to generation in educational level, socio-economic status and religious affiliation.
  
- II. The Deaf Child's Parents - from the time of their births until the present household was established or until the birth of this child
  - A. Personalities of the grandparents and parents
  - B. Deaths, separations, divorces, foster placement, adoption
  - C. Socio-economic status and changes over time
  - D. Educational experiences and expectations and values about education
  - E. Experiences with illness or handicaps in the extended family
  - F. Methods of discipline
  - G. Reactions to developmental stages and major life events
  - H. Siblings: differences, similarities
  - I. Differences between attitudes towards and treatment of boys and girls.
  
- III. The Present Situation
  - A. The Child: Primary Parent
  - B. Is Primary Parenting Shared?

TABLE 1 (continued)

- C. The Secondary Parent
- D. Supportive others (family, friends, organizations)
- E. Relationship between the primary parent(s) and secondary parent (i.e. marital status, stability of relationship, conflict, relationship of secondary parent to the child, place of residence of the secondary parent, composition of the household in which the child lives.)
- F. Siblings
- G. Current family problems
- H. Current socio-economic status

#### D. EDUCATIONAL SERVICES

The concept of a sensitive period for learning language during the earliest years has been well established. Since hearing is the most important sensory avenue for language learning and for the development of a communication system, it follows that a hearing deficit seriously hinders such learning. The failure to develop language skills has been found to be a frequent cause of both emotional and educational problems later in life. Thus, programs which provide early intervention for hearing-handicapped infants have the intrinsic goal of supporting emotional and cognitive growth through the development of an effective system of communication. Central to this growth is the establishment of a healthy reciprocal relationship between parent and infant. As discussed previously, this is the underlying philosophy of the HI-MAPS Project.

Two types of educational services were provided -- individual sessions and nursery groups. In both types of sessions, the teacher tried to stimulate the child's auditory, language and social skills and to support the parent-child relationship. However in the individual sessions it was possible to tailor the activities more to the needs of both the parent and child. In the group sessions, it was possible to provide activities facilitating peer interaction among the children, to help the parent and child separate from each other, and to provide special services to the parents.

##### 1. Individual Educational Sessions

Upon entry into the HI-MAPS Project, children and their parents were seen for individual educational sessions by one of the two teachers. The focus of the weekly one hour sessions was on the child's development of a formal language and communication system. It was anticipated that this

development would facilitate the social, cognitive and emotional development of the child as well as promote positive parent-child interaction. A Total Communication Approach which incorporated the use of hearing-aids, the language of signs, speech, and auditory training was used to facilitate speech/language development.

During the initial educational sessions the teacher became familiar with the family, observed the nature of the parent-child interaction, and assessed the level of the child's development at program entry. Individual educational plans were developed for the child and family after approximately one month.

#### Goals For Children In Individual Sessions

In working with the child and family, the teacher focused on supporting the parent-child bond and promoting the child's skills in four areas: 1) auditory development; 2) speech development; 3) sign language development; 4) social-emotional development. Individualized goals were designed for each child depending on his/her needs and existing skills. The following is a representative list of the kinds of specific goals and activities used in each of the four general areas.

##### 1) Auditory Goals

- a. Use of hearing-aid on a regular basis.  
Sample activities: 1) Parents, siblings, and teacher model wearing of hearing-aid for child and praise each other for wearing the aid. 2) Child wears hearing-aid for short periods of time during which a favorite toy of child is shown to child and played with. Teacher and child put hearing-aid on a doll and "praise" doll. Child is given much praise and encouragement while wearing aid.
- b. Awareness of environmental sounds and voice.  
Sample activities: 1) Child is given the opportunity to play with a variety of loud, moderate, and soft noisemakers and sound-producing toys. Teacher communicates with the child about the sounds made by those toys. 2) Parent

and teacher talk in a normal conversational tone with child. Any responses by child (head turn, cessation of activity) are noted.

- c. Localization of sounds and voices.  
Sample activities: Sound is produced out of the child's visual range and teacher observes responses by the child to the sound. If no response, teacher gets child's visual attention and produces sound again. Child is then encouraged to "listen" to the sound and look for the sound source.
- d. Attention to the onset and termination of sounds.  
Sample activities: 1) Child and teacher play with a record player. Teacher lets child turn it on and responds "It stopped. I don't hear it." 2) Child, parent, and teacher march or dance to music. When music is stopped, the marching or dancing is stopped.
- e. Recognition of different sounds in environment by identifying the sound source.  
Sample activities: Child is exposed over a period of time to the doorbell in the room which produces a loud buzzing sound and lights up when pushed. Child's attention is directed to doorbell whenever anyone comes to the door. Child eventually will associate buzzing sound with doorbell and turn to it or go to door and open it.

## 2) Speech Goals

- a. Usage of undifferentiated vocalizations.  
Sample activities: Parents, siblings and family friends are encouraged to continue to talk and sing to child while feeding, clothing, bathing, or playing with him/her to stimulate vocalizations.
- b. Use of voice to get attention.  
Sample activities: Parents, and teacher reinforce the child's vocalizations when used appropriately to get and maintain contact with others.
- c. Imitation of adult vocalizations.  
Sample activities: Parent and teacher model vocalizations that correspond to the activity engaged in e.g., "grr" noise while moving car on track, animal sounds while playing with toy animals, etc. Child is encouraged to imitate the adult vocalizations.
- d. Usage of non-segmental voice pattern varied in intensity and duration.  
Sample activities: 1) Parent and teacher draw on chalkboard. Long line is drawn and long vowel produced ("ahh--") then short strokes drawn and corresponding short

vowels produced ("ah-ah-ah"). Child is encouraged to imitate. 2) Some other activities in which vocalizations varied in intensity and duration can be modelled for the child include painting, drawing on paper, moving cars and airplanes in different patterns.

- e. Spontaneous use of voice in combination with sign language.  
Sample activities: Model words that the child can use to control his environment or to make things happen such as "stop," "up," "rock." For example, child is rocked on rocking toy. Parent and teacher signs and says "rock, rock, rock." Teacher or parent then stops toy and signs/says "stop." This game is played on a variety of gross motor toys. Child is encouraged to use voice and sign "stop" or "rock" depending on his/her desires.

### 3) Sign Language Goals

- a. Child visually attends to manual communication of others.  
Sample activities: Parent and teacher expose child to simple signs geared to child's developmental level and interest. Parent and teacher are careful to be at child's eye level so child can easily see the signs. Signing is done while child is watching and adults are careful not to intrude on child's play.
- b. Comprehension of several meaningful signs.  
Sample activities: Parent and teacher observe child's play and determine child's favorite activities. Then, expose child to several signs of interest consistently for a given situation until the language is learned. Parent and teacher hold toy by own face at times to gain child's visual attention for teaching language. Facial expressions and affect are used to interest child.
- c. Use of pointing and gesturing as means of communication.  
Sample activities: When child uses body language, pointing and gesturing to communicate his/her wants or needs, parents and teacher immediately respond to the communication by acting, gesturing, pointing, and/or signing. All communication modes utilized by child are reinforced and later expanded upon.
- d. Use of sign language to communicate wants and needs.  
Sample activities: Parent and teacher consistently label the names of objects the child uses and encounters and the events that she/he sees or participates in. Every day situations are used to teach the sign language associated with situations such as bathing, dressing, cleaning, preparing snacks, and playing with toys.

- c. Combines sign language into 2 or more sign phrases to express ideas and thoughts.  
Sample activities: Teacher and parent continually expand on child's language. Once child uses a few nouns and verbs, adjectives and adverbs are taught through play activities. Some activities used are doll play, art activities, gross motor activities, kitchen play, and reading books.

4) Social/Emotional Goals

- a. Maintains eye contact with meaningful people.  
Sample activities: Parent and teacher maintain eye contact with child by playing Peek-A-Boo, blowing bubbles, moving own hand toward own face while talking, and getting down on child's eye level while playing with toys.
- b. Forms relationship with teacher.  
Sample activities: Through continued interaction among the teacher, parent and child the child is able to form a trusting relationship with the teacher.
- c. Expresses feeling states through activity and formal sign language.  
Sample activities: 1) Parent and teacher label child's feeling state for child and expose child to the formal signs for emotions (happy, mad, sad, frustrated). 2) Parent and teacher also label their own emotions ("I'm mad"). 3) Doll play can be used to act out different emotions and situations with the child.
- d. Learns appropriate attention getting techniques in order to engage others.  
Sample activities: Parent and teacher model the following attention getting techniques: tapping table or floor; tapping lightly on shoulder; vocalizing, waving and/or showing object to get other's visual attention; pointing, gesturing, and signing.
- e. Engages in pretend and imaginative play activities.  
Sample activities: Doll play; kitchen play; dress-up; play with imaginary objects; using an object as if it was another object i.e., pretending a block is a cup.

### Goals for Parents in Individual Sessions

Depending on the parents' own needs, the teacher played a variety of roles in the individual sessions. Some parents used the session to observe the teacher/child interaction, using the teacher as a "model" for activities with the child, after which the parents joined in. Still other parents actively participated with the teacher and child throughout the entire session. In all cases, the teacher remained cognizant of the parents' own needs in relationship to their hearing-handicapped child and with this knowledge designed and implemented the individual sessions. This was especially important because family members were the most significant others to the child both in terms of the quantity and quality of interaction. The teacher served to support the parents in their roles, not to displace them.

In working with the parents, the teacher had two goals. One was to give parents technical information about deafness and help in parenting deaf children. The other goal was to provide parents with emotional support so that parents not only felt competent to raise their children but also were able to express both positive and negative feelings about being the parent of a deaf child. Both goals were equally important and inter-related.

The first goal involved presenting parents with educational information concerning four major issues -- auditory, speech, sign language, and social-emotional issues. Examples of the types of topics discussed are listed on Table 2.

TABLE 2

Educational Topics Discussed with Parents

- I. Knowledge and Understanding of Auditory Issues
  - a. Care and maintenance of the child's hearing-aid
  - b. Reassessment of the functioning of the hearing-aid and its benefit to the child.
  - c. Ways to utilize everyday auditory experiences for their child.
  - d. Auditory developmental stages in young deaf children.
  - e. Anatomy and physiology of the ear
  - f. Causes of deafness
  - g. Hearing tests and the audiogram
  - h. The use of appropriate volume of voice when speaking to child
  
- II: Knowledge and Understanding of Speech Issues
  - a. The development of pre-speech and speech skills in young deaf children
  - b. The effect and degree of child's hearing loss on the child's understanding of speech
  - c. The loudness of the various sounds of speech
  - d. Vocal stimulation games and techniques
  - e. Reinforcement of appropriate vocalizations and speech
  
- III. Knowledge and Understanding of Sign Language Issues
  - a. Techniques to get and maintain eye contact
  - b. The stages of development of sign language skills in young deaf children
  - c. The importance of learning sign language at parent's own pace in order to gradually increase comfort and fluency in using sign language
  - d. The importance of exposing child to signs that are age and developmentally appropriate
  - e. The difference between the Manual Alphabet, American Sign Language, and Signed English Sign System

TABLE 2 (Cont'd)

- f. Record keeping techniques to maintain accurate record of child's receptive and expressive language.

IV. Knowledge and Understanding of Social/Emotional Issues

- a. Normal child developmental stages
- b. The development of socialization skills
- c. Discipline and limit setting
- d. Realistic expectations for the child's future
- e. The importance of play in a young child's development

The second goal of providing parents with emotional support was implemented in conjunction with the counseling component of the program. An ongoing dialogue of questions, answers, and explanations took place so that parents were able to gain awareness of the special needs of their deaf child and feel comfortable and supported in fulfilling those needs. It was extremely important that the teacher remain sympathetic to the parents' feelings of shock, denial, and/or anger stimulated by the diagnosis of deafness. It was crucial not to overwhelm the family with too much new and technical information in the beginning when the family was recovering from the shock of having a handicapped child. The teacher remained sensitive to the parents' feelings in order to appropriately gauge the proper type and amount of educational information to impart to the parents. At times the teacher took a less active role and was available to listen and to empathize with the parents' feelings about the problems they were facing. At this important and sensitive time, the teacher and the parent counselor worked closely together to share information in order to fully integrate the educational and counseling aspects of the HI-MAPS Program. In some cases, the teacher would refer the family to the parent counselor for individual counseling sessions in addition to the sessions offered at program entry.

Parents were encouraged to bring other family members and friends to sessions so that all the significant people in the child's environment were exposed to specific communication skills and techniques adapted for hearing-handicapped children. It was important that the extended family understand the child's handicap, the treatment being given, and the ways in which to communicate with the child.

### Sample Schedules

The teacher determined the format of the individual sessions by considering both the parent's needs and expectations and the child's developmental level and skills. The activities selected were developmentally appropriate to the child's cognitive, social, emotional and physical skills. For example, Peek-a-Boo was used with 9-month infants to promote social interaction and to help infants conceptualize the disappearance and reappearance of people. For 18-month infants a surprise box and Jack-in-the-Box were used to help them practice making objects disappear and reappear. See Tables 3 and 4 for sample schedules which illustrate the format of the individual sessions.

After each individual session, the teacher summarized the parent's and child's behavior. See Table 5 for a sample of a completed summary form for a child who had been in the program for two months.

TABLE 3

Sample Individual Session Schedule No. 1: 10-Month Old

10:00 - 10:10	Welcome and greetings Discuss family's questions and concerns Share information regarding events of the past week or upcoming events Check child's hearing aid Give child time to explore room and materials
10:10 - 10:25	Gross motor activities - slide, trampoline, scooters, steps, rocking horse, bouncing/ rolling on large ball, crawling through tunnel, etc.
10:25 - 10:40	Manipulative materials - puppets, stacking rings, Busy Box, Jack-in-the-Box Play records, child plays with musical instruments Water play - splashing games, making and blowing soap bubbles Building and stacking with large blocks
10:40 - 10:50	Food activity - juice and cookies, cheese and crackers, fresh fruit, cereal with milk
10:50 - 10:55	Discussion with parents regarding follow-up activities at home Selection and exchange of toy or manipulative material Book library
10:55	Prepare to leave - put on coats and hats
11:00	Session ends Teacher walks with child and parent(s) back to lobby to say goodbye

TABLE 4

Sample Individual Session No. 2: 18-Month Old

10:00 - 10:10	Welcome and greetings Discuss family's questions and concerns Share information regarding events of the past week or upcoming events Check child's hearing aids Give child time to explore room and materials
10:10 - 10:25	Gross Motor Activities = slide, trampoline, rocking horses, etc. Ball games - throw and catch, rolling the ball, Hide and Seek, Peek-a-Boo
10:25 - 10:40	Varied Cognitive Activities Water Play - bathing the doll while naming the body parts - making and blowing soap bubbles - water pouring activities Manipulative Materials - simple puzzles, stacking rings, Surprise Box - Block building and stacking (large & small blocks) Auditory activities - Record player, present loud sounds (drum beat, symbols) out of child's visual scope and reinforce child's locating sound source Speech Activities - Child imitates teacher's vocalizations, making faces in mirror, blowing feathers and bubbles Arts and Crafts Activities - painting, coloring, clay
10:40 - 10:50	Food Activity - pudding, peanut butter and jelly with crackers, popcorn
10:55	Prepare to leave - put on coats and hats
11:00	Session Ends - Teacher walks with child and parents back to lobby to say goodbye.

HI-MAPS  
Individual Session Summary

8th week of program

Name J. Parent(s) Present: X Mo.      Fa. Date services

Others Present: Infant sister Child's Health Good

1. General attention span: appropriate <sup>X</sup> inappropriate
2. Child's general affect: content; happy; sad; angry; flat; other
3. Parent's general affect: content; happy; sad; angry; flat; other
4. Parent-child interaction:

Amount: all most some uninvolved

Quality: good fair poor

Child initiates: usually <sup>some-</sup> times seldom

Eye contact w/pa.: freq. looks some-times seldom looks  
sustained looks fleeting glances

5. Activities:

<u>Fine Motor</u>	<u>Mastery or Exploration</u>	<u>+Affect</u>	<u>Parent Inv.</u>	<u>Attn. Span</u>	<u>COMMENTS</u>
<u>    </u>	<u>    </u>	<u>    </u>	<u>    </u>	<u>    </u>	J very active today. Had difficulty attending to any particular activity. Turned out to be tired toward end of session. Did briefly enjoy ball game with mother, sister and teacher.
<u>    </u>	<u>    </u>	<u>    </u>	<u>    </u>	<u>    </u>	
<u>    </u>	<u>    </u>	<u>    </u>	<u>    </u>	<u>    </u>	
<u>Gross Motor</u>	<u>+Affect</u>	<u>Parent Inv.</u>	<u>Attn. Span</u>		
<u>Ball game</u>	<u>X</u>	<u>X</u>	<u>X</u>		
<u>    </u>	<u>    </u>	<u>    </u>	<u>    </u>		
<u>    </u>	<u>    </u>	<u>    </u>	<u>    </u>		
<u>Pretend/ Symbolic Play</u>	<u>+Affect</u>	<u>Parent Inv.</u>	<u>Attn. Span</u>		
<u>    </u>	<u>    </u>	<u>    </u>	<u>    </u>		
<u>    </u>	<u>    </u>	<u>    </u>	<u>    </u>		
<u>    </u>	<u>    </u>	<u>    </u>	<u>    </u>		

6. Child's Humor

7. Amt. parental signing: all most some none Amt. gestures: very freq. often some seldom

8. Overview/Plans: Mother had a lot of question re hearing language and could it be corrected

- Auditory training
- Discuss book for charting language
- Wash baby doll

## 2. Parent-Child Nursery Groups

After four to six weeks of individual sessions and parent orientation, the staff evaluated the family's readiness to enter one of the parent-child nursery groups. The focus of the weekly one and one-half hour groups was to foster socialization skills among the children and to provide special services for the parents. During group sessions, parents attended a parent counseling group and a sign language/communication class, in addition to participating in the play activities with the children and teacher. The number of children in each nursery group ranged from three to five. In general the teacher conducting the children's individual educational sessions was also the teacher of the nursery group for these children. In addition to the teacher, one or two assistants aided the teacher depending on the size of the nursery groups.

### Goals for Children in the Group Sessions

The Auditory, Speech, Sign Language, and Social/Emotional goals for the children in the group sessions were similar to those listed for the individual educational sessions with three additional goals unique to the group sessions: 1) easy separation from parents; 2) facilitation of peer interactions and 3) school readiness skills.

It was possible to help parents and children to learn to separate from each other, because parents left the playroom for 75 minutes for their communication class and counseling group. Language relevant to separation issues was taught to the children (e.g. "See mommy and daddy later;" "Mommy come back after a while"; "You're sad"). The children were able to comfort each other and learn to empathize with other children. They also had the opportunity to learn about and identify feeling states (e.g. "John's crying;" "He's sad"; "I'm mad"). These experiences prepared the children for pre-school at age three and the separations from their parents that would occur at that time.

The group also offered the opportunity for the children to play with, communicate with, and learn from peers. Activities that facilitated interaction among the children were stressed. Some examples were dancing and marching to music, pulling each other in wagons, playing ball games, and playing with dolls. Learning to take turns and share in games such as sliding, follow the leader, zoo and farm lotto also was an important part of the curriculum. For most of the children, the play groups were the only times that they could interact with peers who used the same language system.

The third goal unique to the nursery group was the facilitation of school readiness skills. The group continually provided opportunities for the children to learn and practice those academic and social skills which would benefit them in a pre-school setting where there is only one teacher for five or six children (e.g. sitting and attending to a task, learning to interact in a group, being independent, following directions, cooperating with adults, and utilizing appropriate means of attracting attention and expressing emotion.)

Goals for Parents in The Group Sessions

The uniqueness of the group format offered parents the opportunity to be exposed to three additional types of experiences: 1) separation from child; 2) meeting other parents of deaf children and 3) seeing other deaf children.

Just as most children had difficulty separating from their parents, most parents also felt uneasy about leaving their children. The separation sequence was an ideal situation for staff to observe separation and reunion between child and parent, and to present ways tailored to each parent-child dyad/trio in which a comfortable separation could be achieved. Parents



learned important signs to use in order to communicate to their child about where they were going and why. The importance of transitional objects (blankets, bottles, and special toys) as aids in the separation process was discussed. Staff also described the developmental stages children go through in understanding separation as well as behaviors parents may expect from their children at these various stages.

The group sessions also gave parents the opportunity to meet other parents of deaf infants so they could share experiences and develop a support network. Since parents were able to observe other deaf children and their interaction with their parents, there was much discussion among parents around the developmental stages of play and social skills among young children and the individual differences that occur. Discussion of these experiences occurred with the teacher in the nursery group and also with the parent counselor and the sign language/communication specialist during the parents' groups with them. See sections II Parts E and F for a description of these groups.

#### Sample Schedules

The group activities were similar to those in the individual sessions; they were selected to be developmentally appropriate to the children's skills. Children of similar ages were generally grouped together. In a few cases where an older child was placed in a group of younger children the teacher planned activities so that the older child helped facilitate interaction among the younger children. This experience proved valuable to the older child in increasing his/her self-confidence and social skills. The younger children also benefitted from the greater social interaction and exposure to the older child's more advanced communication skills. A

sample schedule which illustrates the format of the group sessions is given in Table 6.

After each group session the teacher and aide(s) summarized each child's behavior with respect to the activities engaged in, reactions to separation and reunion with parent, peer interaction and affective state. See Table 7 for sample of the summary form.

### 3. Program Variations

The needs of each family varied greatly. Programming was flexible in order to try to successfully engage all the families in the program. Due to such factors as transportation difficulties, work schedules, siblings' needs, or family problems, many families were unable to attend twice a week for both an individual and group session (see section III part C). Various alternatives were offered to the families such as individual sessions every other week. Another variation was the "Drop-In" Group session once a week. (See section III p.1 for a description of the "Drop-In Group").

### 4. Materials Used

#### Curriculum Materials

The following bibliography in Table 8 lists the books and curriculum guides used in planning activities for the parent/child nursery group and individual educational sessions. Several of the curricula designed for hearing children have been adapted for use with the HI-MAPS population.

TABLE 6

Sample Group Session Schedule (2-3 yr. olds)

1:00-1:05	Welcome and greetings amongst children, parents, and staff Check hearing aids to see that they are in good working order Discuss plans for session, answer questions of parents, share any current events, information re: parent meetings, conferences, media specials, etc.
1:05-1:30	Parents leave room for Sign Language/Communication Class "Gross Motor" Room Activities -Slide, trampoline, rocking horse, tunnels Group Games - Ring-around-the-Rosie, Marching with musical instruments, dancing to music Ball games, Hide and Seek
1:30-2:15	Parents attend parent counseling session with social worker, Children switch to "Cognitive Room" Activities -Housekeeping/Doll Playing -Sand/Water Play -Arts and Crafts Manipulative Materials - Table games, puzzles, stories and books, puppet play, cars and trucks
2:15-2:30	Parents return from parent group Food Activity - a simple snack is prepared by the children e.g. pancakes, popcorn, cheese and crackers, juice
2:30	Group Ends

Absent L (ill)

TABLE 7  
HI-MAPS PROJECT  
Group Sessions

Group Monday-morn  
Date 2/9/81

Name	Activities (Indi/group)	Separation/Return	Affect	Peer Interaction	Comments
A	1. Drawing on board 2. Valentine card 3. Books	Separation-angry when mother left, ignored mother Returned-A happy, Drucie angry that Andy had wet his pants.	angry silly	Initiated "chase" with Adam, Andy enjoyed but Adam was neutral and wary. Initiated interaction with Keith reading books.	
B	1. Valentine cards, pasting 2. Drawing on board 3. Tricycle	Separation-cried, calmed self, watched others Return-happy	quiet, withdrawn	Cautious in interaction with Andy-initiated "drawing" on board	
K	1. Valentine cards 2. Climbing steps 3. Books	Separation-fine Return-mother greeted, Keith didn't respond and mother didn't follow through further	happy in gross motor room quiet in cognitive room	Andy initiated couple times, Keith didn't respond	

s: Cognitive Room - art activity  
Gross Motor Room - lotto

Food: tacos lettuce  
tortillas, tomato

Cheese:



TABLE 8

Bibliography Used in Designing Parent/Infant Curriculum and Activities

1. Brown, Sara and Donovan, Carol, Developmental Programming for Infants and Young Children Volume Three, The University of Michigan Press, Ann Arbor, Michigan, 1977.
2. Clark, Thomas and Watkins, Susan, The Ski-Hi Model - Programming for Hearing-Impaired Infants Through Amplification and Home Intervention, U.S. Office of Education, Washington, D.C., 1978.
3. Experiences - Our World, Our Words, Bill Wilkerson Center, Nashville, Tennessee, 1976.
4. John Tracy Clinic, Correspondence Course for Parents of Young Deaf Children, Los Angeles, California, 1979.
5. Kames, Merle, Small Wonder, American Guidance Service, Circle Pines, Minnesota, 1981.
6. Northcott, Winifred, Curriculum Guide for Hearing Impaired Children Birth To Three Years and Their Parents, Alexander Graham Bell Association for the Deaf, Washington, D.C. 1972.
7. Northcott, Winifred, I Heard That! A Developmental Sequence of Listening Activities for the Young Child, Alexander Graham Bell Association, Washington, D.C. 1978.
8. Sitnick, Rushmer, Arphan, Parent-Infant Communication - A Program of Clinical and Home Training for Parents and Hearing Impaired Infants, Domac, Beaverton, Oregon, 1977.

### Playroom Materials

The project used two adjoining classrooms which were specially designed for hearing-handicapped children. One room was called the gross motor room, because it was equipped with large gross motor toys such as a slide, trampoline, tunnel, rocking horse. The other room, the cognitive room, contained toys for older children -- a water table, tricycles, and a play kitchen area with stove, refrigerator, table and chairs. Each of the rooms contained puzzles, blocks, shape sorters and other small toys. Both rooms were used during group sessions for older children. The gross motor room was used for the first 45 minutes and then children moved into the cognitive room for the last 45 minutes. Nursery groups for younger children remained in the gross motor room for the entire sessions if the children had difficulty changing rooms.

### Parents' Box

Each of the two playrooms had a "Parents' Box" in it. This box contained a variety of materials relating to hearing loss as well as events of interest. Topics included information about Chicago and Suburban Clubs for the Deaf, newspaper articles, television specials, legislation, the Chicago Theatre of the Deaf, and book/toy catalogs. Parents were encouraged to take materials home and also to place materials of interest in the Parent's Box. In addition, parents could take home child-oriented sign language books to share with family members.

#### E. SIGN LANGUAGE AND COMMUNICATION CLASS

In conjunction with the Project's emphasis on serving deaf children's emotional and social needs as well as their cognitive-linguistic needs, the use of sign language was viewed within the framework of the reciprocal interaction between parent and child and their existing modes of communication. While parents were learning to communicate with their infants using tactile, vibratory and visual stimulation, they needed special supplementary skills appropriate for deaf infants.

In helping parents, the staff built upon the existing style of parent-child interaction and communication to support the parents' feeling of adequacy. The staff discussed with parents the importance of their existing nonverbal forms of communication. They were then taught how to make their communication through gestures, facial expressions, etc., more effective. New techniques were gradually introduced as the parent and teacher interacted with the child. For example, vibratory stimuli are very effective attention-getting devices for deaf children. When the teacher stomped her foot on the floor to get the child's attention, she would point out to the parent the effectiveness of vibratory stimuli immediately after the child oriented.

Understanding individual differences in parents' emotional and psychological reactions to the diagnosis of deafness was especially critical in deciding how and when to introduce sign language for each parent. Learning sign language was often stressful and anxiety-producing for parents as its use made both child and parent appear "different".

In addition, the task of learning a manual language that's very different from spoken language created even more anxiety. In these cases, HI-MAPS staff introduced sign language very gradually, trying not to overwhelm parents.

Signs were presented singly, and parents were shown how to integrate signs into their existing modes of communication by combining a sign with a point, gesture or appropriate facial expression.

1. Type of Sign Language System Modeled

Sign language systems vary greatly with respect to their relationship to English. American Sign Language (ASL) is the native language of deaf adults in the United States and its syntactic system is not based on English. In the HI-MAPs Project, the sign language and communication skills specialist, who was a hearing native signer of ASL, taught staff a sign language system combining features of ASL and English syntax. Pure ASL was not used with parents and children because of the belief that using English word order would facilitate speech, speech reading, and future reading skills of deaf children. The sign language and communication specialist created a sign language system that combined features of ASL with those of English so the children would learn a language system that had some of the flexibility and economy of a natural language, but would also facilitate the acquisition of English. The following aspects of ASL were incorporated:

- 1) verb agreement where the location of the objects and people involved in the action are incorporated into the sign itself;
- 2) use of pointing, facial expression and body language as a formal part of sign language; and
- 3) use of ASL signs whenever possible.

In ASL, some verb signs such as LOOK-AT or GIVE incorporate the location of the subject and object; the sign is made from the direction of the subject and ends in the direction of the object. Thus in signing the sentence "Look at the book" to a child, the person starts the sign Look in the direction of the child and moves the sign toward the book. ASL also includes pointing, facial expressions and body language as part of the

syntax. Negation is indicated by a head shake, questions by raised eyebrows; these are obligatory parts of the language. These features of ASL were retained by the communication skills specialist when she developed the sign language system used in HI-MAPS. Furthermore, she retained much of the sign vocabulary of ASL. When ASL signs referred to concepts different from those underlying English words, the sign language and communication specialist used the ASL signs. For example, in ASL different signs were used for the several concepts of "on". The sign ON, used in "Light ON" was different from the sign ON<sub>2</sub> for "Books are ON the table" which in turn was different from the sign ON<sub>3</sub> for "The TV is ON". The three different signs representing the different concepts "ON" were modeled by HI-MAPS staff instead of using a single sign for "on" in English.

The English features of the sign language system used by HI-MAPS included: 1) English word order; 2) modification of the ASL lexicon by initializing signs; 3) use of English morphemes in noun and verb tense endings; and 4) use of signs to reinforce syllables and the rhythm of speech. All these features were used to facilitate acquisition of English and to reinforce residual hearing and lipreading.

Many ASL signs were initialized; for example YESTERDAY in ASL is made with an A-hand shape. In the HI-MAPS Project, YESTERDAY was made with a Y-hand shape to help the child learn to speak and to speech read. Initialization was also used when ASL used the same sign for concepts that are differentiated in the English lexicon. To differentiate the sign for coat from the sign for shirt, the sign COAT was made a C-hand shape, while the SHIRT was made with a S-hand shape. To further aid speech and speech reading skills, signs were performed in rhythm with the spoken word. If the English word had three syllables (e.g. "Grandmother"), the sign was performed in three movements if possible (e.g. GRANDMOTHER was signed by making three outward movements). In addition the sign started and stopped

in synchrony with speech. As the child's sign skills and attention span increased, nouns and verb tense endings were added to the signs based on English morphology. Signs for the past tense, the progressive (-ing) plurals, and possessive were gradually used with some of the older children, when they started signing 3- and 4- sign utterances. Past tense endings were first modeled, and then when the child started to produce the past tense ending, more endings were used.

The preceding description of the sign language system modeled by the HI-MAPs staff is not necessarily true for either the parents' or the children's sign language systems. Just as hearing children gradually acquire the syntax of the language they hear, so too the deaf children initially did not show verb agreement, initialization, verb and noun endings, and so on. In fact none of the children in the project had complete mastery of verb agreement by the time they left the program. Research with deaf children of deaf parents suggests that for these children acquisition of verb agreement only begins around the age of 30 months when they start signing three signs together.

Furthermore, the sign language system used by the staff was not forced on the parents. Parents were told about sign language systems more similar to English such as signed English, and they free to choose the sign language system they wanted to use. When parents used signs different from the used in those program, the staff tried to use the parents' sign when interacting with that child to maintain consistency between the educational sessions and home environment. In fact such consistency was often more important for the hearing parent than for the deaf children. Deaf children are usually very good at code-switching, adjusting their language to the environment, and parents were told that most children adapt

easily. This issue became very important to parents when the child was ready to enter a school program. Parents worried that the some of the signs used in the HI-MAPS Project were different from those used in the school their child would enter. Parents were again reassured about the adaptability of deaf children in code switching.

## 2. Sign Language/Communication Class

The HI-MAPS Project provided a sign language/communication class for parents attending the parent-child nursery groups for two reasons: 1) the structure and orientation of the sign language/communication class needed to be consistent with the project's emphasis on parent child interaction and parents' issues and concerns; and 2) the absence of sign language classes in the community that were oriented for young deaf infants.

It was critical that the sign language/communication class be sensitive to parents' needs and to individual differences in parental reactions to the diagnosis of a hearing loss in their child. Some parents in the Project had difficulty accepting the diagnosis which interfered with learning sign language. The class had to avoid overwhelming parents of newly diagnosed deaf infants. The class also needed to show parents ways to appropriately use signs with children so as not to disrupt the parent-child relationship. Optimally, this required that the sign language/communication specialist have an opportunity to observe each child interacting with the parents so that the instruction could truly be individualized.

Unfortunately most of the sign classes offered in the community by speech and hearing centers, public schools or colleges, were conducted like foreign language classes for professionals working with deaf persons or for adults interested in learning a different language. These classes

usually did not initially teach vocabulary appropriate for infants; they focused on learning fingerspelling and extensive vocabulary and signing phrases or sentences. These classes often overwhelmed parents of newly diagnosed deaf infants who had no previous contact with a deaf adults or children. Consequently most parents were initially advised not to attend community sign classes until they were more comfortable with signing.

The Project<sup>4</sup> offered its own sign language/communication classes which were designed to support the parent-child interaction as manifested by each parent-child dyad. The classes also gave parents an opportunity to meet and share with other parents of deaf children their successes and problems in raising and communicating with their deaf child. Deaf parents regularly attended two of the sign language/communication classes, and they had a chance to express their concerns and problems in raising their own deaf children as well answer hearing parents' questions about their childhood experiences. The class allowed deaf and hearing parents time to interact and share experiences with each other.

#### Structure and Content of the Class

The initial goal of the sign language/communication class was to facilitate the effective reciprocal communication between parents and their deaf child. The structure of the 30 minute class was informal. The sign language/communication specialist was available to encourage parents to ask questions about deafness, sign language and communication; this allowed her to respond to parents' individual needs.

The sign language/communication specialist first taught parents that communication with any child is initially affective. Then she introduced the concept of sign language as their child's first formal language system by which parent and child could communicate symbolically. Repeated

explanations of Total Communication were given.

The sign language/communication specialist did not have a formal list of signs for the parents to learn. Instead, the parents asked for signs they wanted to learn, signs that were specifically related to their own family's individual needs. The sign language/communication specialist suggested that parents initially not request more than five signs each class. They were told this because it was difficult for some parents to remember the signs and because parents needed to learn how to use signs with their child. Play was discussed as the "work" of childhood and the language of signs was taught in that context.

The sign language/communication specialist stressed the appropriate use of signs so as to engage or maintain the child's attention and interest. Too much sign language stimulation or pulling on the child's chin or cheek to get their attention may encourage visual avoidance of the parent by the child and interfere with the child's attachment to the parent. It was essential that parents learn to sign in the child's visual field and not interrupt the child's activity. Furthermore, parental discomfort in signing phrases or sentences may be transmitted through the parent's body to the child especially if the parent is holding the child while signing. Discomfort with signing may also result in presentation of signs in a stilted or actually assaultive manner.

The sign language/communication specialist showed parents how to sign to children and not interrupt their play. The parent can sit close to the child and sign within his/her visual scope. Or if the child is on a tricycle or rocking horse, the parent can play with him/her and when the child stops riding or rocking, the parent can sign and say "Stop" and then "go". The formal language becomes part of a game without interfering with the parent-child relationship.

Signs for feeling states were introduced by the sign language/communication specialist with discussion of the importance of consistency between the sign and one's facial expression. For example, a parent may have signed HAPPY but facially expressed a flat affect; the message received by the child is not one of happiness. One of the most difficult signs for the parents was identification and acknowledgment of anger either for themselves or for their child. Often the affect shown was smiling instead of anger when they signed ANGRY or MAD. Parents had more difficulty signing SAD than the descriptive sign CRYING.

The parents varied greatly in how quickly they learned and used signs. Differences in the proficiency levels and the presence of deaf parents in some of the sign language/communication classes facilitated their learning from each other. As parents felt comfortable with signing, they learned and asked for as many signs as they wanted. Family members and friends were welcome to attend the classes and there was much discussion about communication in difficult situations such as separation of the child from the parent, toilet training, weaning the child from the bottle, and leaving the program and going to a new school as the child's third birthday approached. In connection with teaching parents signs appropriate to the parents' and child's needs, it was necessary to the sign language/communication specialist to create new signs.

Until the last few years, linguists have estimated that there have been only two to three thousand signs in the ASL lexicon and most of these signs are for an adult language system. Any expanded vocabulary was finger-spelled. Thus there were few signs for transitional objects used in helping the child separate from the parents, e.g. "teddy bear"; even a specific sign for the word "toy" was lacking. To meet this need the sign language/communication specialist created signs for child-oriented words if

there were none. These signs were created so they would be conceptually and configurally consistent with existing ASL signs. For example, the sign TEDDY for "teddy bear" was created keeping the concept of a transitional object in mind. The right hand with the "t" hand shape was placed on the palm of the left hand and then moved to the heart and tapped twice to reinforce the syllables and rhythm of speech. The existing ASL sign for bear was added to complete the phrase "teddy bear".

Parents were encouraged to keep a dated notebook at home so that when there were particular words. They needed to sign to their child at home, could write down those words in the notebook. In the next sign language/communication class they could ask for the signs and write clues for remembering the signs next to the word. Later on parents used the notebook to record the signs their child produced or comprehended. Recording their child's language growth was especially helpful. As the child began to respond to signs and to sign expressively, parents felt successful and motivated to continue to learn more signs and to sign phrases or short sentences. The list of the child's vocabulary was also useful when the child went to school. The parents could give this list to the child's new teacher and model the child's diction.

The above is a general description of the philosophy and content of the sign language/communication classes offered by HI-MAPS. The structure of the classes was modified for parents of the younger children.

#### Sign Language/Communication Class for Parents of Young Children

Because parents and children between the ages of one and two years were not yet comfortable separating for each other, the sign language/communication specialist developed a special kind of class for this group of parents. The class was designed in the following way.

The sign language and communication specialist joined the parent infant nursery group in the nursery room for 30 minutes. This arrangement allowed the sign language/communication specialist to observe parent-child, child-teacher, child-child and parent-parent interaction. The active role of the sign language/communication specialist was to be available to answer sign language or communication questions without separating the parents and children. However, the parents were informed that eventually when they were comfortable they would have a formal sign language and communication class in a room of their own without the children. This design worked particularly well as it allowed the parents and children to remain together and receive sign language/communication instruction and allowed the sign language/communication specialist to observe the various interactions.

When the parents were playing with their child or observing the teacher playing, they began to ask for signs, staying by their children's side. If there was an experienced parent in the room, the sign language/communication specialist encouraged that parent to teach the newer parents. The parents were able to see other parents and their children in a non-threatening environment, learning and struggling to learn and use the new language.

Gradually the sign language/communication teacher moved to a small table and encouraged the parents to join her. Different parents began at different times to group at the table, each at their own speed and comfort level. They were somewhat more removed from their children, but they were still visually and physically available. This initial grouping at the table was in preparation for the move to a separate room of their own away from their children.

The final step was to move out of the room; the decision was made by the parents themselves with the help of the sign language/communication specialist.

The parents decided the timing as they were able and willing to separate from the children and as they began to want to have their own time and out of the nursery.

The several stages the parents went through to move out of the room allowed the children to gradually separate from the parents and to begin learning the formal language concerning separation (e.g., "Bye Bye", "Mama", "after while", "see you later", "Mama come back after while").

The children followed their parents to the parents' classroom, which was directly across the hall so they could see where their parents would be. They also saw that the room was not interesting to them with no toys or pictures for children. The nursery teachers then took them back to their own familiar play room. The sign language/communication specialist and parents later went back into the nursery for 15 minutes to participate in a food activity which was planned by the parents during the sign language/communication class.

#### Food Activity

The sign language/communication specialist introduced the planning and carrying out of food activity shortly before the parents of the younger children moved out of the nursery room for their sign language/communication class. Parental planning of the food activity continued once the parents moved to their own room.

During the class, the parents planned the food activity, and then actually carried out that activity during the last 15 minutes of the nursery group when they rejoined their children. The sign language/communication specialist asked the parents to think of foods they and their child liked to eat especially foods that the child and parent prepared together. The parents decided among themselves the food activity

they wanted to do in the nursery room as a group with their children. The sign language/communication specialist then taught the signs for these specific foods and also signs and techniques for getting and maintaining their child's interest and attention. Parents were able to practice their skills when they carried out the food activity in the nursery room and hopefully these skills were transformed to home situations.

With the younger group of children, the food activity was quite simple. Foods such as crackers and juice were used, since these foods involved limited preparation and were similar to the food activities at home. Also, parents and children in the younger group were not ready for more elaborate food preparation until they learned to function as a group and until parents learned to use more than one or two signs comfortably.

When parents became more comfortable, peanut butter or cheese were added to the activity, and the sign language/communication specialist taught the signs WITH, ON and later combinations of two signs such as WANT CRACKER or WANT JUICE both as questions and as statements. In order to use "WANT JUICE" as a question to ask the children if they wanted juice, parents were taught to use a questioning facial expression while signing. To convey through "WANT JUICE" the knowledge that the child did in fact want juice, a head nod and an affirmative facial expression were necessary.

When children had developed longer attention spans and were better able to wait, more complex food activities such as making popcorn were introduced. Initially, for the younger children the process of making popcorn was simplified. They saw the communication specialist pour in oil and popcorn and sign POPCORN. Then while they waited, a "Waiting Song" was sung and signed to help the children wait. When the popcorn started popping everyone signed POP. With older children the complexity of the both the process and language gradually increased. The children themselves poured

in the oil and added the popcorn; prepositions were introduced; the oil was described as bubbling, etc. By the time the children left the program the popcorn activity was used to expose the children to the concepts of sequences of events, cause and effect and future actions and events.

The food activity was a positive experience for parent and child. Children demonstrated their competency in preparing the food and enjoyed eating the food they helped make. Parents gained self-confidence in communicating with their children about food. Because the food activity was so pleasurable, it was always included at the end of each nursery group session.

#### F. THE PARENT COUNSELING GROUPS

The groups were based on the model of group psychotherapy rather than on a parent training or educational model. During this 45 minute session parents introduced the topics for discussion and addressed their remarks to each other. The parent counselor connected themes, clarified the problems being discussed and monitored the emotional climate. Occasionally, factual questions were answered. There were four objectives for the counseling groups:

- 1) To help the parents overcome their feelings of isolation.
- 2) To provide a safe place where negative feelings such as anger and guilt could be expressed.
- 3) To develop comfort with a self-concept of parent as advocate.
- 4) To learn to manage the stress caused by the handicap and other family problems.

Each group was composed of four or five families. Groups became cohesive more quickly if the entire group started at the same time. If this was not possible, it was best to have one "old" parent join a newly forming group. It was more difficult to have one "new" parent join a group that had been meeting together for some time.

Groups were more productive when fathers participated (see Section III Part F) and when there were disparities in age, ethnic identify and socio-economic background. In a group composed of people very different from themselves, parents could get in touch with their basic humanity. This helped them overcome feelings of isolation caused by the stigma of deafness and by lack of support from relatives. Getting to know people who were experiencing different life passages from themselves gave them perspective.

Throughout their participation in the groups, the parents expressed sorrow about the children's deafness. Even after termination, there was open expression of grief when parents returned for reunions. If deafness were a specific condition whose limitations could be easily comprehended, the parents could be expected to complete their grief work. But the effects in a very young child are not fully evident so it is difficult to comprehend. It takes a long time to understand the subtle effects of sensory deprivation and the complex problems in human relationships which result. The sorrow of the parents is thus chronic.

Superimposed on this underlying theme were five distinctively different phases in the counseling groups, each with its own characteristic issues and predominant affective tone.

In the first phase, the feelings most commonly expressed were anger and shame. The anger was directed towards the medical system and towards strangers in the community who were hostile or rude towards the deaf child. A common issue in the first phases was the question of whether or not a deaf child is "normal". The parents compared the children's accomplishments despite their deafness as part of their efforts to overcome their shame at having an imperfect child. Another important theme was over-protection. Usually, one parent in each couple acknowledged a need to keep the child a baby. This was related to their own feelings of helplessness. It was important for this issue to be addressed very early while the children were in the normal separation-individuation stage of development. If the mothers and fathers did not feel competent to be parents, they clung to the child for their own consolation.

The second stage was characterized by the parents turning their anger towards the deafness and towards the child. There was by then enough trust in the group to make expression of these uncomfortable negative feelings possible. But the process of doing so usually had a disorganizing effect upon the sessions. Information was frequently distorted or misunderstood. During this phase the parents began to take in the full emotional significance of the burden of a deaf child. They expressed resentment that their own needs were not being met.

In the third stage, anger was expressed by the partners towards each other. It was important to urge both parents to continue attending the group even if they were estranged. There was often guilt and blame around the issue of the cause of deafness. During this phase, some parents worried that they would become child abusers.

In the fourth phases, the parents reintegrated and regained their confidence as parents. Their growing sense of mastery in being able to communicate with the child helped them feel competent to become advocates as well. They were then ready to learn about the rights of handicapped children and procedures for negotiating with school bureaucracies.

In the fifth phase, the termination phase, the parents required special attention to their emotional needs. As the child's third birthday and "graduation" approached, parents reviewed the progress the child had made and wondered if they had worked hard enough. If there were behavior problems, the parents worried about the child being acceptable in the new school. Any kind of summing up was feared even as it was eagerly requested. Issues of competition between parents tended to surface. The recounting of the children's accomplishments during the termination period paralleled a similar occurrence during the initial phase of participation. At

both times, there was a struggle to feel acceptable as the parent of a "less than perfect" child.

The parents talked most about their fears of separating from the child and the child's ride alone on the school bus. They wondered how to tell the child what would happen. Many children had enough sign language to understand about a new school, especially if they had been taken to visit. It was more difficult to explain about leaving HI-MAPS. This anticipated loss was painful to the parents and reawakened memories of earlier losses.

In addition to the groups, a series of individual sessions with the parent counselor helped parents work through the termination process. The parent counselor then assessed the need for individual or family therapy and made appropriate referrals.

Parents were invited to continue attending the counseling groups even though their child was no longer in the program. Most preferred to return in a group for a regularly scheduled re-union, as bringing the children back was important. (See Section IV Part C for Followup Services)

## G. AUDIOLOGY SERVICES

Early diagnosis of hearing impairments in infants and young children was considered crucial to the HI-MAPS Project. If the most sensitive period for both language and emotional development is the first three years of life, then it is essential to provide the early utilization of amplification, the introduction of language systems appropriate for young deaf children and the necessary education and counseling for families. Without special intervention in this time period, the language development and the psycho-social maturation of young deaf children can be severely delayed or seriously interrupted.

The need for early identification of a hearing loss, determination of the degree of residual hearing and the etiology of the loss led to the combined use of Auditory Brainstem Response testing (ABR or BSER), Otolaryngologic examination, behavioral audiologic testing and acoustic impedance measures.

While it was the combination of these measures that supplied the most complete information, the ABR test was the single measure relied upon for the first identification of hearing impairment or as a confirming opinion.

ABR is an electrophysiologic test that records the changes in the electrical activity of the human brain in response to sound. Somewhat similar to the brain wave test or electroencephalogram (EEG), neural activity of the auditory (VIIIth) nerve and the auditory pathways in the brainstem is recorded through electrodes pasted to the head and analyzed by means of a small average response computer. ABR is a non-invasive technique that does not require the active cooperation of the child but does require that the infant or child lie quietly, preferably asleep for

about one hour. A mild sedative may be prescribed to help the more active infant sleep through the test. Although ABR as used in the HI-MAPS project did not provide a complete picture of hearing at all frequencies, it did reveal whether or not the child had a hearing loss and the degree of that loss in the 2000-4000 Hz range. Hearing in this frequency range is critical for the understanding and subsequent development of speech. A loss of hearing for these mid-high and high frequencies as measured by the ABR technique indicated that the infant was educationally hearing-impaired and was therefore a potential candidate for the HI-MAPS program.

Care was taken to coordinate all findings to date and have them clearly interpreted to the parents by a Clinical Audiologist at the time of the ABR appointment. It was important to give information and offer help for the child and family as soon as possible. The parents' anxiety surrounding the diagnostic process and its interpretation is an important factor that seems to have far-reaching effects on the future of the child and the emotional well-being of the parents. We attempted to be sensitive and respond to this throughout the test procedures.

The diagnosis was considered complete when the child had been examined by an ENT physician, undergone ABR testing and was seen by Clinical Audiologists for observation of behavioral response to sound in a sound field situation. Sound field testing involved presentations of different sounds to the child without using earphones. Some children received portions of the diagnostic services at other facilities and for a few children, audiologic and hearing aid management remained outside the Siegel Institute. Parents were welcome to transfer hearing aid care to the Audiology Department of the Siegel Institute.

Continuing audiologic care by Siegel Institute began after the diagnosis was confirmed and was concurrent with enrollment in the HI-MAPS program for the duration of a child's participation. This care included a hearing aid evaluation, individual recommendation for a hearing aid, medical clearance for earmold use and the hearing aid fitting and after-care. Testing services were provided at no cost to the children in the HI-MAPS program.

Hearing aid use was recommended for every child regardless of the degree of hearing deficit. Fewer than 5% of the families exceeded the maximum income requirements of the Division of Services for Crippled Children (DSCC), a state agency for programming medical care of handicapped children and providing financial assistance for special services or prosthetic devices, specifically, hearing aids and accessories. Those few families who purchased hearing aids privately were given the recommendation/prescription directly and had the option of having their child fitted through the Siegel Institute Hearing Aid Dispensary or being referred to a qualified dispenser in the community. For the majority of families receiving service through DSCC, the recommendation was transmitted in writing to the appropriate office with a request that the Siegel Dispensary be allowed to fit the hearing aid and provide continuing care.

The procedures necessary for the application to DSCC, approval of hearing aid purchase from the state office, transmittal to the local office, release of the purchase order and actual procurement of the hearing aid required a substantial amount of time, usually 3 to 6 months. To provide amputation for children during the waiting period, the Siegel Institute purchased seven strong-gain but variable body-borne hearing aids

to be used on loan with custom earmolds by HI-MAPS children until their own instruments were obtained. The cost of these instruments and the service of them (including cords, harnesses, batteries, earmolds, receivers and repairs) was borne by the Siegel Institute. This was considered necessary for two reasons: 1) to begin the auditory experience of the children soon after program entry and 2) to reduce the anxiety of the parents who held great hope for the promise of amplification.

The actual fitting of the hearing aid was carried out by the clinical audiologists responsible for the child's evaluation and the hearing aid recommendation. Careful explanation and instruction was given to the parents (usually the mother) concerning the introduction of the hearing aid into their lives as well as the mechanical manipulation and maintenance. Parents were provided with their own earmold or a listening stethoscope and were instructed to complete daily listening checks. Printed material was developed for the HI-MAPS parents help them identify problems in the performance of the hearing aid. Electroacoustic checks were completed by the audiologists on a regular basis and when necessary, the aids were sent to the manufacturer for repairs.

Philosophically, the audiologists at the Siegel Institute supported the use of binaural hearing aids which allow for separate amplification of the sound to each ear and where appropriate gain was available, the use of ear-level, binaural hearing aids. Financial consideration imposed by DSCC and the practical concern for durability, resistance to loss or damage usually led to fittings of body-borne hearing aids with Y-cords. All hearing aids were insured against loss or damage for two years following purchase.

Continuing Otolaryngologic consultation and Audiologic care included ENT examination and audiologic evaluation every six months or sooner as needed. This kept current the medical clearance for earmold use and provided on-going clinical information on hearing levels as well as the child's development of auditory capabilities. Through acoustic impedance measures, information was gained on the status of the middle ear mechanism which is subject to recurrent otitis media in young children.

As the children participated in the HI-MAPs program and their auditory skills developed, it was expected that the extent of residual hearing and precise thresholds of hearing could be determined through conditioned play audiometric techniques. This involved placing earphones on the children and conditioned them to perform a response like dropping a block into a can when they heard a sound through the earphones. The audiologists worked closely with the teachers in selecting those children with adequate development and attention span to accept earphones and establish a conditioning bond in the test situation.

Usually the conditioned response was taught to the child by the teacher during the child's educational session and later, was transferred into the test room with the Audiologist, teacher and/or the parent present. The presence of both the parent and teacher enhanced the child's comfort and ease in the test situation and allowed a sharing of information that the teacher could utilize and reinforce in later sessions.

By age three, most children were capable of completing audiologic data. Information was considered complete when the following measures were available air conduction thresholds for both ears; bone conduction thresholds when present; speech awareness thresholds for both ears; aided threshold of awareness for speech and aided thresholds for narrow bands of

noise in sound field. This information was summarized on an audiogram and described narratively and transmitted to either the parochial or public school the child would attend. Some children, because of delays in development, neurologic interference, behavioral problems, inconsistent participation in educational sessions or maximum hearing deficit terminated the HI-MAPS program without complete audiologic information. The children continued audiologic care through the Siegel Institute, however, and the information was obtained later through a continuing clinical relationship.

## H. MEDICAL SERVICES

In addition to the audiological and otological services described in the previous section, deaf children in the HI-MAPS project received a second group of medical tests to determine whether there were additional handicapping conditions and to investigate the probable cause of the hearing loss. These tests consisted of an Electroencephalogram (EEG) and Pediatric Neurological and Ophthalmological Examinations. The Bayley and Gesell Developmental Tests were administered by an occupational therapist. Appointments for the tests were scheduled during the first year of the child's participation in the program except for the Bayley and Gesell which were administered at program entry and exit. At the time of each test, the child's audiological and medical records including prenatal care, birth records and subsequent hospitalizations were made available.

Because of the higher incidence of additional handicapping conditions in hearing-impaired children, the medical tests were useful in diagnosing other medical problems and in evaluating the program's ability to meet the child's most pressing needs. If necessary, the child was referred for supplementary services in other programs such as occupational therapy or was transferred to another program.

It was especially important to give deaf children an ophthalmological examination, for the incidence of ocular abnormalities is 38 to 58% higher in hearing-impaired children compared to hearing children. Problems in using vision to learn about the environment and to learn to communicate effectively with others could cause additional delays for hearing-impaired children. An ophthalmological examination was also useful in trying to determine the etiology of the hearing loss. Abnormal eye findings are

associated with heredity syndromes such as Usher's and Waardenburg Syndromes as well as with congenital hearing loss due to environmental factors such as the congenital rubella syndrome.

Knowledge of the etiology of the hearing loss was essential for genetic counseling. Determination of the cause of deafness was also important for the parents psychologically. Often parents blamed themselves. Resolution of this issue was important for the process of accepting the deafness and becoming engaged in the program. The diagnostic medical tests gave parents opportunities to ask questions about etiology as well as about other aspects of their children's development. Parents often used the parent counseling groups to rehearse questions they wanted to ask.

The diagnostic tests were administered at no charge to the families; however, if parents were referred for genetic counseling it was paid for privately. The diagnostic tests described in this section were given only to the deaf children who regularly attended the program.

## I. INTERRELATIONSHIP AMONG STAFF

### 1. Division of Responsibility

In the HI-MAPS Project, the responsibility for solving concrete problems rested with the teacher. This included coordination with the Division of Services for Crippled Children for financial assistance in obtaining the hearing aid, with the American Red Cross or other volunteer groups for transportation, and with public and private schools for school placement at age three. The teacher arranged medical testing with the Siegel Institute scheduling coordinator. The audiologists worked with the teacher to schedule the child's six-month otological/audiological examination. Referrals for other appointments such as genetic counseling were generally made by the teacher. In addition, the teacher maintained contact with other services or programs (occupational/physical therapy, other parent-infant programs) in which the children were involved.

This division of labor among the staff helped the parents develop a firm commitment to the goals of the program through the bond with the teacher. At the beginning of the child's participation in the program, the parents were not always able to see rapid results from the educational activities. By concentrating solely on educational goals, the teacher would have missed the opportunity to build a relationship with the parents by solving concrete problems together. This practical activity helped reduce the parents' stress and give them the experience of respect and support from the teacher. Their pleasure in working together as a teacher-parent team helped the parents become ready to learn new ways of communicating with their child.

## 2. Multidisciplinary team approach

Since various staff members discussed the same problems or issues with the parents from different perspectives, it was necessary to work together as a team, discussing the parents' needs and coordinating efforts. An example of this process was the work done with the parents around the hearing aid.

For most of the parents, the most pressing practical problem was arranging for its payment through the Division of Services for Crippled Children. This was frequently a long and complex process that the teacher monitored. However, it was essential for the parent counselor to be knowledgeable about this process and be aware of difficulties individual parents were having. They would frequently discuss these frustrations in the parent counseling groups. For some, waiting for authorization for payment was a humiliating reminder of their poverty and/or inability to provide for the child themselves. For others, the delay was welcome as they worked through their feelings of denial. Initial resistance to the need for the hearing aid and subsequent expectations for magical benefits were explored in the groups. Once the hearing aid was obtained and the struggle to get the child to accept it was over, parents still had to deal with the reactions of relatives and strangers to this visible stigma of the handicap. Finally, the most bitter experience was to have worked through all of these problems and then not be able to see the hearing aid make any difference to the child initially. In some cases, more seasoned parents helped the newer ones to be patient by giving examples of their children's eventual benefit from the hearing aid.

The family history which the parent counselor had taken from each parent individually during the parent orientation helped in understanding

the varying meanings which hearing aids had for parents. For example, when a young mother's own mother had been a depriving mother, there was more anger and impatience with a system which promises, yet frustrates and deprives. Especially during November and December, these young mothers talked longingly about their desire to "give my baby his hearing aid myself."

A second example of the multidisciplinary team approach used by the HI-MAPS project concerned the parents' questions about sign language. At first parents were confused about the difference between American Sign language and Signed English. There were questions about whether learning sign language would interfere with the development of speech. An understanding of the philosophy of Total Communication developed very slowly.

These questions were answered definitively by the teacher and the sign language/communication skills specialist, especially by the latter person who had deaf parents and was a native signer. However, it was significant that parents often brought up their negative feelings about sign language in discussion with a non-expert on the subject, i.e., the parent counselor. The same was true about questions regarding the deaf community. The parent counselor facilitated open discussion on these subjects. Permission was given for the expression of ambivalent or negative feelings. Many parents continued to express such feelings throughout the time when they were progressing satisfactorily in learning sign language.

### 3. Staff Meetings

It was essential for the entire staff to maintain weekly communication with each other about the parents' progress in these areas:

- 1) Gradual acceptance of the reality of deafness.
- 2) Growth in the feeling of competence in the role of parent to

a handicapped child.

- 3) Development of skills in working with professionals and agencies.
- 4) Status of specific problems.

The parent counselor, teacher, communication specialist and teaching assistant met weekly after each nursery group. In these 30 minute meetings, staff discussed the parents' progress in the above areas, the children's emotional, social and communication skills, and the parent-child interaction. These weekly meetings gave staff regular opportunity to discuss diagnostic information concerning the parents and children in the nursery groups and to exchange information about child and parent progress.

The entire staff and chief audiologist attended the weekly administrative HI-MAPS meetings. The chief audiologist presented new cases at the that meeting. In addition general issues concerning many of the HI-MAPS families were discussed at the administrative meeting.

### III. CHARACTERISTICS OF THE POPULATION SERVED

#### A. REFERRAL SOURCES

Referrals of children suspected of having hearing impairments to the Siegel Institute for audiological testing and program placement came from the medical staff of Michael Reese Hospital and from outside referral sources. During the first year of the project, a description of the program was sent to hospitals and agencies in the Chicago Metropolitan area, announcing the service available to hearing-impaired children and their families. Referrals for diagnostic testing and for program placement of deaf infants came from a variety of sources including:

- 1) Otolaryngologists
- 2) Audiologists
- 3) Neonatologists
- 4) Pediatricians
- 5) Parents of deaf children who had received HI-MAPS Services
- 6) Agencies and organizations serving the deaf
- 7) Nurses
- 8) Educators
- 9) Speech/language clinicians
- 10) Michael Reese Hospital Staff

B. DEMOGRAPHIC CHARACTERISTICS OF THE POPULATION

Demographic data was collected for 26 days and 10 hard-of-hearing children who had attended seven or more educational sessions between January 1, 1981 and December 31, 1981 when the HI-MAPS model was fully developed. The data forms (See Appendix) were filled out by the Teachers and the parent counselor.

Child demographic information concerning sex, race, birth order, suspected etiology, other handicapping conditions and other program participation is presented in TABLE 9. The mean age that a hearing loss was suspected for these children was 8.3 months (S.D.=6.19); the mean age these children entered the HI-MAPS Project was 18.2 months (B.D.=8.14).

Material and paternal demographic information concerning educational level, occupational status maternal age at child's birth, household income and geographic location is presented in Tables 10 and 11.

TABLE 9

CHILD DEMOGRAPHIC CHARACTERISTICS

	Number	Percentage
<u>Sex</u>		
Male	16	44.4%
Female	20	55.6%
<u>Race</u>		
Black	17	47.2%
Hispanic	5	13.9%
Caucasion	12	33.3%
Mixed	2	5.6%
<u>Birth Order</u>		
1st Born	14	38.9%
Later Bom	22	61.1%
<u>Suspected Etiology</u>		
Premature <sup>a</sup>	10(4)	27.8%
Rubella <sup>b</sup>	5(1)	13.9%
Rh Factor	2	5.6%
Hyperbilirubinemia only	1	2.8%
Hereditary	4	11.1%
Meningitis	2	5.6%
Unknown	12	33.3%

TABLE 9 (Cont'd)

	Number	Percentage
<u>Other Handicapping Conditions</u>		
None	24	66.7%
Physical & Ophthalmological only	3	8.3%
Developmental Delay Only	5	13.9%
2 or more handicapping conditions	4	11.1%
<u>Other Program Participation</u>		
HI-MAPS only	21	58.4%
Other parent-infant program <sup>c</sup>	6 (1)	16.7%
PT/OT or other program	9	25.0%

---

a Includes 4 children was also had hyperbilirubinemia.

b Includes 1 child who was premature and had hyperbilirubinemia.

c Includes 1 child who was enrolled in another parent infant program and received OT/PT.

TABLE 10

MATERNAL DEMOGRAPHIC CHARACTERISTICS

	Number	Percentage
<u>Age at Child's Birth</u>		
16-20 years	8	22.2%
21-25 years	9	25.0%
26-30 years	3	8.3%
31-40 years	9	25.0%
over 40 years	2	5.6%
Missing	5	13.9%
<u>Educational Level</u>		
8 years or less	2	5.6%
9-11 years	7	19.4%
High School Graduate/G.E.D.	6	44.4%
1-3 years college	6	16.7%
College Graduate/ Professional Degree	3	8.4%
Missing	2	5.6%
<u>Occupational Status</u>		
Housewife	11	30.6%
Business	1	2.8%
Maid	1	2.8%
Secretarial/Receptionist	2	5.6%
Student	2	5.6%
Nurse/LPN	2	5.6%

TABLE 10 (Cont'd)

	Number	Percentage
<u>Occupational Status</u>		
Shipping Clerk	2	5.6%
Journalist	1	2.8%
Teacher	1	2.8%
Missing	13	36.1%
<u>Household Income</u>		
Public Aid or SSI	15	41.7%
\$5,000-10,000	1	2.8%
\$10-000-20,000	7	19.4%
\$20,000-30,000	3	8.3%
over \$30,000	2	5.6%
Missing	8	22.2%
<u>Geographic Locaton</u>		
City	26	72.2%
Suburbs	8	22.2%
Rural	1	2.8%
Missing	1	2.8%

TABLE 11

PATERNAL DEMOGRAPHIC CHARACTERISTICS

	Number	Percentage
<u>Educational Level</u>		
8 years or less	1	2.8%
9-11 years	9	25.0%
High School grad/GED	6	
1-3 years college	7	19.4%
College grad/Professional degree	5	
Missing	8	22.2%
<u>Occupational Status</u>		
Bus Driver	1	2.8%
Welder	1	2.8%
Assistant Store Manager	1	2.8%
Machinist	2	5.6%
Cab Driver	2	5.6%
Laborer	2	5.6%
Burial Vaults	1	2.8%
Small Business Owner	1	2.8%
Mechanic	2	5.6%
Steel Worker	2	5.6%
Student	1	2.8%
Rabbi	1	2.8%
Army (Soldier Officer)	1	2.8%
Babysitting	1	2.8%

TABLE 11 (Cont'd)

<u>Occupational Status</u>	Number	Percentage
Camera Repairmen	1	2.8%
Accountant	1	2.8%
Utility Worker	1	2.8%
Non-employed or Unknown	13	36.1%

80

### C. SPECIAL PROBLEMS OF AN URBAN POPULATION

Because of the diversity of the population served by the HI-MAPS Project, there were large differences in the needs of the families. The project was a center-based program offering services from 8 a.m. to 5 p.m. on weekdays only. It was the responsibility of the individual families to provide their own transportation and to adjust their schedules to fit the hours of the center. This section describes these and other problems that families faced in regularly attending and forming a commitment to the program. Part D describes some of the changes made by the project to better meet the needs of a diverse population.

#### 1. Transportation

Because HI-MAPS served a large geographical area including four counties, transportation was a problem for families without cars. HI-MAPS did not provide, or pay for transportation, and bus fare was relatively expensive. The cost of one adult riding the city bus twice a week to bring the child to the center was \$4 a week. In addition, it was difficult for families with small infants and children to travel long distances by public transportation. While public transportation was good in the central city area, it was much less adequate in the outlying city areas. Furthermore, several parents had medical conditions which made it difficult to use the public transportation system. Several alternative sources of transportation were located by HI-MAPS staff; however, transportation was still a problem even at the end of the project. These alternate sources were as follows:

- 1) American Red Cross - volunteer drivers
- 2) Michael Reese Volunteer Office - volunteer drivers
- 3) Illinois Department of Public Aid - occasionally would include bus fare in family's monthly grant
- 4) Supplementary Security Income Office - occasionally would provide MediCar services
- 5) Carpooling amongst parents

The severe winter weather of Chicago further complicated the transportation problem. Program was cancelled during extremely cold weather (temperatures of -20°) and on days with heavy snow accumulation. However, transportation was still extremely difficult during the winter, and also the children were more prone to illness. Inconsistent attendance during the winter months was common.

## 2. Hard-to-Engage Families

As described in the previous section, the population served by the HI-MAPS Project varied considerably in parent's age, race and socio-economic status and the child's medical status and age of diagnosis. The following groups posed special problems for the HI-MAPS Project:

- 1) Children with chronic medical problems or other handicapping condition
- 2) Children with teenage single mothers.
- 3) Minority-status children.
- 4) Children with a history of child abuse or neglect.
- 5) Families desiring an oral program
- 6) Children diagnosed late.

Children with medical problems had difficulty attending the program regularly due to illness. Often there were long periods of absence (four weeks or more) due to surgery, illness or the undesirability of exposing the child to inclement weather. Some children with other handicaps also did not attend the program regularly if they were receiving additional services such as occupational/physical therapy. Parents of these children often had difficulty keeping several appointments in different places each week.

The second group of children, children of teenage single mothers was especially difficult to engage. Sometimes the mother was attending high school and had difficulty bringing the child to the center. Often these mothers were trying to cope with emotional and financial problems independent of the problems of being a parent of a handicapped child. In addition, some of the adolescent mothers may have been insecure about their own parenting skills, and may have felt threatened by seeing a competent professional interacting with their children.

Minority-status families also were difficult to engage. Differences between the socio-economic and racial characteristics of the staff and these families sometimes interfered with the family's identification with and commitment to the program. For some, 50-minute individual sessions may have been overwhelming especially if the teacher's style of interacting with their children was very different from their own style. The program's child development focus was interpreted by some parents as stressing "only play" and was not seen as being relevant to their child's hearing problem.

Families with a history of child abuse or neglect were one of the most difficult types of families to engage unless a court order and supervision by the Department of Child And Family Services provided structure. A beginning was made for working with other agencies such as the Visting Nurses' Association in cases where there was "medical neglect".

Families who desired an oral education for their children posed very different problems for the project. These families were very reluctant to involve their deaf child in a Total Communication program, but there were very few free oral programs in the Chicago area. Most of the parents were well-educated professionals who were very concerned that their children received a college education and have a professional career. They feared that sign language would interfere with the development of good oral skills and saw sign language as a last resort to be tried only if their child failed to develop good speech. Staff worked closely with these parents providing both reading materials and extensive parent counseling orientation by the parent counselor. Most of these families, however, transferred to private speech therapy.

The last group of children, children who were diagnosed late, were not necessarily difficult to engage, but rather could not be given full program services because of time constraints. Children who were referred to the project within six months of their birthday would enter a preschool program on their third birthday and consequently were involved in HI-MAPS only on a short-term basis. The priorities for these children were obtaining their hearing-aids and helping them learn to use their aids before they started the preschool program.

3. Problem Related to Coming to the Center

Scheduling appointments at the center between 8 and 5 on weekdays frequently posed three types of problems. For some families child care was a major problem. While families were encouraged to bring siblings to the individual sessions, generally siblings could not regularly attend. The nursery group sessions because of lack of space and staff. It was not always possible to provide child care services during the Parent Orientation Sessions. In addition, parents' own schedules needed to be arranged around the time constraints of school buses, carpools, and the like. Thus participation of some families in the program was limited by their inability to find child care services.

The fact the center was not open in the evenings and/or on weekends posed problems for working parents, especially when both parents wanted to participate. Both HI-MAPS staff and families attempted to accommodate work schedules. In some cases, one parent brought the child to the program while the other parent worked. Some parents had flexible working hours. Other parents used vacation time or holidays to attend the program. Phone calls were made and letters written to employers to discuss the HI-MAPS Project with them as well as the importance of the parents' participation in the program. During periods of unemployment, many fathers were able to attend. Some parents who could not attend arranged to have babysitters or other family members bring the child to the center. In these cases, contact was maintained with the parent through phone calls, letters, and occasional scheduled appointments. Every effort was made to include both mothers and fathers in the child's programming.

A third problem concerned late arrivals for appointments. Children in the HI-MAPS Project were scheduled for one hour individual sessions and/or 1½-2 hour group sessions. A number of families who participated in HI-MAPS were used to more traditional hospital clinics, where a clinic is scheduled for 1:00 p.m., but patients are seen on a "first come, first served" basis. Thus some may not be seen until 3:00 or later after waiting several hours. In HI-MAPS, however, children and families were seen at the scheduled times. Some families were able to accommodate, and arrived on time for appointments. Others were unable to arrive on time consistently and frequently did not call or cancel appointments.

D. Adaptation of HI-MAPS to Special Needs

1. Drop-In Group

The "Drop-In" Group was started in September 1981 to try to meet many of the special needs of the families described in the previous section. The goal of the group was to engage families who did not regularly attend the program. In first two years of the grant these families were often referred to other programs, because of their failure to keep regularly scheduled appointments.

The format of the drop-in group was more informal and unstructured than that of the nursery groups. The group met weekly for one 75 minute session; siblings, friends and family members were welcome to attend the group. The adults stayed in the group with the children during the whole time period so that the group served as a social group for the adults as well as being an educational session.

The play activities during the drop-in group were similar to those previously discussed in the nursery group sessions. In addition take-home materials were developed by the teacher's aide to help the families remember the activities of the day and help them share this information with other family members and friends. Family members were given picture cards related to the group food and/art activities which showed the activity and the sign for that activity.

Attendance in the group ranged up to five program children plus siblings and family members at any one session. The drop-in group was staffed by the teacher's aide plus one or two teachers depending on the number of children attending.

The drop-in group was helpful in maintaining contact between the program and families who had difficulty regularly and/or committing themselves to the program. These families could be served at the level of involvement desired by the family. Also, the group was very appropriate for children who were diagnosed late. These children received hearing-aid training and exposure to nursery group activities prior to their enrollment in school programs.

## 2. Program for Hard-of-Hearing Children

The HI-MAPS Project expanded its services to include hard-of-hearing children and their families in July 1980. A speech pathologist who was also a child development specialist was hired to serve children whose hearing loss ranged between 25 and 80 decibels.

A Total Communication approach was used by the hard-of-hearing teacher to facilitate the children's development of a functional system of communication. It was reasonable to expect that many of the hard-of-hearing children, especially those with moderate hearing losses, would develop adequate speech, and Total Communication was viewed as being compatible with that goal. The purpose of the hard-of-hearing program was similar to that of the main program: 1) A Total Communication approach to facilitate oral and manual language learning and 2) promotion of positive parent-child interaction.

The child and parent attended weekly 50-minute individual educational sessions. There were no nursery group sessions or parent counseling groups, individual parent counseling, parent orientation or sign language/communication skills classes for the parents of

hard-of-hearing children due to the lack of staff time. The activities of the individual sessions were similar to those described in the section (See Section II D). Speech related activities were tailored to the specific skills of each child.

### 3. Participating of Deaf Parents in the Counselling Groups

Use of a sign language interpreter was require when deaf parents joined the counselling groups. Even if the parent counselor had been fluent in sign, this would have been necessary. If the counselor had to speak for the deaf parents and sign for the hearing parents, these activities would have focused too much attention on her. By using an interpreter, the hearing parents were able to look at each other and still hear the communications of the deaf parents through the voice of the interpreter. Most deaf parents keep their eyes focused on the interpreter while they signed or spoke even though their remarks were addressed to a particular group member. If the parent counselor had been attempting to do the interpretation, this continual eye contact with the deaf parents would have interfered with her therapeutic role. The counselor must respond empathically and with sustained attention to all members of the group.

The interpreter was carefully selected. He/she needed to be accurate in interpreting the degree and nuance of affect so as to mirror as faithfully as possible the personality style of each individual group member. It was important for her/him to stay in the role of interpreter. An interpreter who was judgmental or gave advice would have been inappropriate. Discretion and absolute confidentiality were essential.

Occasional absences of the interpreter were utilized to encourage the hearing parents to try their wings. As they urgently needed the groups to express their feelings, this motivation was powerful enough to help them overcome self-consciousness. When the interpreter returned, an opportunity was provided to them to discuss the experience and their feelings about it.

While the primary purpose of the group was the expression of and working through feelings about the children's deafness, the presence of deaf parents helped to achieve other important objectives. They were able to practice relating to deaf people and could ask questions about their experiences growing up. The deaf parents served as adult models which gave hearing parents hope for their children.

E. NUMBER OF CHILDREN SERVED AND PROGRAM PARTICIPATION

Over the three year funding cycle of HI-MAPS, 68 deaf children and their families were referred for potential program placement and/or received project services. The length and type of program participation by the families varied considerably, depending on factors previously discussed in this section. Twenty-one children and their families received the comprehensive services of HI-MAPS described in Section II including both individual and group educational sessions (with accompanying sign language/communication skills class and parent counseling) and medical diagnostic services. Seventeen children and their families attended once a week for seven or more sessions, receiving either group educational sessions (with accompanying sign class and counseling) or individual educational sessions depending on their needs and schedules. Both individual and group services were not offered to these families because of their difficulties in maintaining regular weekly attendance or in attending twice a week due to the child's medical status or problems with transportation, child care or work schedules. After the creation of the Drop-In Group in September 1981, nine children who could not attend regularly were placed in the Drop-In Group and no longer received individual educational sessions. Nineteen children were inactive and could not be engaged in the program, or their parents decided to place them in another program. Children who were inactive were referred to another program that was better able to meet the child's and family's needs. Often these children were referred to the Chicago Public School Parent-Infant Program which provided transportation for the families. The attendance information is summarized in Table 12.

During the second year of funding, the hard-of-hearing program was started. Twenty-one hard-of-hearing children and their families was received educational services from July, 1980 to June 1982. Ten children actively participated in the program, attending for seven or more sessions. Eleven children who only served for a short-time, between three and six sessions.

TABLE 12

DEGREE OF PROGRAM PARTICIPATION

<u>Deaf Children (7/79-7/82)</u>	<u>Total 68</u>
1. Active participation: <sup>a</sup>	
a. Individual <u>and</u> group sessions	21
b. Individual <u>or</u> group sessions	17
2. Short term participation <sup>b</sup>	2
3. Drop-In Group (9/18-7/82)	9
4. Inactive/Transferred <sup>c</sup>	19

<u>Hard-of-Hearing Children (7/80-6/82)</u>	<u>Total 21</u>
1. Active participation <sup>a</sup>	10
2. Short-term participation <sup>b</sup>	11

- 
- a Attend 7 or more sessions.  
b Attended between 3 and 6 sessions.  
c Attended less than 3 sessions.

F. INCREASING COMMITMENT OF PARENTS TO THE PROGRAM

There were three factors which helped to increase commitment:

1) The attachment to the teacher; 2) understanding by staff of apathy as an adaptive defense; and 3) increased involvement by fathers. The primary factor in developing was trust in and attachment to the teacher. The teacher's confidence that child could learn was especially important at the beginning. If their relationship became strong, it sustained the parents through the months where gains were slow.

It was also helpful to have a teacher's aide who was a minority group member and was hard-of-hearing. Her presence in the playroom provided the parents many opportunities to ask her questions about her experiences growing up, how she acquired speech, attended college, and about her hobby of dancing.

The second most important factor in increasing commitment by parents was one understanding by staff of the way apathy was manifested at various times. Apathy can be described as an apparent lack of emotion, a lack of interest, a listless spiritless condition. It looked like indifference and lack of concern. Soon after the diagnosis, some parents were in a state of shock. Like accident victims, these parents were stunned, bewildered, docile and unresponsive. Not only was the news very difficult to comprehend but these families were also exhausted from having made prolonged and strenuous efforts to get help and a diagnosis. Often when they had presented their first suspicions to a pediatrician they were told: "He is just slow" or "You aren't stimulating him enough".

Some parents complied but many began a long and complex search to find specialists who would take them seriously and who knew where to refer them. When the diagnosis was finally made, many parents wanted a second opinion. Therefore, it was not surprising that they were overwhelmed with fatigue by the time they were ready to hear the definitive diagnosis. They were also angry about what they had been through and ashamed of their anger. It took time before they were able to trust professionals again.

Apathy re-surfaced at other times in the child's participation in the program. At those times it was best understood as a defense against unbearable shame and sorrow. Participation in the counseling groups helped parents express and resolve these feelings.

Involvement by fathers was the third factor which helped increase commitment to the program. The child needed to learn to communicate with both parents, and the mother needed the father's support. Many mothers found it difficult to explain technical information they were learning to other family members.

Involvement of the fathers in the group counseling sessions enlarged the range of topics discussed and the depth of feeling expressed. Often a mother and a father experienced the grieving process on a different timetable. In the group, each could find another parent who experienced similar emotions.

Several steps were taken to help bring fathers into the program. When the first contacts with the family were made, the importance of participation by both mothers and fathers was stressed. Orientation sessions were offered late in the day if this made it possible for

fathers to attend. Encouraging the families to bring siblings to the individual educational sessions prevented mothers and fathers from having to take turns babysitting.

Most important was acceptance by staff of non-traditional family structures. Some men functioned as parents even though they were not the child's natural fathers. Others, though natural parents, did not live in the same household as the child. Fathers who were unemployed were able to attend sessions during the day, yet felt sensitive about their lack of a well-defined role in the work world. A norm was set that all fathers were needed even those who were temporarily or permanently estranged from the mothers. During the three-year grant period, a few families were provided with some additional services which promoted the development of commitment to the program:

- 1) crisis counseling at the time of time of diagnosis
- 2) flexibility in scheduling educational sessions
- 3) resolution of transportation problems
- 4) prompt delivery of the hearing aid

The lack of these services for many of the parents was a serious hindrance to full commitment by all referred families.

#### IV. OTHER SERVICES

##### A. FACTUAL INFORMATION: EDUCATIONAL LECTURES AND WRITTEN MATERIALS

Throughout their participation in the program, the parents asked many questions. It was important for them to ask these questions in a variety of situations such as individual counseling sessions during the orientation. Group counseling and group educational sessions, weekly sessions with the teacher and with the sign language and communication specialist and consultations with audiologists and medical staff. The parents' questions can be grouped into eight themes:

- 1) What is the cause of deafness?
- 2) How is hearing tested?
- 3) Is there a cure for deafness?
- 4) Will my child speak?
- 5) How can I manage my child?
- 6) How will my child's deafness affect our family?
- 7) What will my child's future be like?
- 8) How can we relate to the community?

See Appendix for a list of some of the questions asked.

During the middle phase of the parents' involvement in the program, special educational sessions were scheduled to provide the parent groups with lectures on some of the above topics, e.g., Cochlear Implants (Dr. Laszlo Stein), Audiological Testing (Theresa Jabeley, Chief Audiologist) Auditory Brainstorm Response Test (Dr. Stein), Speech Development (Edith Goodman). These lectures provided a group of parents with the same

information by an "expert" in the field. Parents thus had an opportunity to talk with other parents who had heard exactly the same factual information and thereby clear up misunderstandings and at the same time express feelings raised by the topics.

The timing of the lectures was very important. Although most of the lectures were presented to parent groups in the middle of their program involvement because the parent counselor position was vacant, that time period was also psychologically appropriate for them. In the beginning phase, parents had difficulty processing complex factual information due to their shock and anxiety. As one parent in the middle phase said, "They explained everything to me at the beginning, but I couldn't hear it. Now I'm ready for a brush-up". The termination period was also unsuitable, for strong feelings resurfaced as parents prepared to terminate from the program and anticipated problems in their children's adjustment to school. Thus the middle period was the most appropriate time for the educational lectures and the ensuing discussion among parents.

To supplement face-to-face discussions, written materials were given to parents. These materials were designed to aid the parents in remembering verbal explanations and to help them interpret the program to their families, especially at the beginning of their participation. It seemed difficult for them to process large quantities of new information when they were overwhelmed by the shock of the diagnosis of deafness. If the father and other relatives were unable to attend regularly, they were dependent upon the mother to inform them. Written materials lessened the pressure on the mother to explain deafness to those whose support she needed.

At the Intake Session, parents were given a brochure describing the the program in layperson's language and listing the names and titles of the staff. This brochure helped parents remember the people they met and understand their roles. The brochure also described the Total Communication philosophy of HI-MAPS in order to aid parents who were comparing programs and different educational philosophies. The description of the medical, academic, and psychological components was usually more helpful to parents after they had experienced a few sessions and their initial anxieties had been allayed.

A second set of written materials described the nature and purposes of the audiological and medical tests given to the children (See Appendix). These fact sheets on testing were written in language that parents with an eighth-grade or high school education could easily understand. They were not appropriate for parents who had a limited reading ability or for parents who were still emotionally overwhelmed by the child's diagnosis.

The fact sheets were used on an individual basis by the staff after parents' questions were first answered verbally. Each page was independent and separate from the other pages; the staff decided on the appropriateness of giving each page for each family based on the parents' educational levels, desires for additional information and emotional states. If staff felt that a page would reduce rather than increase anxiety or would help to clarify the verbal explanation, that page was given.

Two additional types of written materials were developed to meet parents' more general concerns about developmental issues. The "Child Development Bibliography" (See Appendix) listed 21 books on child

development and child-rearing issues and presented a brief description of each book emphasizing its applicability to children with hearing impairments. The purpose of the bibliography was to help parents understand and deal with their hearing-impaired children using a child development perspective. In conjunction with the bibliography, a baby-sitting pamphlet (See Appendix) was developed that enabled parents of hearing-impaired children to give babysitters information about their children. Often parents felt very uneasy about leaving their children with people unfamiliar with deaf children. The babysitting pamphlet listed ways to get the child's attention, commonly used signs such as "EAT," "SLEEP," and information about the child's toileting, eating and sleep habits.

B. SCHOOL REFERRAL

In the State of Illinois, public education is mandated for hearing-impaired children from the age of three. Children "graduated" from the HI-MAPS Project near their third birthday at the time of their school placement. Children from suburban areas attended special education programs in suburban cooperative school districts. Children who lived in the city itself could either attend the Chicago public school program or a private school with a total communication philosophy, Holy Trinity. Ann Russell, Coordinator for Programs for Deaf Children for the Chicago Public Schools, was invited to a parent counseling group to explain the procedures for registering children in the Chicago public schools. Many parents, however, chose the program at Holy Trinity because of staff preferences.

HI-MAPS and Siegel Institute staff maintained contact with appropriate individuals in all the school programs in order to facilitate a smooth transition process for the children and their families. With the parent's permission, preliminary audiological, medical and educational information was sent to the perspective school prior to the child's entry. At the time of actual enrollment, a more comprehensive report with follow-up information was sent. Parents were encouraged to visit several school programs and meet with staff prior to program entrance. HI-MAPS staff were available to parents and classroom teachers for consultation regarding program placement and educational goals/objectives.

Towards the end of the third project year, there were complex changes in school registration procedures in the Chicago Public Schools. For this reason and because of threatened reductions in programs for

handicapped children, the parent counselor felt that the parents needed additional training in the advocacy role. For this purpose, a special workshop was provided on a Saturday morning. Former HI-MAPS families, potential enrollees and other area parents were also invited. (See the following section concerning Follow-Up Activities).

### C. FOLLOW-UP SERVICES

Organized follow-up services were instituted during the third year of the Project because the staff realized that the termination and transition process was especially stressful for parents. Many of the parents were also experiencing other family problems at the same time. Since the schools do not provide the degree of support and counseling which had been available in the HI-MAPS Project, it was important to extend these services at least while the school adjustment was being made.

The staff was also interested in receiving feedback from the parents about their problems with the new school systems and the children's reactions so as to be able to provide better transitional services in HI-MAPS. Three types of follow-up services were provided; these services were only offered on a trial basis in order to determine whether the services were desired by parents.

- 1) Reunions for parents and children which included a nursery group, a sign and communication class and a counseling group.
- 2) A parent counseling group for graduates which met for three sessions.
- 3) A three-hour advocacy skill training workshop.

#### 1. Reunion and Graduates' Groups

Eighty-three percent of the parents who graduated between August, 1981 and April, 1982 attended one or more of the Follow-up Meetings; this indicated a need for continuing support services.

The major themes discussed in the reunions and graduates' groups were parental acceptance of the deaf child and the child's place in the wider community. The parents explored such concerns as guilt over the

child's conception and compromises to their own identities caused by the special needs of the deaf child. Pressure from relatives or lack of support from them was a continuing problem.

The parents had many problems to solve as they assisted the child in becoming accepted by other neighborhood children. There was interest in safety precautions as the children began to venture out for greater distances. Lack of acceptance of sign language by neighbors and relatives continued to produce anger and shame. The deaf mothers wondered if their children's behavior problems were caused by their being deaf.

## 2. Advocacy Workshop

The advocacy workshop was designed for parents of hearing-impaired children up through elementary school, and notices were sent to all parents in both city and suburban school programs as well as to all HI-MAPS families who were or had been in the program. The following is a list of the outside organizations that presented at the workshop:

- 1) The Department of Services for Crippled Children - "Service to Your Child".
- 2) Illinois Parents of the Hearing-Impaired - "Parent Organizations".
- 3) MENDAC, Siegel Institute - "Mental Health Services for Children and Families".
- 4) The Chicago Hearing Society - "Program Offerings".
- 5) Coordinating Council for Handicapped Children - "Effective Parent Involvement In the IEP".
- 6) Legal Assistance Foundation - "The Legal Rights of Children in Special Education".

Over 50 parents and relatives attended the workshop. See the appendix for copies of the program and a report on the workshop.

Because of the large number of parents who attended the advocacy workshop and the follow-up counseling groups, it was decided to make both types of follow-up activities a regular part of the Parent Component. The success of these follow-up activities indicated the great needs of parents of school age hearing-impaired children.

D. SPECIAL ACTIVITIES FOR CHILDREN AND FAMILIES

Special parties were planned for birthdays, Christmas, and graduation of children from the program. These parties took place in the parent-child nursery groups or in the Drop-In group, and included special snacks and activities appropriate for the occasion. In addition to the HI-MAPS Christmas party, all families were invited to the annual Siegel Institute Christmas Party. Entertainment, gifts, and refreshments were provided. In 1981 a group known as the "Hands of Signs" provided entertainment with Christmas songs and poems performed in sign language. Santa Claus and his "signing" elf also attended. At this party parents and children had the opportunity to meet the other families enrolled in the HI-MAPS Program and attending other programs at Siegel Institute.

HI-MAPS families also had an opportunity to meet many of families in the program during field trips to the Lincoln Park Zoo. In June 1981 and May 1982, arrangements were made for a tour of the zoo with a guide who knew sign language. Children had an opportunity to touch and hold animals in the Children's Zoo, and see farm animals at the farm section. Transportation to the zoo and a sign language interpreter for the deaf parents were provided by the program. On both occasions, the local ABC-TV affiliate filmed the visit which was spotlighted on the local news. A photograph of one of the children holding a rabbit also appeared in the Chicago Tribune newspaper.

E. REFERRAL OF CHILDREN TO OTHER AGENCIES

If a family was referred to HI-MAPS and the program as not appropriate for the child, every effort was made by staff to offer assistance to the family in locating an appropriate program placement.

Families were referred to the following agencies and programs:

- 1) Illinois Deaf-Blind Service Center
- 2) Public School Parent-Infant Programs
- 3) Chicago Association for Retarded Citizens and its affiliated agencies.
- 4) Easter Seal Society
- 5) Illinois Institute for Developmental Disabilities
- 6) Chicago Hearing Society
- 7) Illinois Department of Children and Family Services
- 8) Juvenile Protective Association
- 9) Private Birth-3 Programs for Multiply Handicapped Deaf Children
- 10) Private Speech Pathologists and Educational Audiologists

V. EVALUATION OF CHILD PROGRESS

While there has been much documentation of the effects of early hearing deficits on the linguistic, academic and social skills of hearing-handicapped children and the need for early intervention, there has been little investigation of the effectiveness of such programs. Detailed evaluations of child progress are essential if parent-infant programs are to be truly effective. Because language delays have been one of the most visible and important problems associated with deafness, the present project was most concerned about evaluating the children's progress in developing communication/language skills.

Initially Dr. Steven Quigley and Cindy King, a doctoral graduate student of Dr. Quigley, designed the assessment procedures in their roles as consultants to the project. Because of the time and skills needed to implement the assessment procedures, a developmental psychologist was added to the project staff in 1981 as research coordinator. The original procedures were altered to include more information about the communicative functions of the child's communicative acts and the conversational skills of the child. Additional measures were added as a result of collaboration with Dr. Mark Greenberg, a psychologist at the University of Washington who recently completed an evaluation study of a parent-infant program for deaf children in Vancouver, British Columbia. Dr. Greenberg agreed to share his data with the HI-MAPS Project. His additional data was used as a first step in determining the typical levels of performance of deaf children who have received intervention services.

A. HI-MAPS SAMPLE

Six children and their parents who entered the project during the first year of the grant were studied. All these children were 24 months or younger at the time of entry and remained in the program for at least 14 months. One of the children had been in a deaf-blind program for 5 months before her vision in one eye improved and she was placed in the HI-MAPS Project. All the children had at least a severe hearing loss. Two of the children had additional handicaps, the child previously mentioned was blind in one eye and the another child had severe motor delays but no cognitive delays. Child characteristics for the following variables are presented in Table 13: age; hearing loss; age of diagnosis; age hearing aid received; age at first intervention; etiology; other handicaps; other program participation and age of first and last videotapes.

Parents of all six children were hearing parents, data on two children of deaf parents were collected but not analyzed because of time and personnel constraints. The maternal age at time of program exit ranged from 25 years to 41 years ( $\bar{X}=31.4$ , S.d.=6.21); parental age ranged from 23 years to 50 years ( $\bar{X}=32.9$ , S.d.=10.27). Maternal education ranged from high school degree to a bachelor's degree ( $\bar{X}=13.1$ , S.d.=2.20), while parental education ranged from the tenth grade in high school to a bachelor's degree ( $\bar{X}=12.2$ , S.d.=2.77).

TABLE 13

HI-MAPS CHILD CHARACTERISTICS

	<u>S1</u>	<u>S2</u>	<u>S3</u>	<u>S4</u>	<u>S5</u>	<u>S6</u>	<u>X̄</u>	<u>S.D.</u>
Age (months)	39	36	36	40	35	36	37	1.83
Age Suspected	birth	12	13	18	6	--	9.8	6.94
Age Diagnosed	11	13	12	23	14	14	14.5	4.32
Age received aid	16	17	16	26	17	18	18.3	3.83
Age at First Intervention	12	14	15	24	17	14 <sup>a</sup> , 20 <sup>b</sup>	16	4.24
Age began sign training	12	14	15	24	17	18	16.7	4.18
Hearing Loss (unaided)	95	70	110	80	90	90	89	13.57
Hearing Loss (aided)	45	38	60	44	35	40	44	8.82
Etiology								
Genetic	X						1	
Meningitis			X					
Rubella		X				X	2	
Unknown				X	X		2	
Handicap								
None		X	X	X	X		4	
One minor						X	1	
One major	X						1	
Parity								
Adopted						X	1	
First Born		X			X		2	
Later Born	X		X	X			3	
Other Program Participation								
Other Parent-Infant Program (once/week)	X					X		
OT/PT (4 times/week)	X							
Age at First Videotape	23	17	16	24	20	22	20.3	3.27
Age at Last Two Videotapes	35, 39	33, 36	33, 36	38, 40	31, 35	33, 36	33.8, 37.0	2.40, 2.0

- 
- a. Date of entry into Deaf-Blind Program.  
 b. Date of transfer from Deaf-Blind to HI-MAPS.  
 The date of entry into the Deaf-Blind program was used to calculate the mean date of entry.

B. PROCEDURE

Each family was videotaped at least five times during their program participation at approximately three to five month intervals. The first videotape was made near the time of program entry and the last videotape at the time of program exit. Each child was videotaped in a free play situation with one or both parents in the center's gross motor room which contained a slide, trampoline, tunnel, rocking horse and stairs in addition to small toys. Initially the parents were told to engage in specific activities such as blowing bubbles, making popcorn, and hiding objects under boxes. However, if the child wanted play with other toys, the parents were told that they could follow their child's interests.

The first videotape was filmed as close to the time of program entry as possible, depending on the parents' comfort in the program. One child had been receiving parent-infant services at Siegel for 11 months before the videotaping was started. The videotape equipment and operator were located in the one corner of the groups motor room. Parents were told that the purpose of the videotaping was to evaluate changes in their child's language and communication skills. The length the initial videotaped sessions ranged from 23 to 35 minutes, and included a three to five minute separation sequence where the parent(s) left the child in the room. The separation occurred during the middle of the videotape session; if it was difficult to quiet the child when the parent returned, the videotaping was stopped until the child was calmer. A separation episode was included in the final and middle videotapes.

The videotape procedures were altered by the research coordinator so that the separation sequence came at the end and not in the middle of the free play period. The videotape equipment and operator were placed in the adjacent observation room with a one-way mirror so the videotaping was less intrusive. The final changes in protocol was that if both mother and father were present, each was videotaped individually with the child. Two children were videotaped interacting with mother and father separately. For this report, only the data for the child-father interaction are presented. The other four children were videotaped only with their mothers.

1. Coding Procedures

The videotapes were transcribed for all the child's communicative acts-- gestures, points, signs, communicative vocalizations. Communicative vocalization were defined as either vocalizations accompanying a gesture, point or sign or as vocalizations where the child tries to make eye contact. A distinction was made between gestures and action-gestures. Action-gestures were defined as the following types of actions involving: 1) showing an object; 2) requesting objects; 3) refusing by pushing away the object and 4) giving an object where a response is expected beyond accepting the object, e.g., giving mother the jar of bubbles so mother will open the jar. Gestures did not directly involve any objects; for example, raising one's shoulders and holding one's hands palms up was coded as a gesture for "I don't know". Action-gestures were coded for only the first 12 minutes of the videotape.

The research coordinator and at least one hearing native signer coded all the children's communicative acts in the last two videotapes. For four of the children, a hard-of-hearing coder who was fluent in ASL was a third coder. In cases of disagreements between the native signer and the hard-of-hearing coder, the sign language/communication specialist, a hearing native signer, was consulted. Whichever of the two transcriptions that agreed with hers was accepted; if all three coders agreed that the child was signing but differed in their transcriptions, then the utterance was coded as an unintelligible signed utterance.

All the parents' utterance, gestures, action-gestures, and points were transcribed by a single coder for the first 12 minutes of the last two videotapes. In remaining portions of the videotapes, only parental utterances that directly preceded or followed a child communicative act were transcribed.

Transcription of the videotapes is still in progress. In this report only data from the last two videotapes for all six children are presented. Since reliability checks on the entry videotapes have not yet been completed, no comparisons of the first videotapes with the final videotapes are presented in this report.

Reliability checks on the parents' communicative acts and utterances performed on 20% of the videotapes. There was 89% agreement on morphemes, 94% agreement on signs, 89% agreement on attention-getting gestures, 72% agreement on points.

To assess children's linguistic skills the upper bound of the six longest signed utterances was calculated for each child for each of the last two videotaped sessions. The length of the signed utterances was calculated using Hoffmeister, Moores and Ellenberger's 1975 guidelines with the exception that verb signs which incorporated location were counted as two signs units rather than a single sign unit.

The children's conversational abilities were also examined. Each of the child's communicative acts was coded for its conversational function with respect to the preceding parental utterance. The conversational codes were based primarily on Bloom, Rocissano and Hood (1976). The child's communicative act was not coded as a turn in the conversation if its pragmatic function could not be determined (e.g., in the air to no visible object and parent makes no response or parent asks "What?" with no response from child). Communicative acts that were only imitative in function were also not coded as a turn (e.g., parent directly elicits the imitated act and child imitates without adding any new information in that act or subsequent acts).

Turns in a conversation were coded into two mutually exclusive categories: non-adjacent and adjacent acts. If there were no preceding parental utterances within 3 seconds of the child's act, the child's act was coded as nonadjacent. If there was a preceding parental utterance, the act was coded as adjacent and was further differentiated into the following four categories:

- 1) New aspect: The child's act introduce a new activity with the same object or introduces a new topic related to the original topic (e.g. Mother "Get the doll's shoes", Child "Wash" (wants now to wash the doll)).
- 2) Expansion: The child's act adds new information to the preceeding utterance without changing the topic. (e.g., Mcther "See ball", Child "Big").
- 3) Maintain: Child's act maintains the topic without adding new information (e.g. Mother "This is a dog", Child: Nods heads).
- 4) Unrelated: The child changes the topic of the conversation (e.g., Mother: (pts. dog) "Dog", Child: "Want bubbles")

Each communicative act or series of acts by parent and child was counted as a turn in the conversation, except for unrelated acts that did not elicit a related response from the other person.

The coding of each of the child's communicative acts for their sematic and pragmatic functions is still in progress. Halliday's categories of pragmatic functions are being used, but realiability checks of the coding have not yet been made.

### C. RESULT AND DISCUSSION

#### 1. Upper Bound of Communicative Acts

The upper bound of each child's communicative acts varied from 2.0 to 7.5 in session 4, the second to last videotape ( $\bar{X}=3.47$ , S.d.=2.03). All the children each produced at least six utterances containing two sign units. However, since pointing and gestures were counted as a sign unit using Hoffmeister et al's guidelines, it should not be concluded that all six children were productively combining two signs, not including pointing as a sign. Only three children combined two or more signs together on session 4; and only two of these children produced at least three 2-sign utterances.

In the last session, session 5, the upper bound varied from 2.2 to 8.5 ( $\bar{X}=3.67$ , S.d.=2.5). Three children produced at least three 2-sign utterances, and one child signed three single verb signs which incorporated the location of the object. Thus there were large individual differences in the children's linguistic skills. At one end there was one child with an upper bound of 7.5 and 8.5 sign units while at the other end there were some children who were just starting to combine two and three signs together in a single utterance. The variations in the speed with which deaf children acquire linguistic skills may depend heavily on factors such as etiology of the hearing loss, parental sibling sign skills, and child's level of cognitive development and pretend play skills. The most advanced child in the sample was unique in that all the members of the immediate family were very fluent signers and started learning to sign soon after the diagnosis. In other families, usually only there was only one if any fluent signers.

There were also wide variations in how the children used their communicative acts. Although the classification of the semantic and pragmatic functions is tentative pending reliability checks, the preliminary coding indicates that the deaf children rarely used their communication modes to ask questions, to engage in imaginative play, or to convey information unknown to the audience (i.e. information not already present in the context or setting; this does not include requests for absent objects). Instead most communicative acts were used to request objects, express desires, and to engage in social interaction (e.g. attention getting devices, ritualized games, and naming objects where the parent already knew the sign label).

Other researchers (e.g. Day 1982) have also found that young deaf children ask few questions and only rarely communicate about absent objects or past/future events. Most questions that are asked are "where" questions which function as requests for objects rather than requests for information. In the present study only two children produced three or more acts with the heuristic function. Only one child, the most linguistically advanced child produced more than three acts with the information-giving and imaginative functions in sessions 4 and 5. Interestingly, most of that child's information-giving utterances related to imaginary pretend play. Of the 76 utterances in sessions 4 and 5 with an information function, 11 were responses to real questions, 18 were not related to pretend play and 47 involved imaginary pretend play. These preliminary data suggest that imaginary pretend play may be very important for the expression and/or development of the information function of language. While Bates and others have demonstrated that hearing children's language development parallels

their symbolic play development, the present preliminary suggest a more specific relationship between language and imaginary pretend play. More research is critical in trying to understand how to promote the language development of deaf children especially with respect to their use of language for information purposes. Analysis of the parents' communication systems in all the videotapes is planned as a first step in examining the role of parental input on deaf children's development of linguistic skills.

## 2. Modality of Communicative Acts

The HI-MAPS Project used Total Communication in order to facilitate the deaf children's development of both speech and sign language and the simultaneous use of both modalities. The mean percentages of modality use in sessions 4 and 5 are presented in Table 14. Bimodal use of voice with signs, gestures and pointing comprised 38% of the communicative acts in both sessions 4 and 5. Sign language was the dominant modality for the group as a whole; about 45% of the acts contained one or more signs.

TABLE 14

Mean Percentage of Modality Use in Sessions 4 and 5

Mode	Session 4		Session 5	
	$\bar{X}$	SD	$\bar{X}$	SD
1. Vocalize Alone	11.7	6.9	15.2	13.9
2. Pointing Alone	17.3	14.1	13.2	8.0
3. Gesture Alone	7.8	8.9	8.2	6.6
4. Sign Alone	24.5	17.6	25.7	16.9
5. Pointing & Vocalize	11.5	9.3	6.5	5.4
6. Gesture & Vocalize	3.2	2.6	8.7	8.9
7. Sign & Vocalize	22.8	17.1	23.0	10.5
8. Unimodal (Modes 1+2+3)	62.5	12.5	61.7	7.5
9. Bimodal (Modes 5+6+7)	37.5	12.5	38.3	7.5

The average rate of communicative acts per minute was 3.46 acts/min. (SD=2.11) in session 4 and 3.2 acts/min. (SD=.91) in session 5. About half of the communicative acts were spontaneous. Spontaneous communicative acts were defined as acts that were not directly elicited (i.e. not a response to a command or question) and not imitated. In session 4, 48.2% of the children's communicative acts were spontaneous (SD=14.3), and in session 5, 57% (SD=13.9) were spontaneous. Directly elicited acts were the second most frequent types of communicative acts:  $\bar{X}$ =33.7%, SD=6.9 for session 4;  $\bar{X}$ =34%, SD=12.7 for session 5. Imitated communicative acts where the child did not add any new information were the least frequent:  $\bar{X}$ =18.2%, SD=17.2 in session 4;  $\bar{X}$ =15%, SD=14.7 in session 5.

There were large individual differences, however, in the percent of imitated utterances especially. For five children, spontaneous and directly elicited communicative acts were the most frequent and second more frequent communicative acts respectively in both sessions 4 and 5. But for one child, imitated acts comprised 40% of the total communicative acts in both sessions 4 and 5. Imitation without comprehension was a problem for this child.

### 3. Conversational Skills

Analysis of the children's skills in initiating and maintaining conversations indicated that the average length of a conversation across all the children was 3.2 turns/minute (SD=.43) in session 4 and 3.5 turns/min. (SD=.72) in session 5. The average frequency of conversation between child and parent was 1.39 conversations/minute (SD=.74) in session and 1.22 conversations/minute (SD=.43) in session 5.

Expansion of the preceding parental utterance was the most frequent conversational function served by the children's communication acts in session 4 for the group as a whole as well as for each individual child, group  $\bar{X}=43.5\%$ . This was also true in session 5 except for one child, group  $\bar{X}=34.5\%$ . The second most frequent conversational function of the children's acts was to initiate or attempt to initiate conversations with their parent using nonadjacent acts. This was true in session 4 and 5 for the group as a whole as well as for each individual child, group  $\bar{X}=30.7\%$  in session 4; group  $\bar{X}=34.7\%$  in session 5. See Table 15 for the average percentages of all the conversational functions.

More detailed analysis of child's conversational skills will be conducted after the parents' utterances are analyzed.

TABLE 15  
 MEAN PERCENTAGE OF CONVERSATIONAL FUNCTIONS  
 IN SESSIONS 4 and 5

Conversational Function	Session 4		Session 5	
	$\bar{X}$	SD	$\bar{X}$	SD
Nonadjacent Acts	30.7	4.5	34.7	11.20
Adjacent Acts				
New Aspect	11.8	8.5	7.7	7.7
Expand	43.5	11.8	34.5	11.5
Maintain	9.7	6.7	20.7	13.7
Unrelated	4.5	2.5	2.8	2.7

4. Comparison of HI-MAPS sample with Vancouver sample

Twelve children who had recently graduated from the Deaf Children's Society, a parent-infant program in Vancouver Canada, were studied by Dr. Greenberg. (See Greenberg (1982) for his full report). Table 16 presents the demographic data for the children in the Deaf Children's Society. These children were videotaped with their mothers in a 15 minute free play situation, a four minute puzzle-making sequence and a three minute picture drawing sequence.

Unfortunately the HI-MAPS sample and Vancouver sample were not well matched due to the following differences: 1) The average age of the HI-MAPS sample was 8 months younger than that of the Deaf Children's Society ( $p < .05$ ); 2) The average aided hearing level of the HI-MAPS program was significantly better than that of the Deaf Children's Society ( $p < .001$ ). Furthermore, additional caution is needed in interpreting the results of any comparison of the two samples because the tasks and the settings were very different in the samples. The Vancouver group was videotaped in their homes, and their communicative acts were analyzed only during the puzzle making and picture drawing sequences which were much more structured than the free play situation. Mothers were told to have the child put two puzzles together and draw a picture of a person with their child. In contrast the HI-MAPS samples were videotaped at the center in a free play situation.

TABLE 16  
CHILD CHARACTERISTICS OF  
VANCOUVER, CANADA PROGRAM

	$\bar{X}$	SD
Age (months)	43.8	9.2
Age Suspected	8.3	6.9
Age Diagnosed	12.4	6.9
Age Received Aid	17.2	5.4
Age at First Intervention	20.4	10.1
Age Began Sign Training	20.8	10.0
Hearing Loss (unaided)	97.1	12.7
Hearing Loss (aided)	72.5	15.7
Etiology		
Genetic	4	
Rubella	0	
Meningitis	2	
Unknown	6	
Handicap		
None	9	
One Minor	1	
One Major	2	
Parity		
First Born	4	
Later Born	8	

Table 17 presents the distribution of use of manual vocal modes of communication for the two samples. In order to make the categories comparable across samples, the categories pointing, gestures and action-gestures were grouped together. Greenberg's categories of verbalization and vocalizations were combined into one category. The HI-MAPS data was based on the average percentage of modality use of all six children in the session 5. Only the first 12 minutes of session 5 were used since action-gestures were coded only for that time period. There were no significant differences between the two samples; however, the HI-MAPS group tended to use more bimodal communicative acts,  $t(16)=1.89$ ,  $p < .10$ . This tendency of HI-MAPS children to use their voice more than the Vancouver children when signing and gesturing may reflect their lower aided hearing loss. Thus even though the children in HI-MAPS and those in the Deaf Children's Society were not well matched for age, aided hearing loss, they appeared to be very similar in their distributions of the use of different modes except in their use of bimodal versus unimodal communicative acts.

The frequencies of communicative acts per minute and percentage of spontaneous imitated and directly elicited acts were measured in both samples but the variables for two groups were not compared due to the large differences in the testing situations. These variables can be strongly affected by task, so that such comparisons would not very meaningful.

TABLE 17

Mean Percentage of Modality Use

Mode	HI-MAPS		Deaf Children's Society	
	$\bar{X}$	SD	$\bar{X}$	SD
Vocalization & verbalization alone	13.4%	13.5	28.2%	31.0
Sign alone	17.8%	10.6	27.9%	32.5
gesture/action-gesture/ pointing alone	28.8	11.7	22.0%	24.2
Voc/verb & sign	21.6%	17.9	15.7%	
Voc/verb & gesture/ action-gesture/pointing	18.4%	14.36	6.2%	12.4
Total vocalization & verbalization	54.2%	10.23	50.1%	
Total use of signs	39.6%	27.3	43.6%	38.6
Total use of gesture/ action-gesture/pointing	47.2%	23.8	34.2%	36.1
Unimodal	60.0%	13.0*	78.1%	36.1
Bimodal	40.0%	12.9*	21.9%	36.1

\*p < .10

## 5. Conclusions

This evaluation of six children in the HI-MAPS Projects clearly indicates that these children have made progress in developing effective communication systems including a formal linguistic system based on sign language. The results of the present study are consistent with the teachers' records and observations. At the time of program exit, all of the children were starting to combine two signs together and all had vocabularies of over 70 signs. However, equally striking to both staff and parents themselves were the enormous individual differences in rate of language development. Furthermore most of the deaf children fail to show all the pragmatic functions of communicative acts that hearing children exhibit.

At present little is known concerning the factors that are responsible for individual differences among deaf children with respect to both the speed of acquisition of linguistic systems of communication and the kinds of functions expressed by their linguistic acts. The fact that hearing parents are usually not native signers of ASL and that the deaf children are usually not exposed to native signers makes the study of individual differences in deaf children extremely complicated. The research coordinator will continue to analyze the videotapes to examine how parental input and children's pre-existing communication skills at time of program entry affect rate of language development including semantic, pragmatic and conversational functions. Only when we have more knowledge about these issues will we be able to develop optional programs for each individual deaf child.

## VI. DEMONSTRATION AND DISSEMINATION ACTIVITIES

Demonstration/dissemination activities of the HI-MAPS Project

served several purposes:

- 1) increasing the general public's awareness of the issues and services related to hearing impairment;
- 2) providing specialized information about the project to professionals in the area of deafness and early childhood education and;
- 3) providing information to medical professionals about the identification and referral of hearing-impaired children;

Staff developed several types of dissemination activities for each of the different goals. Technical assistance in the area of demonstration/dissemination was provided by Ms. Jeffri Brookfield of WESTAR. With her input, staff members were able to develop a program format that would be effective for the various target populations.

### A. INCREASING GENERAL AWARENESS

The media was the most effective method for providing information concerning hearing impairments and its effect on the child and family. In 1978, WBBM-TV, the local CBS affiliate, produced a television documentary called "The Signs of Love" about a deaf child and his mother who participated in the Siegel Institute Parent-Infant Program. This film has been aired several times, and was used extensively in HI-MAPS presentations to medical, professional and general public audiences. It provided an excellent description of the importance of early diagnosis, the emotional impact on the family, and the similarities and differences in raising a deaf child.

The HI-MAPS Project itself has been featured in several news programs. The local ABC network aired two newspots concerning trips to the zoo, and the Cable News Network aired a short 2-part feature on the

impact of the HI-MAPS Project on deaf infants and their families. The latter feature was shown nationwide, and presented the children interacting with their parents and the staff in the nursery groups. Parents and staff were also interviewed, and their statements focused on the effects of deafness both with respect to the child's development and the parent-child relationship.

Public awareness on issues related to deafness was also increased by talks to local services organizations, such as the Infant Aid Society and volunteer hospital groups. Slides and films were especially effective in obtaining the audience's attention and interest. In these talks, staff described the need for parent-infant programs and the kinds of services offered by the HI-MAPS Project.

B. INFORMATION TO PROFESSIONALS IN THE AREA OF DEAFNESS  
AND/OR EARLY CHILDHOOD EDUCATION

HI-MAPS staff members provided information to professionals working with children or deaf persons through presentations at local, state and national meetings and conferences and through tours of the program. At the state and local levels, presentations were made to organizations such as the Chicago Association for the Education of Young Children, The United Cerebral Palsy Symposium, The Illinois Parents of The Hearing-Impaired, and Illinois Teachers of the Hearing-Impaired. In addition, in-service training and lectures about the program were given to early childhood and special education students at local universities (e.g. Erickson, Roosevelt University, Loyola University). At the national level, presentations were made at the A. G. Bell Association of the Deaf, the DEC/HCEEP Conference, and the INTERACT Conference on Infants. (See Appendix for a list of all presentations).

Information about the program was also disseminated through tours of the program and attendance at conferences. Tours of the program were especially useful in demonstrating its child development focus. Visitors to the program varied greatly and included audiologists, staff at affiliated agencies, teachers from other parent-infant or preschool programs, and university students and faculty. In addition attendance at conferences provided staff with opportunities to meet and talk with professionals from other parts of the country (See Appendix for conferences attended). As a result of attendance at one such conference, the Society for Research in Child Development, contact was

established with Dr. Mark Greenberg who has shared his evaluation data of a parent-infant program in Vancouver, British Columbia with HI-MAPS. (See Section V Part C for comparison data).

Queries from other programs serving deaf children have resulted from the dissemination efforts. Letters have been received from programs in Canada as well as programs in Illinois concerning the kinds of services to give deaf children and their parents, as well as program materials developed by HI-MAPS such as The Data Base Form and The Child Development Bibliography.

C. INFORMATION TO MEDICAL PROFESSIONALS

As part of the medical emphasis of the project, staff members provided monthly in-service training to third-year medical students from the University of Chicago and Chicago Medical Schools, as well as to residents in Pediatric Medicine at Michael Reese Hospital. The topic stressed the most was the importance of early identification of a hearing loss and the availability of the ABR Test for infants. In connection with this subject, staff members noted that many parents' early concerns about possible hearing loss had been discounted by professionals. Additional topics of the in-service training included causes of deafness in early childhood, the emotional problems associated with accepting the child's deafness, the importance of parent-infant programs, and an overview of the HI-MAPS Project.

Information about the project was also presented to the medical staff at Michael Reese Hospital as well as the general public through the "Michael Reese News", a monthly publication of the Medical Center. Several articles were written about the program describing the needs of the children and families and the services provided. Copies of the "Michael Reese News" were distributed to all departments and public areas within the Medical Center.

## VII. PROGRAM DEVELOPMENT AND ADMINISTRATION

### A. STAFF DEVELOPMENT

As part of a training session on Staff Development conducted by Jeffri Brookfield of WESTAR, HI-MAPS staff developed descriptions of each independent role. In some cases, one staff member served two roles (e.g. Director and Head Teacher), but the duties of the roles are described below independently. The descriptions were updated as responsibilities changed and duties evolved.

#### DIRECTOR

##### I. Staff supervision

##### II. Project Development

1. Develop staff development system
2. Develop demonstration/dissemination plan
  - a. Target audiences
  - b. Message
  - c. Timelines
  - d. Resources/Responsibilities
  - e. Method/Distribution
  - f. Evaluation
3. Complete Program Development and Administration section of Final Report

##### III. Public Relations

1. Connect with referral sources, maintain ongoing contact
2. Make contact with media to publicize program
3. Develop brochure and slide presentations
4. Maintain school contacts to facilitate placement of project children through phone calls, visits, and correspondence
5. Advisory Council

- a. Schedule
- b. Develop agenda for meetings
- c. Chair meetings
- d. Invite members to observe direct services

IV. Training

1. Supervision of Staff
2. Organization of in-service sessions
  - a. mental health
  - b. child development
  - e. assessment formal, informal
  - f. sign language
  - g. hearing aids
  - h. ABR
3. Group meetings
  - a. weekly administrative meetings of HI-MAPS staff

V. Demonstration/Dissemination

1. Schedule visits by interested persons in the community
2. Make contact with agencies, organization, and universities regarding project
3. Follow-up visits with evaluation and feedback
4. Prepare papers/workshops for interested groups
5. Respond to phone calls and letters regarding project services

VI. Reporting

1. Prepare semi-annual progress reports for federal government and hospital departments
2. Meet with hospital Fund Accountant

VII. Budget Management

1. Review expenditures
2. Review with department head purchase of project materials, supplies, equipment, etc.
3. Develop with department head, yearly project budget

HEAD TEACHER

- I. Provide supervision to teacher(s) (weekly one hour individual meetings)
  1. Child/parent interaction
  2. Child developmental stages
  3. Teaching techniques
  4. Language development
  5. Auditory training
  6. Administrative/Coordination tasks
  7. Parental involvement and concern
  
- II. Intra-Staff Communication
  1. Coordinate teaching activities with other teachers and staff regarding individual/group sessions
  2. Placement of children within project.
  
- III. Intake
  1. Informal assessment of child's language and communication mode
  2. Informal assessment of parent's needs and readiness for program
  3. Informal assessment/observation of parent/child relationship
  4. Explanation of program
  5. Answer parents' questions regarding hearing loss

TEACHERS (Head Teacher & Teacher)

- I. Assessment
  1. Assessment of parent's communication modes
  2. Assessment of child's communicative skills
  3. Integrate information from Bayley/Gesell into program
  4. Integrate information from Otological/Audiological assessments into program

5. Record keeping of individual sessions
6. Record keeping of group sessions
7. Videotaping child-parent interaction

II. Direct Service

1. Prepare lesson plans
2. Develop ongoing short-term objectives for child/parent
3. Evaluate each session
4. Develop IEP for child

III. Skills with Parents

1. Explain testing results
2. Answer questions
3. Train in use/care of hearing aids
4. Demonstrate/model communication techniques

IV. Administrative Tasks

1. Coordinate patient records
2. Participate in hiring procedure for new staff

V. Demonstration-Dissemination-Program Development

1. Lecture to medical students about HI-MAPS project
2. Presentations at conferences
3. Coordinate observation/discussion of program for visitors
4. Complete Educational Component Section of final report
5. Develop new program services

VI. Multidisciplinary Team Interaction

1. Weekly meetings with other staff regarding play group, sign/communication class and parent group

2. Weekly administrative HI-MAPS meetings
3. Arrange diagnostic medical appointments for children

VII. Coordinating Transition to Other Programs

1. Visitation of other programs in the area (parent/infant, pre-school)
2. Give information on programs to parents 6 months before termination
3. Send reports and information to school personnel
4. Follow-up

VIII. General Agency Coordination

1. Awareness of referral sources and agencies
  - a. collect program brochures
  - b. program visitation/correspondence
  - c. maintain file on agencies
2. Refer parents for needed additional services (in conjunction with Parent Counselor)
  - a. individual counseling
  - b. Department of Public Aid
  - c. Division of Services for Crippled Children
  - d. transportation
  - e. medical services
  - f. coordination with other pre-school programs
  - g. Supplementary Security Income Office
3. Coordinate referrals from outside agencies
4. Maintain ongoing communication with other agencies who have received referred parents

ASSISTANT TEACHER

I. Direct Service

1. Assist teachers in providing services to groups of parents/children
2. Assist in the development of long and short term goals for children and parents
3. Assist in evaluating sessions

II. Assessment

1. Assist in recording keeping of group sessions
2. Assist in reviewing videotapes

III. Multidisciplinary Team Interaction

1. Weekly meeting with other staff regarding each play group, sign/communication class and parent group
2. Weekly administrative HI-MAPS meeting

PARENT COUNSELOR

I. Direct Service

1. Crisis Counseling at the time of diagnosis
2. Intake (with the Head Teacher)
3. Parent orientation including counseling, taking the family history, completing the data base form, providing information about deafness
4. Group counseling
5. Short-term Individual and marital counseling
6. Preparation for termination
7. Follow-up including reunions and short-term groups
8. Organize educational sessions and advocacy training for parents
9. Prepare written material for parents

II. Multidisciplinary Team Interaction

1. Weekly meeting with other staff regarding play groups, sign and communication classes, and parent counseling group
2. Weekly administrative HI-MAPS meeting
3. Discussions with audiologist, electrophysiologists, and teachers regarding individual children

III. Assessment

1. Administer the Schmerber Parent Attitude Survey and the Inventory of Parent Experiences
2. Develop assessment tools
3. Collect and analyze demographic information
4. Maintain records of group counseling sessions

IV. Administrative

1. Participate in interview and selection procedures for new staff

V. Demonstration/Dissemination

1. Respond to phone calls and written requests for information
2. Speaking engagements and presentations
3. Complete Parent Component section of Progress Reports and Final Report
4. Develop new program services

TEACHER FOR HARD-OF-HEARING CHILDREN

I. Assessment

1. Record keeping of individual sessions
2. Assessment of child's communicative skills
3. Assessment of child's auditory skills
4. Assessment of child's emotional-social skills

II. Direct Service

1. Write goals/objectives for child progress
2. Answer questions
3. Train in use/care of hearing aids
4. Demonstrate/model communication techniques
5. Develop goals for parents

IV. Coordinating transition to other program

1. Arrange visit schedules
2. Contact other agencies
3. Interpret information from other agencies to parent
4. Send appropriate reports
5. Arrange transition to other programs

V. Multidisciplinary Team Interaction

1. Consult with teacher(s) regarding speech/language development of deaf infants and toddlers
2. Gather speech/language materials for staff review
3. Assist with instrument development
4. Attend administrative HI-MAPS meetings
5. Participate in hiring new staff
6. Develop Child Development Bibliography

SIGN LANGUAGE AND COMMUNICATION SPECIALIST

I. Parent Communication Classes

1. Plan and conduct sessions
2. Prepare and distribute relevant materials
3. Integrate parent requests into class format
4. Relate observation of classroom information to parents
5. Answer parents' questions
6. Plan food activity and carry out food activity with parents in nursery group
7. Discuss teaching techniques related to language of signs

8. Discuss language development related to language of signs
9. Participate in designated group activities to observe child's communication skills

II. Staff Communication Classes (as needed)

1. Plan and conduct sessions
2. Prepare and distribute relevant material
3. Integrate child data/parent request/teacher's request into class
4. Relate information to teacher from parent communication class
5. Answer teacher's questions
6. Discuss teaching techniques related to language of signs
7. Discuss language development related to language of signs

III. Multidisciplinary Team Interaction

1. Attend weekly meeting with other staff regarding play group, sign/communication
2. Attend weekly administrative HI-MAPS meeting
3. Participate in hiring new staff

IV. Assessment

1. Record keeping of communication class
2. Child data collection in group
3. Check transcription of video-tapes as needed

V. Demonstration/Dissemination

1. Public speaking engagements
2. Complete Sign Language/Communication Class section of Final Report

RESEARCH AND ASSESSMENT COORDINATOR

I. Research

1. Development of assessment forms and administration for of videotapes

- a. language development and communication skills
  - b. parent-child social skills (with parent counselor and hard-of-hearing teacher)
  - c. parent's communication skills (with communication specialist)
2. Development of assessment forms for teachers' assessment a child's communication skills
    - a. child's communication skills
    - b. parent's communication modes
    - c. child's play activities
    - d. record forms for individual and group sessions
  3. Analysis and reporting of data from videotapes

II. Training of Coders

1. Develop and implement training procedures for:
  - a. transcribing videotapes
  - b. use of assessment forms
2. Evaluate training
  - a. check reliabilities for assessment tools

III. Supervision of Outside Students

1. selection of students for placement
2. provide orientation
3. report to educational institution
4. develop training schedule (selection of experience)
5. training

IV. Administration

1. hiring
2. staff evaluation
3. OSE proposals and reports
4. reports for Siegel Institute
5. budget

V. Multidisciplinary Team Interaction

VI. Demonstration/Dissemination

1. Respond to phone calls and letters requesting information
2. Prepare papers for presentations

VII. Direct Intervention

1. maintain ongoing contact with project families through participation in parent/child groups

Staff were selected to represent the following multiple disciplines:

- 1) Head Teacher (1979-82) Valerie Feldman, M. Ed. in Early Childhood Education, Erikson Institute.
- 2) Teacher (1979-80) Rose Ann Rodabaugh, B. Ed. in Deaf Education and Elementary Education, Bowling Green State University; Certification from Portland State University and Infant Hearing Resource Center as Parent-Infant Specialist for the Hearing Impaired.
- 3) Teacher (1980-82) and Assistant Teacher (1979-80) Miriam Sherman Kaplan, B.S. in Communication Disorders with a focus on Auditory Disorders, University of Wisconsin.
- 4) Assistant Teacher (1981-82) Hershella Hearn, B.A. in Business Administration, Gallaudet College.
- 5) Hard-of-Hearing Teacher (1980-82) Edith Goodman, M.A. in Speech Pathology, Northwestern University; M. Ed. in Early Childhood Education, Erickson Institute.
- 6) Sign Language and Communication Specialist (1979-82) Rhoda Haight, R.I.D., consultant for programs for deaf-blind children, multi-handicapped and emotionally disturbed deaf children and autistic/psychotic children in addition to HI-MAPS Project.
- 7) Parent Counselor (1979-81) Marci Enos, M.A. in Educational Psychology, University of Chicago.
- 8) Parent Counselor (1981-82) Sylvia Clark, M.A. in Social Services Administration, University of Chicago.
- 9) Research Coordinator (1981-82) Diana Pien, Ph.D. in Psychology, UCLA.

The project attempted to integrate the widely varying perspectives of the staff within the overall child development philosophy of the program.

A variety of training activities were available to the HI-MAPS staff to enhance their understanding of the issues and developmental processes affecting deaf children and their families. These included in-service training sessions provided by Michael Reese staff (See

Appendix), attendance at workshops, conferences and seminars, visits to schools and programs for young deaf children, and circulation of books and articles related to early childhood deafness.

In addition to staff development activities for HI-MAPS staff members, the Project also provided training for two graduate-level early childhood education students from Erickson Institute. This training involved student placement in a supervised student teaching format to provide training in working with parents and their hearty-handicapped infants (see Appendix for a detailed description of the student training program).

B. BUDGET/FISCAL MANAGEMENT

The HI-MAPS annual budget was prepared by the Director of Siegel Institute (HI-MAPS Principal Investigator) and by the HI-MAPS Project Director. It was submitted to the hospital Research Administration Department for approval before submission to the U.S. Department of Education. The HI-MAPS administrative secretary developed a ledger account system which facilitated record keeping of all actual project expenditures. The hospital's computerized accounting system ran several weeks late, so the ledger system provided ongoing up-to-date information as to HI-MAPS expenditures. The ledger were balanced with the hospital accounting system. Ongoing liaison was maintained with hospital Fund Accountant, who supervised the preparation of annual Financial Status Reports.

C. INTER-AGENCY COOPERATION

While HI-MAPS staff interacted with a wide variety of agencies throughout the Chicago metropolitan area, there were a few primary agencies with which we established ongoing liaison:

1. The Division of Services for Crippled Children

This state agency purchased hearing aids for children whose families were financially eligible. HI-MAPS staff had ongoing contact with DSCC representatives in various geographical areas. Contact was maintained through phone calls and letters, and DSCC representatives visited the program several times.

2. Chicago Public Schools

The coordinator of placement services for deaf children, Mrs. Anne Russell, served on the HI-MAPS Advisory Council. In addition, contact was maintained through phone calls and letters. Mrs. Russell visited the HI-MAPS Project several times to observe children and/or talk with staff. Through Mrs. Russell, the Chicago Board of Education participated in collecting demographic information on children enrolled in school. HI-MAPS staff made visits to the parent-infant program and preschool classes in Chicago. Mrs. Russell was extremely helpful in facilitating preschool placement and transition into the schools. For children placed through the Hard-of-Hearing Program, Dr. Lolita Bacon was the coordinator with whom we maintained contact.

3. Holy Trinity School

This private parochial school in Chicago accepted children of all religions. Many parents chose to send their children to Holy Trinity. Ms. Phyllis Winter (principal) and Ms. Katie Kruse (preschool

teacher) served on the HI-MAPS Advisory Council. HI-MAPS staff made a number of visits to Holy Trinity, and ongoing contact was maintained through phone calls and letters. Holy Trinity staff visited the HI-MAPS Project on several occasions.

4. Illinois Department of Children and Family Services

A number of children who participated in HI-MAPS were under the supervision of DCFS. Ongoing progress reports were given to case workers by phone and through letters.

5. American Red Cross

This organization was able to provide volunteer drivers and cars for a few HI-MAPS children in need of transportation. We maintained liason with a contact person in the Motor Transportation Department as well as with the individual drivers.

6. Suburban School Districts

A small number of HI-MAPS children lived in suburban Chicago. There were three primary areas for programs serving the low-incidence handicapped: South Metropolitan Association (south); DuPage/West Cook Special Education District (west); and Low Incidence Cooperative-Agreement (north). Contact was maintained in each with the person who coordinated the placement of HI-MAPS children into preschool classrooms.

#### D. HI-MAPS ADVISORY COUNCIL

The Advisory Council formally met five times during the final two years of the HI-MAPS Project. Members contributed in the following ways:

1. Attendance at Advisory Council meetings
2. Gave advice and shared expertise with project staff
3. Functioned in a public relations role and as community liaison for the project
4. Provided names for mailing list of people interested in HI-MAPS
5. Referred families to the project for services
6. Provided ongoing feedback to project staff regarding HI-MAPS services (this was done in particular by parents who sat on the council)
7. Provided follow-up information on those HI-MAPS children placed in preschool programs (public/private school Council members)
8. Gave input regarding collection of child progress and parent data
9. Read project documents and materials

Ongoing contact was maintained with Council members by phone and through letters. Council members visited the program to observe children and families so that they could provide feedback to staff regarding HI-MAPS activities. Council members have agreed to continue to function in an advisory role as services continue in the coming year.

## E. PROGRAM NETWORKS

HI-MAPS staff participated in a variety of program networks that were related to the development of services for young handicapped children. This activity gave HI-MAPS staff the opportunity to receive information about other programs and activities throughout the State of Illinois as well as to disseminate information about the HI-MAPS Project. These networks included:

### 1. Illinois First Chance Consortium

The Consortium included representatives from currently funded HCEEP projects, formerly funded projects and the Illinois State Board of Education. This network was an excellent resource forum in which to discuss project development and to receive and give informal technical assistance. The Consortium met quarterly and, in the interim, members stayed in contact through phone calls, letters; and workshops. The representative from the Illinois State Board of Education apprised the Consortium of pertinent developments at the state level that affected First Chance projects. The Consortium developed a pamphlet on First Chance projects throughout Illinois and worked on a cost effectiveness study.

### 2. Illinois Network for Parents

This network was originated by Dr. Jennie Swanson of the PreStart Project at Loyola University Medical Center. Groups met in four different regions of the state. In the Chicago area, participants included those from First Chance projects, Illinois Department of Mental Health/Developmental Disabilities, Illinois Department of Children and Family Services, Chicago Board of Health, Chicago Department of Human Services, Governor's Planning Council on Developmental Disabilities, Juvenile

Protective Association, parents of handicapped children, and others. The group shared information regarding the services available to young handicapped children and worked to better coordinate the services of the various groups within the Chicago area. A brochure was developed and distributed to parents of newborns in several hospitals and medical centers. The brochure served as a resource guide for services available to newly born infants and their families.

The HI-MAPS Project was involved in two additional networks: Advisory Board, Grant on Continuing Education for Services to Children, School of Social Service Administration University of Chicago; and the Planning Committee, Governor's Conference, International Year of Disabled Persons.

## VII. CONCLUSION

During the three years of federal funding , the HI-MAPS staff developed an effective model demonstration program for deaf children from birth to three and their parents. The model has included a medical diagnostic component, an educational component based on Total Communication and psychological component for supporting the parent-infant bond.

This report has described each component as provided during the past three years. Based on the past three years of experience, we are recommending the following changes in services:

- 1) Extension of the medical and psychological components to cover all hearing-handicapped children including the hard-of-hearing and children who do not attend regularly.
- 2) Integration of hard-of-hearing children and deaf children were appropriate.
- 3) More comprehensive services to hearing-handicapped children with additional handicapping conditions and medical problems.
- 4) Greater individualization of psychological and educational services to better meet the needs of families that have in the past been difficult to engage.
- 5) Provision of earlier psychological services to parents of newly diagnosed hearing-handicapped children in order to aid and stabilize the parents during this crisis.
- 6) Expansion of sign language/communication classes so that classes are available for all parents and families.
- 7) Expansion of follow-up services especially psychological counseling services to parents during their children's adjustment to their new school program.

The HI-MAPS Project has been fortunate in receiving generous support from the Foundation for Hearing and Speech Rehabilitation, Chicago, Illinois that will enable the program to continue for another year. During the upcoming year we are planning to implement some of the preceding recommendations as permitted by staff and center constraints. The ongoing integration of the clinical services of HI-MAPS and research

concerning hearing-handicapped children and their families will ensure the continued excellence of the HI-MAPS Program.

APPENDIX 1

HI-MAPS  
DATA BASE FORMAT

DATE \_\_\_\_\_

I. CHILD INFORMATION

Code Number \_\_\_\_\_  
Name \_\_\_\_\_  
Date of Birth \_\_\_\_\_  
Age at Program Entry \_\_\_\_\_  
Sex: \_\_\_\_\_  
Race \_\_\_\_\_  
Birth Order \_\_\_\_\_  
Parent Living With \_\_\_\_\_

II. FAMILY INFORMATION

A. Father

Name \_\_\_\_\_  
D.O.B. \_\_\_\_\_  
Race \_\_\_\_\_  
Address \_\_\_\_\_  
Telephone Number Home \_\_\_\_\_  
Work \_\_\_\_\_  
Occupation \_\_\_\_\_  
Income Level \_\_\_\_\_  
Educational Level \_\_\_\_\_  
SES Level (Hollingshead) \_\_\_\_\_

B. Mother

Name \_\_\_\_\_  
D.O.B. \_\_\_\_\_  
Race \_\_\_\_\_  
Address \_\_\_\_\_  
Telephone Numbers \_\_\_\_\_  
Occupation \_\_\_\_\_  
Income Level \_\_\_\_\_  
Educational Level \_\_\_\_\_  
SES \_\_\_\_\_

C. Siblings

Name \_\_\_\_\_  
D.O.B. \_\_\_\_\_  
Sex \_\_\_\_\_  
Live With Child \_\_\_\_\_

D. Others Living in Home \_\_\_\_\_  
Relationships \_\_\_\_\_  
Ages \_\_\_\_\_

Referred by: \_\_\_\_\_  
Family Physician: \_\_\_\_\_  
Address \_\_\_\_\_  
Phone Number \_\_\_\_\_

- Parent's description of child's problem -
- What do you hope this program will be able to do for your child -

III. MEDICAL HISTORY

A. Pregnancy and Birth

Health during pregnancy \_\_\_\_\_ (verbal)

(coded rating). very poor / poor / fair / good

<u>Target Health Issues</u>	yes	no				
German Measles	<input type="checkbox"/>	<input type="checkbox"/>	Trimester	1st <input type="checkbox"/>	2nd <input type="checkbox"/>	3rd <input type="checkbox"/>
High Fevers	<input type="checkbox"/>	<input type="checkbox"/>				
Accidents	<input type="checkbox"/>	<input type="checkbox"/>				
Illnesses	<input type="checkbox"/>	<input type="checkbox"/>				

Hospitalization

Excess Weight Gain

False Labor

Drug Therapy

X-Ray Treatment

	Y	N
Bleeding or Spotting	<input type="checkbox"/>	<input type="checkbox"/>
Convulsions	<input type="checkbox"/>	<input type="checkbox"/>
Rh Incompatibility	<input type="checkbox"/>	<input type="checkbox"/>
Substance Abuse	<input type="checkbox"/>	<input type="checkbox"/>

Other \_\_\_\_\_

Length of Pregnancy:

Infant Birthweight:

Was baby premature:

Number of miscarriages:

Total Pregnancies:  When \_\_\_\_\_

Hospital where born: \_\_\_\_\_ Attending Doctor: \_\_\_\_\_

Address: \_\_\_\_\_

Length of Labor: \_\_\_\_\_

Labor: Natural \_\_\_\_\_ Induced \_\_\_\_\_

Delivery: Vaginal \_\_\_\_\_ Ceasarean \_\_\_\_\_

Baby born: Head first \_\_\_\_\_ Feet first \_\_\_\_\_ Buttocks first \_\_\_\_\_

	Y	N		Y	N		Y	N
Was baby jaundiced	<input type="checkbox"/>	<input type="checkbox"/>	'blue	<input type="checkbox"/>	<input type="checkbox"/>	bruised/scarred	<input type="checkbox"/>	<input type="checkbox"/>

Explain: \_\_\_\_\_

Any breathing problems:  Describe: \_\_\_\_\_

Any feeding problems:  Describe: \_\_\_\_\_

Weight at birth  Present weight  Problems: \_\_\_\_\_

Length at birth  Present height

Apgar Scores:

Bilirubin Level:

Other:

Describe any other medically diagnosed disorders at birth: \_\_\_\_\_

Was baby in high risk or special care unit  Y  N

If not in special care unit, how long before infant came home?  
\_\_\_\_\_

Discharge diagnosis from nursery: \_\_\_\_\_ (Rank)

If in special care unit, where? \_\_\_\_\_

How long \_\_\_\_\_

Attending Physician \_\_\_\_\_

Any special procedures: \_\_\_\_\_ Rank

Surgery: \_\_\_\_\_ Rank

Medications: \_\_\_\_\_ (Rank)

Discharge Diagnosis: \_\_\_\_\_ (Rank)

B. Illnesses

Indicate dates at which your child had any of the following:

	Y	N	Date		Y	N	Date		Y	N	Date
Meningitis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Pneumonia/Virus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Head Injuries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Encephalitis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Strep Infections	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Dizziness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Rheumatic Fever	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Allergies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
German Measles				Tonsillitis				Vision Problems			
Chicken Pox				Ear Infections/ Drainage				Accidents			
Mumps				Convulsions				Other _____			

C. Hospitalizations

List all hospitalizations of your child:

<u>Hospital</u>	<u>Reason</u>	<u>Dates</u>	<u>Physician</u>
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

D. Medications

Indicate any medication (your/~~the~~) child now takes (or has taken regularly) for the following: seizures, over activity, or other medical problems \_\_\_\_\_

\_\_\_\_\_

Date of most recent physical examination \_\_\_\_\_

Doctor/Clinic \_\_\_\_\_

IV. INFORMATION CONCERNING HEARING PROBLEM

1. How and when did you first suspect your child was hearing impaired?  
(What clues, what did parents do to confirm suspicions?)
2. How did pediatrician respond to your questions/worries about child's hearing?
3. Where and when has your child received otological/audiological/ABR examinations?

<u>Facility/Doctor</u>	<u>Kind of Examination</u>
_____	_____
_____	_____

4. How did doctor/audiologist explain the results of the hearing tests to you?

---

---

5. What do you think might be related to your child's hearing loss?
6. What was the hardest part about the diagnosis for you?
7. How have your feelings changes since you first heard the diagnosis, and now?
8. What kinds of things have you done since the diagnosis?
- a. Have you searched for new information? (gone to other doctors, programs, etc.)
  - b. Has the diagnosis affected your relationship with your child?
  - c<sub>1</sub> Who else have you told about the child's hearing loss?
  - c<sub>2</sub> How did these people respond to you; to the child?
9. What has been most helpful for you since hearing the findings?
10. What do you feel would help you most, as a parent of a hearing handicapped child, in the months to come?
11. What kinds of goals and expectations do you have for your child?
- In the next year?
- In the next few years?

1. ABR Report: \_\_\_\_\_  
\_\_\_\_\_

2. Audiological Findings:

3. Otological Findings:

4. Etiology of hearing loss:

5. Age of onset of hearing loss  
Suspected: \_\_\_\_\_ Confirmed: \_\_\_\_\_

6. Hearing Aid  
a. Type: \_\_\_\_\_  
b. Use: \_\_\_\_\_

7. Parental Deafness  (Fill in the code)

- Code 0 Both mother and father, normal hearing before age 6.
- 1 Both mother and father hearing loss before age 6.
- 2 Mother hearing loss before age 6, father normal hearing before age 6.
- 3 Mother normal hearing before age 6, father hearing loss before age 6.
- 4 Mother information not available, father normal hearing before age 6.
- 5 Mother information not available, father hearing loss before age 6.

6 Mother normal hearing before age 6, father information not available.

7 Mother hearing loss before age 6, father information not available.

8 Mother and father information not available.

9 One parent deaf, unknown which one.

8. Siblings and Other Relatives Hearing Status

V. VISION

Do you feel your child has a vision problem  Y  N

Describe: \_\_\_\_\_

Has your child had an eye exam by a doctor  Doctor's Name: \_\_\_\_\_

Ophthalmologic Evaluation Results: \_\_\_\_\_

At what age was the problem first noticed \_\_\_\_\_

Do eyes wander?

If yes, which one: Left  Right  Both

Does child see: light \_\_\_\_\_ a person's face \_\_\_\_\_  
large objects \_\_\_\_\_ colors \_\_\_\_\_  
shiny objects \_\_\_\_\_ small objects \_\_\_\_\_  
Does child wear glasses \_\_\_\_\_ or contact lens \_\_\_\_\_

VI. MOTOR DEVELOPMENT

At what age did the child accomplish the following:

Hold head up alone \_\_\_\_\_

Reach with intent \_\_\_\_\_ Grasp objects \_\_\_\_\_

Crawl \_\_\_\_\_

Creep \_\_\_\_\_

Sit alone without support \_\_\_\_\_

Stand with support \_\_\_\_\_

Stand without support \_\_\_\_\_

Walk alone without support \_\_\_\_\_

"Cruising" \_\_\_\_\_

Walk up stairs with help \_\_\_\_\_

Walk down stairs with help \_\_\_\_\_

Feed self with a spoon \_\_\_\_\_

Drink from a glass unaided \_\_\_\_\_

Bowel control: day \_\_\_\_\_ night \_\_\_\_\_

Bladder control: day \_\_\_\_\_ night \_\_\_\_\_

Describe any present problems of chewing, swallowing, or drooling \_\_\_\_\_  
\_\_\_\_\_

Is the child clumsy with his hands \_\_\_\_\_

Does he prefer his right hand \_\_\_\_\_ left hand \_\_\_\_\_ no preference \_\_\_\_\_

Has weight/height development been normal \_\_\_\_\_

Explain: \_\_\_\_\_

Do you feel your child's motor development is normal at this time? \_\_\_\_\_

If you feel there are motor problems, describe: \_\_\_\_\_

Bayley Scales of Infant Development

Date/Age when tested: \_\_\_\_\_

Mental Developmental Index (MDI): \_\_\_\_\_ MDI with language: \_\_\_\_\_

Psychomotor Developmental Index (PDI): \_\_\_\_\_

Gesell Scores

Date/Age when tested: \_\_\_\_\_

Adaptive Behavior: Maturity Level \_\_\_\_\_

Gross Motor Behavior: \_\_\_\_\_

Fine Motor Behavior: \_\_\_\_\_

Language Behavior: \_\_\_\_\_

Personal-Social Behavior: \_\_\_\_\_

APPENDIX 2

DEMOGRAPHIC INFORMATION FORM

I. CHILD INFORMATION

1. Name: \_\_\_\_\_
2. Birthdate: \_\_\_\_\_
3. Sex: // M // F
4. Race/ Ethnic Origin: // B // H // C // O // M // Other \_\_\_\_\_
5. Birth Order#: \_\_\_\_\_
6. Number of siblings: \_\_\_\_\_ Entry \_\_\_\_\_ Exit \_\_\_\_\_
7. Primary/Shared Primary Parenting Role:  
// Mo // Fa // GM // GF // Sib // Other \_\_\_\_\_  
// signs // Signs  
// Does not Sign // Does not sign
8. Secondary Parenting Role:  
A. Sex: // M // F  
B. Relationship to Primary Parent: \_\_\_\_\_  
C. Relationship to Child: \_\_\_\_\_  
D. Place of residence: \_\_\_\_\_  
E. // Signs // Does not sign
9. Supportive Others Involved:  
// Relatives  
// Friends  
// Organizations  
// Persons who sign

10. Geographic Location:  
// City // Suburbs // Rural
11. Age at Program Entry: \_\_\_\_\_
12. Length of Program Participation: \_\_\_\_\_
13. Termination:  
// Parents chose not to participate in any program  
// Parents chose different program  
// Child not appropriate for HI-MAPS  
// Family moved  
// No Show - // Intake // After intake  
// Inconsistent attendance - referred elsewhere  
// Telephone referrals  
// Graduated  
// Other \_\_\_\_\_
14. Other Program Participation:  
// Parent/Infant Program  
// OT/PT Program  
// Other \_\_\_\_\_
15. Other handicapping conditions:  
// Developmental Delay  
// Ophthalmological  
// Neurological  
// Physical  
// None  
// Other \_\_\_\_\_

16. Tests:

- A. Bayley Entry \_\_\_\_ (lang)  
Exit \_\_\_\_ (lang)
- B. Gesell Entry \_\_\_\_  
Exit \_\_\_\_
- C. Ophthalmological // Normal // Abnormal \_\_\_\_  
// Unknown
- D. Neurological // Normal // Abnormal \_\_\_\_  
// Unknown
- E. EEG // Normal // Abnormal \_\_\_\_  
// Unknown
- F. Otological // Normal // Abnormal \_\_\_\_  
(entry) // Unknown
- G. Audiological (entry):
- |                    |                       |
|--------------------|-----------------------|
| a. ABR results:    | b. Behavioral results |
| // Severe          | // Moderate           |
| // Severe/Profound | // Severe             |
| // Profound        | // Severe/Profound    |
|                    | // Profound           |
- H. Audiological (exit/current)
- |             |      |    |
|-------------|------|----|
| SAT unaided | ____ | dB |
| SAT aided   | ____ | dB |

17. Hearing Aid:

// Loaner Date \_\_\_\_

// Personal Date \_\_\_\_

Usage: // never // program only // occasionally // usually

18. Household Income:

- // Public Assistance  
// Supplemental Security Income  
// Under \$5,000  
// \$5,000 - \$10,000  
// \$10,000 - \$20,000  
// \$20,000 - \$30,000  
// Over \$30,000

II. FAMILY INFORMATION

A. Mother

1. // Natural // Adoptive // Foster  
// Other \_\_\_\_\_

2. Name:

3. Birthdate:

4. Age at child's birth:

5. Race/Ethnic Origin:

// B // H // C // O // M // Other \_\_\_\_

6. Occupation

7. Educational level:

// 8 years or less

// 9-11 years

// High school grad/GED

// 1-3 years college

// College grad

// Professional degree

- 8. Other children: / / Y / / N
- 9. Marital Status: / / Married / / Single / / Widowed  
/ / Divorced / / Separated / / Other \_\_\_\_\_
- 10. Relationship to Child's Father : / / Married / / Widowed  
/ / Divorced / / Separated / / Other \_\_\_\_\_

B. Father

- 1. / / Natural / / Adoptive / / Foster / / Other \_\_\_\_\_
- 2. Name:
- 3. Birthdate:
- 4. Age at child's birth:
- 5. Race/Ethnic Origin:  
/ / B / / H / / C / / O / / M / / Other \_\_\_\_\_
- 6. Occupation
- 7. Educational level:  
/ / 8 years or less  
/ / 9-11 years  
/ / High school grad/GED  
/ / 1-3 years college  
/ / College grad  
/ / Professional degree
- 8. Other children: / / Y / / N
- 9. Marital Status: / / Married / / Single / / Widowed  
/ / Divorced / / Separated / / Other \_\_\_\_\_

- 10. Relationship to Child's Mother:  
/ / Married / / Widowed / / Divorced  
/ / Separated / / Other \_\_\_\_\_

II. REFERRAL PROCESS

- 1. Hearing loss first suspected:
  - A. Date \_\_\_\_\_
  - B. Child's age \_\_\_\_\_
  - C. By whom: / / Family member / / Grandparents  
/ / Other professional / / Friend  
/ / Other \_\_\_\_\_
  - D. Reason:
    - / / Child not talking
    - / / No response to sound
    - / / Speech deterioration
    - / / Behavioral concern
    - / / Heredity
    - / / Illness
- 2. First Consultation/ Examination:
  - A. Date \_\_\_\_\_
  - B. Child's Age \_\_\_\_\_
  - C. Place:
    - / / Board of Health
    - / / Hospital
    - / / Doctor's office
    - / / Other \_\_\_\_\_



D. Examiner: // Doctor // Nurse // Audiologist  
// Speech Pathologist // Other

E. Test: // ABR \_\_\_\_\_  
// Behavioral \_\_\_\_\_  
// Other \_\_\_\_\_

F. Diagnosis: // Hearing Loss \_\_\_ deaf \_\_\_ hard-of-hearing  
// Normal hearing  
// Wait  
// Referral  
// Other \_\_\_\_\_

G. Suspected etiology:

// Rubella // Hyperbilirubinemia  
// Prematurity // Rh Incompatibility  
// Meningitis // Unknown  
// Heredity // Other \_\_\_\_\_

3. Additional Exams:

A. Date \_\_\_\_\_

B. Child's Age \_\_\_\_\_

C. Place:  
// Board of Health  
// Hospital  
// Doctor's office  
// Other \_\_\_\_\_

D. Examiner: // Doctor // Nurse // Audiologist  
// Speech Pathologist // Other

E. Test: // ABR \_\_\_\_\_  
// Behavioral \_\_\_\_\_  
// Other \_\_\_\_\_

4

F. Diagnosis: // Hearing loss  
\_\_\_ deaf \_\_\_ hard-of-hearing  
// Normal hearing  
// Wait  
// Referral  
// Other \_\_\_\_\_

4. Referral to HI-MAPS:

Date \_\_\_\_\_

Child's age \_\_\_\_\_

Referral Source:

// Siegel audiologist  
// Hospital  
// Private  
// Other \_\_\_\_\_

5. HI-MAPS Intake

Time: Referral - Intake

// 1-2 weeks

// 3-4 weeks

// more than 4 weeks

6. First Session

Date \_\_\_\_\_

Type: // Individual // Drop-In

7. Parent/Child Group // Not Applicable

Date \_\_\_\_\_

8. Factors causing delays:

// Medical

// Transportation

// Other \_\_\_\_\_

IV. FAMILY HEARING INFORMATION

1. Mother :

A. // Deaf // Hard-of-hearing // Normal

B. If hearing impaired, // signs only // oral only // TC

2. Father:

A. // Deaf // Hard-of-hearing // Normal

B. If hearing impaired, // signs only // oral only // TC

3. Other Family Members: A. \_\_\_\_\_ B. \_\_\_\_\_

A. // Deaf // Hard-of hearing

// signs only

// oral only

// TC

// unknown

B. // Deaf // Hard of Hearing

// signs only

// oral only

// TC

// unknown

APPENDIX 3.

QUESTIONS PARENTS ASK

I. What is the cause of deafness?

1. Why do babies and small children have so many ear infections?
2. Can ear infections cause deafness?
3. Could the TB test I took when I was pregnant cause a hearing loss?
4. What kinds of illnesses that mothers have when pregnant can cause deafness?
5. What time during pregnancy can illness damage the fetus?
6. Can wax or fluid in the ear cause deafness?
7. How does heredity cause deafness?
8. Why is my child deaf? Why me?
9. Is it God's will? Is it fate?

II. How is hearing Tested?

1. Should all babies who have been in special care nurseries be given hearing tests?
2. Should the mother have to ask for hearing tests for babies in the special care nursery?
3. How do you know if the hearing aid helps?
4. What is an audiogram?
5. How great a hearing loss does my child have?
6. Are deaf children ever totally deaf?

III. Is there a cure for deafness?

1. If there is damage to the inner ear, can it get better as part of the normal growth process?
2. Why can't there be a transplant?
3. Can the cochlear implant be used for children?
4. What is the cochlear implant? How does it work?

IV. Will my child speak?

1. What does the speech of deaf people sound like?
2. What does it mean when my deaf child starts to make noises?
3. Is it ever o.k. to tell him to be quiet?
4. How can you tell which children will be able to speak?
5. Would speaking louder help?

V. How can I manage my child?

1. Are deaf children harder to discipline? Is it necessary to use physical punishment more? Are deaf children more stubborn? Why can't deaf children understand us? When can you toilet train a deaf child? How?
2. Can you leave a deaf child with a babysitter? How do you prepare the sitter?
3. What about sex education for deaf children? How can I tell him I am going to have a baby? That I had a miscarriage?
4. Is it o.k. if I have my child wear his hearing aid only at home?
5. How do you find playmates for an isolated deaf child?
6. How can I separate from my deaf child and tell him I'll be back later?
7. Aren't three year olds too young to ride a school bus and go to school all day?
8. Will my deaf child understand why I am placing him in a residential school if I decide later that is best?
9. Are deaf children more likely to be hyperactive?
10. Do deaf children feel pain less?

VI. How will my child's deafness affect our family?

1. Should we move to obtain better services even if it means we would deprive ourselves of our support system?
2. How do you handle reactions of relatives such as disbelief, blame, rejection, and refusal to learn sign?

3. What can I do if the father won't help?
4. Is it allright for the mother of a deaf child to work or go to school?
5. Should we have another child?

VII. What will my child's future be like?

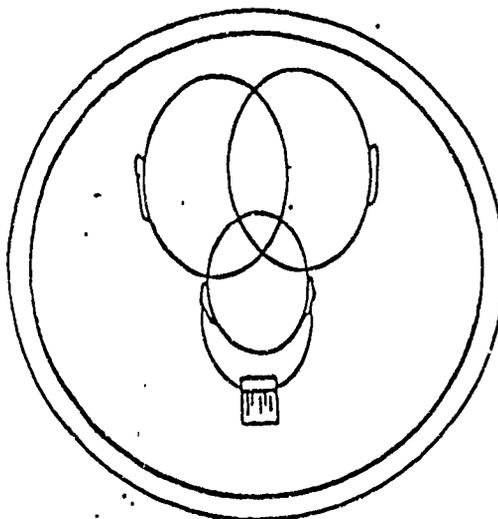
1. When will my child discover he is deaf? How?
2. Will there be enough deaf children in our school district for my child to have friends his own age to socialize with?
3. Can deaf children learn to read?
4. Will my deaf child grow away from me as he gets older and learns more signs in school and from peers?
5. Will my child feel I have made the right decisions for him when he grows up?
6. What can I expect from my child? college? a profession? be able to support himself? communicate with the hearing world?
7. Will my child marry a deaf person? Should parents "allow" this?
8. Do deaf children and adults have any special "rights"?

VIII. How can we relate to the community?

1. How can I meet deaf adults to use sign language with?
2. How do you handle insensitive remarks of people when you are out in public?

APPENDIX 4

HI-MAPS PROJECT



SIEGEL INSTITUTE  
MICHAEL REESE HOSPITAL AND  
MEDICAL CENTER

The HI-MAPS Project helps hearing handicapped children, ages birth to three years, with medical, academic and psychological services. It is funded by the federal government to provide these services to enable the children to communicate with their families.

The program goals are:

- To find the children early.
- To support a healthy parent-infant relationship.
- To help children and parents communicate in many ways using hearing aids, auditory training, sign language, speech, lip reading, gestures, body language, and facial expression.
- To give parents emotional support as they experience deafness in their families.
- To develop a model for services which can be used by other programs.
- To study how deaf children develop and to share this knowledge with others.

Each family and child works with a teacher once a week. There are also weekly parent counseling groups and sign language classes, which parents attend while the children are in a play group. Activities are planned around the kinds of natural situations that happen at home.

Various staff members with different professional backgrounds work together with the parents as a team. The program may vary to meet each family's individual needs.

PROJECT STAFF

Sylvia Clark  
Parent Counselor

Valerie Feldman  
Teacher/Director

Edie Goodman  
Speech and Hearing Specialist

R. Candy Haight  
Sign and Communication Teacher

Hershella Hearn  
Teaching Assistant

Theresa Jabaley  
Audiologist

Marla Lappe  
Audiologist

Diane Pien  
Research Coordinator

Mimi Sherman  
Teacher

Laszlo Stein  
Director, Siegel Institute

SUPPORTING STAFF

Barbara Scully  
Teaching Aide

Susan McGrath  
Interpreter

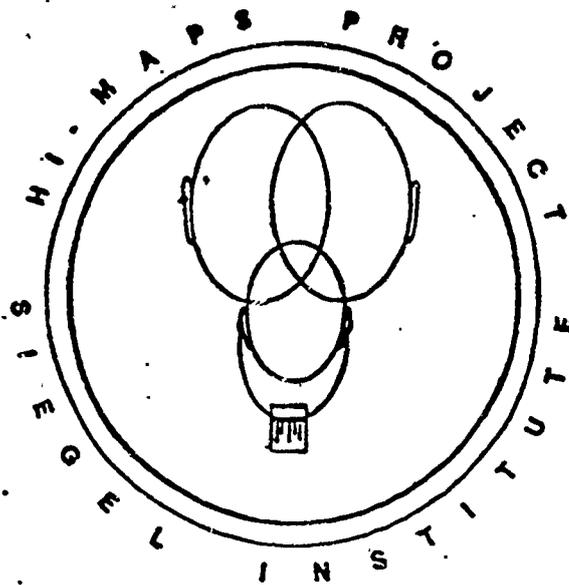
CONSULTING STAFF

Clinical Psychologist  
Otolaryngologist  
Electrophysiologist  
Pediatric Neurologist  
Ophthalmologist  
Occupational Therapist

For more information call:

Valerie Feldman, Director  
HI-MAPS Project  
David T. Siegel Institute  
Michael Reese Hospital and  
Medical Center  
3033 South Cottage Grove Avenue  
Chicago, Illinois 60616  
Phone: (312) 791-2900  
TTY: (312) 791-3449

APPENDIX 5.



### TESTS GIVEN TO THE CHILDREN

There are two groups of tests. The first group is given either here at the Siegel Institute or at another center. These tests help us in finding answers to the following questions:

1. Does the child have a hearing loss?
2. What type of hearing loss is it?
3. How much hearing can be measured?
4. Is there a difference between ears?
5. How well can the child hear when the sound is made loud enough?
6. What power should a hearing aid have?

The tests in the first group are:

#### Auditory Brainstem Response Test (ABR)

Sometimes called BER, BSER or BAER (Brainstem Auditory Evoked Response)

Since this test does not require the active cooperation of the child, only that he be quiet or asleep, a mild sedative is often recommended. The parents stay with the child while the test is done.

Head phones are placed over the ears and three small electrodes are pasted to the head. Sounds are played over the earphones while the brain waves are measured by a computer to see how the ear is working. The test helps the audiologist find out whether the child has a hearing loss and whether the hearing loss is due to damage to the inner ear.

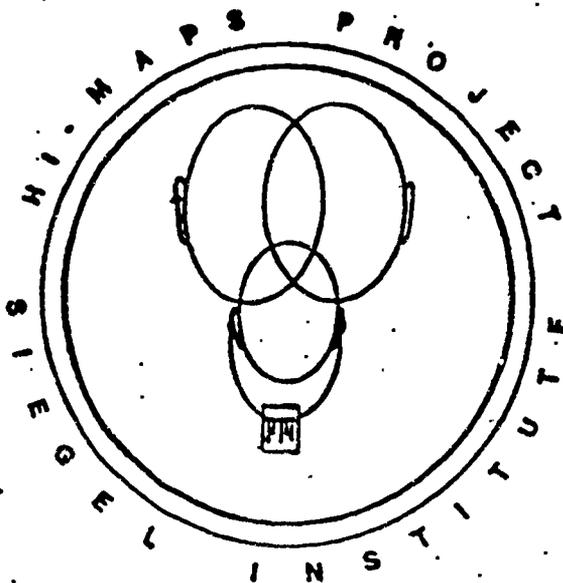
### Otolaryngological Examination

An Otolaryngologist is a medical doctor who treats problems of the ears, nose, and throat. This doctor examines the child's ears to see if there are problems which can be treated with medicine or surgery. Some of these are wax in the ear canal, problems with the eardrum, or fluid in the middle ear. These problems can keep some of the sound from reaching the inner ear and can cause what is called a conductive hearing loss. Sometimes the problems causing a conductive loss can be corrected. But a sensorineural hearing loss or damage to the nerves of the inner ear cannot be corrected and is usually permanent.

### Audiological Examination

This test is different from the ABR because the child is awake and must cooperate in letting the Audiologists know he hears when sounds come through speakers or head phones. Very young children (birth to two years) need to be taught what the Audiologists want them to do. The audiologists and the teachers help the children learn how to listen for sound and make a response each time they hear. This is called conditioning. Around the ages of 2½ to 3 years, children can usually learn conditioning.

All three tests, the ABR, the Otolaryngological and Audiological Examinations, are needed to give information about the child's hearing. The ABR is usually given only once. The Otolaryngological and Audiological Tests are repeated every six months. The purpose is to see if there is any change due to training, use of the hearing aid or because the child is better able to pay attention as he gets older.



The second group of tests is given routinely to all children in the HI-MAPS Project. In addition to trying to find out how much the child hears, these specialists are trying to find the cause of each child's deafness. It is not always possible to find a definite cause. It is also important to make sure the child does not have other medical problems which could interfere with his learning.

After the children have entered the program, there is no cost to the parents for these tests. The teacher arranges for the tests to be scheduled. The first three are usually given near the beginning of the child's participation in the HI-MAPS program. They are spread out so the child doesn't have too much at once. The Developmental Examination is given once at the beginning of the HI-MAPS program and once at the end.

#### Pediatric Neurological Examination and EEG

A brief examination is given by a children's doctor who specializes in the study of the nervous system. He checks to see how the child is growing. The EEG (Electroencephalogram) looks at brain wave patterns to make sure there aren't any special problems. The EEG is done while the child is asleep.

#### Ophthalmological Examination

This is an examination of the child's eyes. By means of this test, the doctor makes sure the eyes are healthy. Good vision is especially important for deaf children who need visual cues to understand what's going on around them.

Developmental Examination

This is given by an occupational therapist to look at how the child moves and uses his muscles, how he is learning and how he communicates. For example, older children are given tasks like putting beads in a cup, stacking blocks and doing simple form puzzles.

The occupational therapist also asks the parent questions about how the child is learning to do things for himself. For example, she asks if he has learned yet to drink from a cup or take off any of his clothes.

HI-MAPS PROJECT  
Student Training Program

EVALUATION

I. Student Activities

How helpful were the following activities in your student training program?

1. Direct work with child/parent dyads -

Not  
Helpful

Somewhat  
Helpful

Helpful

Extremely  
Helpful

Not Applicable

2. Direct work with child/parent groups -

Not  
Helpful

Somewhat  
Helpful

Helpful

Extremely  
Helpful

Not Applicable

3. In-service training sessions

Not  
Helpful

Somewhat  
Helpful

Helpful

Extremely  
Helpful

Not Applicable

4. Sign language/communication class -

Not  
Helpful

Somewhat  
Helpful

Helpful

Extremely  
Helpful

Not Applicable

5. School visits to parent/infant and preschool programs -

Not  
Helpful

Somewhat  
Helpful

Helpful

Extremely  
Helpful

Not Applicable

6. Staffings, case conferences, staff meetings, etc. -

Not  
Helpful

Somewhat  
Helpful

Helpful

Extremely  
Helpful

Not Applicable

7. Curriculum, planning, and evaluation activities -

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="radio"/>
Not Helpful	Somewhat Helpful	Helpful	Extremely Helpful	Not Applicable

8. Supervisory conferences with Child Development Specialist -

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="radio"/>
Not Helpful	Somewhat Helpful	Helpful	Extremely Helpful	Not Applicable

9. Reading materials (books, articles, brochures, etc.) -

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="radio"/>
Not Helpful	Somewhat Helpful	Helpful	Extremely Helpful	Not Applicable

## II. Supervision

1. Did you meet with your supervisor on a regular basis?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Almost Never	Seldom	Usually	Almost Always

2. Were your responsibilities clearly defined?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Almost Never	Seldom	Usually	Almost Always

3. Were you able to fulfill your responsibilities in the time provided?  
(15 hours/week)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Almost Never	Seldom	Usually	Almost Always

4. Were there adequate opportunities for evaluating your performance?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Almost Never	Seldom	Usually	Almost Always

5. Did supervision contribute to your professional growth and development?

Almost  
Never

Seldom

Usually

Almost  
Always

III. Questions/Comments

1. Have you increased your competence in working with young hearing-handicapped children and their families, as a result of your participation in the HI-MAPS Project?

---

---

---

2. Can you suggest any changes in the format of the student training program that you think would be of further benefit?

---

---

---

3. Were the theoretical and clinical aspects of the program regarding hearing-handicapped infants and their families well clarified in terms of their relationship to normal child development?

---

---

---

4. Which in-service training sessions were of greatest value? What additional programs would be of benefit?

---

---

---

---

---

---

5. Was there adequate opportunity for you to become familiar with the HI-MAPS Project as a federally-funded program through the Bureau of Education for the Handicapped HCEEP Programs? (Reading materials, brochures, conferences, discussions, etc.)

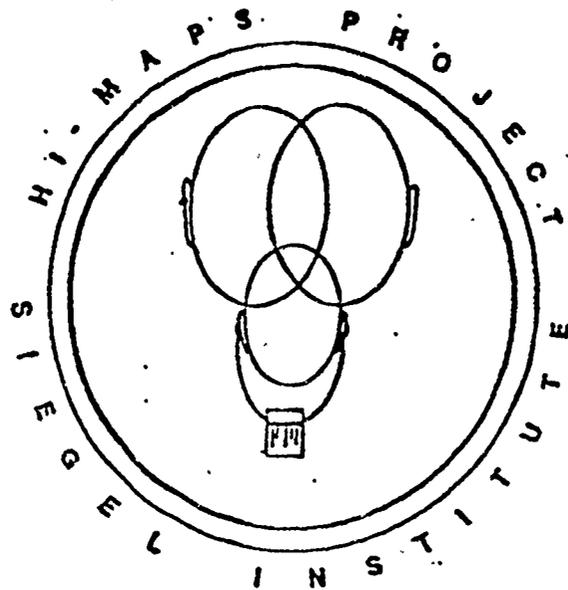
---

---

---

Comments:

APPENDIX 6



The HI-MAPS Project places primary focus on the individual child. While well-fitting properly maintained hearing aids, effective auditory training and the building of a sound language base are certainly critical to the program, an attempt is also made to introduce or reacquaint the valued child to the parent, thus facilitating that earliest and most crucial relationship between infant and parent.

The following bibliography was developed in this spirit; to help parents understand and deal with their hearing impaired children utilizing a perspective of normal child development. Books have been selected which look primarily at the child rather than at the handicap. In addition, we have tried to demonstrate the applicability of each book to the child with a hearing impairment.

© Edith Goodman  
HI-MAPS Project  
CHICAGO, ILLINOIS

Brazelton, T. Berry, M.D., Infants and Mothers: Differences in Development. New York. Dell Publishing Company. 1969.

This book provides a close look at the behavior of infants who are birth to one year of age. Dr. Brazelton presents the contrast between the active baby, the moderately active baby, and the quiet baby. By doing this he tries to dispel the myth of the "ideal baby" or the "typical three month old." Documented clearly in the book is the author's belief that the "newborn affects his environment as much as it influences him."

By looking at important steps in development such as the first time a baby gazes into his mother's eyes, reaches for an object or smiles, parents of hearing impaired children can view their infants within the perspective of normal child development.

Dr. Brazelton describes certain forces, or drives, which he believes propel the infant from one stage of development to the next. These include the need for independence and mastery, the desire to please and the desire to identify and become part of the environment. These needs and desires are certainly characteristic of all infants.

Brazelton, T. Berry, M.D., Toddlers and Parents. New York. Dell Publishing Company. 1974.

Dr. Brazelton continues to describe the step-by-step development of the child, moving in this volume to the toddler's struggle for mastery and independence between the ages of one and three. He discusses the variety of problems facing single parents and working parents. He also discusses issues of concern to all parents such as discipline, toilet training and sibling rivalry. Because the toddler years are an important period for language learning, reading about the ways in which children develop language can be particularly helpful.

Brigg, Dorothy Corkille, Your Child's Self Esteem. New York. Double Day and Company. 1970.

This easily readable book discusses development as it relates to the growth of self esteem. Dorothy Briggs describes parents and others who are important in the child's world as "psychological mirrors" or instruments through which a child can gain feedback about himself as he begins to develop his own self concept. In other words, how people respond to a child may give that child a clearer picture of himself.

The book emphasizes the importance of body language in the communication of thoughts and feelings between parents and children. Because total communication is so important to the way we relate to hearing impaired children, this book is particularly applicable.

Caney, Steven, Steven Caney's Toy Book. New York City. Workman Publishing Company. 1972.

Caney provides the reader with a book which describes more than fifty toys to make, ranging from science-oriented discovery toys, games and design toys, to action toys such as kites and swings.

Shared experiences between the parent and hearing impaired child provide good opportunities for interaction. These interactions in turn call for the development of communication systems which help to make the shared experiences more meaningful.

Church, Joseph. Understanding Your Child from Birth to Three: A Guide to Your Child's Psychological Development. New York. Random House. 1973.

Believing that human psychological development represents a self fulfilling prophecy, Church offers parents a realistic picture of the baby and young child in the hopes of allaying many fears and anxieties. The focus is on the areas of interest to parents such as fears, discipline, separation, feeding, and toilet training. This book is very pertinent and practical for all parents.

Comer, James and Poussaint, Alvin, Black Child Care. New York. Pocket Books (Simon and Schuster). 1975.

The authors present ways to deal with issues pertaining specifically to black children. The book presents a stage-by-stage study of the black child's development from infancy through adolescence. In addition there are race-related questions set up in a question-answer format. This is a valuable guide for both parents and professionals.

Ferris, Caren, A Hug Just Isn't Enough. Washington, D.C. Gallaudet College Press. 1980.

This book was developed from interviews with parents of deaf and hard-of-hearing children. They share their feelings, concerns, expectations, and responsibilities. Delightful photographs accompany the text which is particularly valuable because it identifies issues that many parents, particularly parents of hearing impaired children, have to face.

Friedland, Rennis and Kent, Carol, The Mother's Book: Shared Experiences. Boston. Houghton, Mifflin Company. 1981.

Candid personal discussion by mothers on the emotional aspects of mothering provide the focus for this book. Among topics discussed are pregnancy, working mothers, single parents, teenage parents, handicapped children, surgery, miscarriage, death, and foster parents. Sharing experiences with other mothers may help to prevent parents from feeling isolated and alone, for it becomes evident that many parents must deal with similar issues as they engage in the process of raising children.

Gordon, Ira, Guinagh, Barry and Jester, R. Emile, Child Learning Through Child Play. New York. St. Martin's Press. 1972.

The activities in this book are designed for the two and three year old child. They provide experiences and opportunities for interaction with an adult. Thus, the child is exposed to both concrete materials and an interested adult who first presents the new activities and then encourages the child to play on his own. There are a wide variety of games, crafts, and motor activities plus a short discussion by way of introduction for each general section. Because play is so important in the development of early language, this book is particularly helpful to parents of hearing impaired babies.

Jones, Sandy, Good Things For Babies. Boston. Houghton, Mifflin Company. 1976.

Good Things for Babies, a catalogue and sourcebook for safety and consumer advice about the products needed during the first two years of life, is a good thing for parents. It provides practical advice on how to choose products and describes items ranging from baby back packs to stacking cubes.

Levy, Dr. Janine, The Baby Exercise Book for the First 15 Months. New York. Pantheon Books. 1975.

Early mobility inspires confidence and helps to develop visual, spatial and tactile impressions of the environment. These activities can be especially valuable for hearing impaired children because they emphasize ways other than hearing for exploring the world around them. This book serves as a useful guideline for parents who want to help develop motor activity in newborns and infants. Parents are helped to understand how to work with their baby, taking into account the infant's individual personality and body rhythm. In this way they are taught to help the baby control and feel at ease with his/her own body.

The book is divided into four phases (0-3 months) (3-6 months) (6-12 months) and 9-15 months) with activities and photographs appropriate to each phase.

Levy, Dr. Janine, Sharing the Toddler Years. New York. Pantheon Books. 1981.

In a very readable style, Dr. Levy presents the issues of the toddler years. Directed toward parents, she describes the ways in which the toddler moves out into the world and begins to explore the environment. The author discusses how the baby learns about the world, how feelings grow and are expressed and how the baby develops physically. A final section is devoted to handicapping conditions that may affect toddlers and their parents.

Mahler, Margaret, Pine Fred and Bergman, Anni, The Psychological Birth of the Human Infant. New York. Basic Books. 1975.

Psychological development from the time of birth until age three is the central theme of this book. It focuses on mother-infant interaction and how the nature of interaction changes as the infant matures. Shared experiences and interactions between parent and infant are emphasized.

Mutual eye contact, pointing and gesturing seem to lay the groundwork for later, more advanced communication. Thus this book may provide useful background information for parents and others concerned with the establishment of avenues of communication between infants and parents.

Piers, Maria W. and Landau, Genevieve Millet, The Gift of Play and Why Young Children Cannot Thrive Without It. New York. Walker and Company. 1980.

The authors of the book view play as "the magic ingredient for healthy growth." They describe play as the way in which children explore the world, rehearse for their adult lives, vent fears and frustrations, exercise their imaginations, and heal themselves emotionally of pain or personal loss. Topics such as the effect of T.V., characteristics of a good nursery school and ways to facilitate play are discussed. The reader is left with a new appreciation for the seemingly simple but truly important activity of childhood known as play.

Pulaski, Mary Ann Spencer, Ph.D., Your Baby's Mind and How it Grows. New York. Harper and Row. 1978.

This book helps adults to understand the development of a baby's mind. It focuses on ways in which the baby comes to know about his/her world. Mental growth is reflected in the ways in which the child responds to his surroundings and eventually is able to reach out and gain some measure of control.

Looking at the world from a baby's perspective may help parents deal with anger and frustration in a more constructive way. Understanding the child's development may help parents to more effectively meet their child's needs. This can be particularly valuable for parents of premature infants because it provides a framework other than actual age by which we are able to monitor the baby's development.

Sroufe, Alan, Knowing and Enjoying Your Baby. Englewood Cliffs, New Jersey. Prentice Hall, Inc. 1977.

Sroufe describes the beginnings of emotions. He focuses on the smile, stranger anxiety and "no" gesture as the three central themes during the first two years of life. Sroufe sees tension, a natural result of the infant being stimulated in some way, as an important factor in development.

Feelings are important to all children. This book, which emphasizes the relationship between emotional and intellectual growth, is very useful. Learning to understand non-verbal expressions of emotion is very helpful to parents of hearing impaired babies.

The following books are part of an excellent series which provides the adult and child with a shared experience. The child is treated to excellent photographs and a simple story, while the adult is presented with a more in-depth commentary designed to help in understanding and communicating about sensitive subjects such as sex, birth, death and illness, and handicaps.

Stein, Sara Bonnett, Making Babies. An Open Family Book for Parents and Children Together. New York. Walker and Company. 1974.

This is a very simple but clear and honest discussion of the physical differences between boys and girls, pregnancy and birth.

Stein, Sara Bonnett, That New Baby, An Open Family Book for Parents and Children Together. New York. Walker and Company. 1974.

Sara Bonnett Stein provides an excellent support to use when there is a new baby in the family.

Stein, Sara Bonnett, About Handicaps, An Open Family Book for Parents and Children Together. New York. Walker and Company. 1974.

This book is designed for children who are not handicapped themselves but who are in contact with people who are handicapped in some way.

Other books in the Series: About Dying. A Hospital Story.

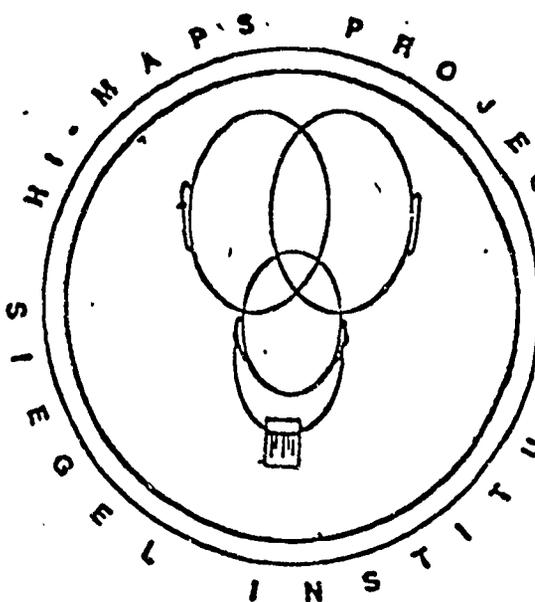
Weinfeld, Nancy Rogovin, Helpful Hints for New Moms and Dads (and Not So New). New York. Rand McNally. 1981.

Personal experiences and conversations among friends often provide the most useful and practical suggestions for child care. Ms. Weinfeld has compiled this information in a useful handbook format for parents. She provides a wide variety of very practical hints from formulas and feeding to toys and traveling.

White, Burton, The First Three Years of Life. Englewood Cliffs, New Jersey. Prentice Englewood Cliffs, New Jersey. Prentice Hall, Inc. 1975.

White provides a stage-by-stage outline of development. He divides the period between birth and three years into seven "developmental phases." Each phase is further divided into topics such as general behavior, interests, educational developments, and recommended materials. The focus is on the intellectual and emotional development of the young child. The book grew out of the Pre-School Project at Harvard University Graduate School of Education. It is primarily designed for parents but provides a good overall view for child care professionals as well.

APPENDIX 7



SUGGESTIONS  
FOR  
BABYSITTERS  
OF  
HEARING-IMPAIRED CHILDREN

This pamphlet was designed to help you better understand the special needs of my hearing-impaired child. My child uses his/her hands and voice to communicate thoughts and ideas. He/she also may point or lead you to things of interest. Hopefully you, too, will learn sign language so that you can communicate easier with each other.

You will need to get \_\_\_\_\_ attention in special ways because he/she may not hear when you call. Some of the ways to get \_\_\_\_\_ attention are:

1. Tap lightly on child's shoulder
2. Stomp your foot on the floor
3. Wave your hand or an object
4. Tap on the table top

The following suggestions may be of help to you in caring for \_\_\_\_\_.

Please feel free to add your own ideas as you and \_\_\_\_\_ get to know each other better.

Child's Name/Sign:

---

---

---

---

---

Sometimes my child is unhappy when I leave the house. These things will help him/her feel better:

---

---

---

---

---

Favorite Foods and Snacks:

---

---

---

---

---

Diapering/Toileting:

---

---

---

---

---

Hearing Aid Instructions:  
Volume# \_\_\_\_\_ On/Off Switch- \_\_\_\_\_

---

---

---

---

---

Bed/Nap Time:  
Time - \_\_\_\_\_  
Bedtime Toys- \_\_\_\_\_

---

---

---

---

---

Other Suggestions, Ideas, Comments:

---

---

---

---

---

Babysitter's Report:

---

---

---

---

---

SIGNS OF INTEREST

EMERGENCY INFORMATION



MOMMY



DADDY



LATER



TOILET



EAT



DRINK



206



PLAY

I can be reached at:

Name: \_\_\_\_\_

Phone# \_\_\_\_\_

Doctor  
Name: \_\_\_\_\_

Phone# \_\_\_\_\_

Friend/Neighbor/Relatives

Name: \_\_\_\_\_

Phone# \_\_\_\_\_

Police  
Phone# \_\_\_\_\_

Fire Department  
Phone# \_\_\_\_\_

Poison Control Center  
Phone# \_\_\_\_\_

Other  
Name \_\_\_\_\_

Phone# \_\_\_\_\_

Name \_\_\_\_\_

Phone# \_\_\_\_\_

This pamphlet was developed by:  
The HI-MAPS Project  
David T. Siegel Institute  
Michael Reese Hospital & Medical Center  
3033 S. Cottage Grove Avenue  
Chicago, IL 60616  
Phone: 312/791-2900 TTY: 312/791-3449

---

APPENDIX 8

207

"PARENTING A HEARING-IMPAIRED CHILD  
IN THE 80's"

MAY 1, 1982

74 persons attended the Workshop.

34 families were represented (34 mothers, 12 fathers, 4 relatives)

	<u>Under 3 years</u>	<u>3-5 years</u>	<u>6 years and over</u>
HI-MAPS	6	8	
other	5	8	7
Total	11	16	

There were five teachers, a psychotherapist for the deaf, an audiologist and three students. One of the students identified herself as a social worker and University of Chicago law student who works with the deaf at the Mandel Legal Aid Clinic. Another student was from Chicago State in Special Education and the third is at Northeastern and has an interest in counseling the deaf.

There were thirteen Siegel staff (Stein, Jabaley, Lappe, Rayson, Green, Collins, Wasserman, Goodman, Hearns, Kaplan, Haight, Pien, Clark) and five outside speakers.

Southside inner city	8 families
far southside/city	5
west inner city	1
north city	2
far northwest city	<u>1</u>
Total Chicago	17 families

western suburbs	3
northern suburbs	4
southern suburbs	4

Bolingbrook	2
Bloomington	1
Chebause (near Kankakee)	1

Wisconsin 2  
(also two teachers)

10 families registered but didn't come.

21 evaluations were returned (19 by parents, 1 by a student and 1 by a teacher).

15 felt that the workshop offered the right amount of information  
3 felt that there was too little information  
2 checked both "right amount" and "too little"  
16 did have their needs addressed  
2 did not  
1 checked both

I wanted to learn

- "more"
- "more in regard to social needs of hearing impaired children"
- "more about different school programs"
- "about parents' rights"

I wanted to hear more about:

- "everything"
- "rights from legal assistance"
- "psychological problems and tendencies of both hearing and deaf."
- "how to begin their education (formal and informal)"
- "psychological difficulties encountered by the children"
- "oral options"
- "how to start an effective parent support group in a rural area"
- "infants"
- "specific rights"

I was confused by

- "mental health"
- "IEP"

Particularly helpful to me was the discussion about:

- "rights"
- "parents' organizations"
- "IEP"
- "school regulations and parents' rights"
- "IEP"
- "school regulations and parents rights"
- "IEP"
- "advocates, IEP"
- "parent needs and parent organizations"
- "parental involvement"
- "due process"
- "due process"
- "legal"

If another workshop is planned, please include:

- "oral options"
- "parents from varying backgrounds who can share experiences"
- "more time"
- "Dr. Patricia Scherer - social and psychological needs of teen and pre-teen children"
- "politicians"
- "helping the deaf child develop socially"
- "information on differences between states"

I believe Siegel should 20, should not 0  
sponsor more programs of this kind.

If Siegel were able to offer a parents' group that met regularly, would you be interested in coming? Yes 12, No 4, 2 daytime, 6 Saturday

- "only if splinter group could be formed in area."
- "but we do have to drive a distance (south of Kankakee)"
- "definitely"
- "distance is a problem"
- "absolutely"
- "no, however it would be good if Siegel did. The travel would be prohibitive"
- "no, I live 130 miles from here."

Additional Comments:

"I think this was a great opportunity for parent discussion. It was great".

"Most parents need to learn the advantages and disadvantages of total communication, as well as those of oral education. Many are extremely naive, as are pediatricians in this regard. Otherwise day was great!"

"Excellent workshop!"

"The meeting was excellent!"

"Perhaps workshop could be split into parts representing certain age groups of children. Much info, while very good, was old hat."

"Thank-you"!!!!

"Thank-you"

"I really enjoyed this workshop. It was a learning experience for me. I hope there will be another workshop in the near future."

"I really enjoyed the conference, and I look forward to another one."

"It would be useful if group was broken down into smaller groups and more time was available to deal with each topic."

"We were very pleased with every part of today's program."

**PARENTING A HEARING-IMPAIRED CHILD IN THE 80's  
Saturday, May 1, 1982**

**I. PROBLEMS, PROSPECTS, RESOURCES**

- 9:00- 9:20 Registration, Coffee and Doughnuts  
9:20- 9:35 Introduction: Barbara Rayson, Psychologist  
9:35-10:00 What do Parents Need?  
Sylvia Clark, Parent Counselor  
10:00-10:15 Services to Your Child—The Department of Services for Crippled Children:  
Carolyn Hooihorst, Medical Social Consultant  
10:15-10:30 Parent Organizations: Dee Hlavacek, Chairman  
Illinois Parents of the Hearing Impaired  
10:30-10:45 Mental Health Services for Children and Families:  
Bernard Green, Psychologist  
10:45-11:00 Program Offerings—The Chicago Hearing Society:  
Melissa Henz, Deaf Advocate  
11:00-11:15 Questions  
11:15-11:30 Break

**II. ADVOCACY**

- 11:30-12:30 Effective Parent Involvement In The Individual Education Program:  
Cindy Christ, Parent-Training Coordinator  
Coordinating Council for Handicapped Children  
12:30- 1:00 The Legal Rights of Children In Special Education:  
Ora Schub, Attorney  
Legal Assistance Foundation - Mid South Office

This Workshop is designed for parents of hearing-impaired children (infants, preschool, and elementary school age). Sorry, we will not be able to provide child care. The Workshop is free and will be interpreted for the hearing impaired.

**LOCATION AND PARKING**

The Psychosomatic and Psychiatric Institute of Michael Reese Hospital and Medical Center is located at 2959 S. Cottage Grove, Chicago, Illinois.

Either the Dan Ryan Expressway or Lake Shore Drive can be taken to the 31st Street exit (see signs for hospital). The Psychosomatic and Psychiatric Institute is located ½ block north of 31st Street on Cottage Grove Avenue.

Free parking is available in the staff parking lot across the street from the Psychosomatic and Psychiatric Institute on Cottage Grove Avenue.

**PLEASE REGISTER BY CALLING:**

Bonita Wright  
Siegel Institute  
3033 South Cottage Grove  
Chicago, Illinois 60616  
(V) (312) 791-2910 (TTY) (312) 791-3449

APPENDIX 9

IN-SERVICE SESSIONS PROVIDED BY HI-MAPS STAFF

1. Residents in Pediatric Medicine
  - A. Michael Reese Hospital
  - B. Wyler Children's Hospital, University of Chicago
  
2. Third Year Medical Students (Michael Reese Hospital/Special Rotation)
  - A. University of Chicago
  - B. Chicago Medical School
  
3. Early Childhood Students
  - A. Roosevelt University
  - B. Erikson Institute, Loyola University
  - C. Governors State University
  - D. Northwestern University
  
4. Special Education Students
  - A. Roosevelt University
  - B. University of Illinois
  - C. Governors State University
  - D. Mundelein College
  
5. Psychology Interns and Externs
  - A. Northwestern University
  - B. University of Chicago
  - C. Illinois School of Professional Psychology
  - D. Illinois Institute of Technology
  
6. Visitors to Program
  - A. Audiologists
  - B. Students
  - C. Advisory Council
  - D. University faculty
  - E. Affiliated agencies (Division of Services for Crippled Children, Chicago Hearing Society, etc.)
  - F. Teachers

APPENDIX 10

## HI-MAPS PRESENTATIONS

1. "The Development of Affect in Deaf Children", (Feldman and Rayson) DuPage/West Cook County Special Education District, Lombard, Illinois, November 1979.
2. "What Makes Parent-Infant Communication Happen? New Methods-Future Rewards", (Enos, Feldman, Haight, Sherman, Rodabaugh), Chicago Association for the Education of Young Children, Chicago, Illinois February 1980.
3. "Developmental Aspects of Deafness: The Early Years", (Feldman), Illinois Speech and Hearing Convention Association Convention, Chicago, Illinois, April 1980.
4. "Mental Health Programs of the Hearing-Impaired: The Causes, the Issues, Referral, Treatment", (Feldman, Litoff, Rayson, Green, Birnberg), Illinois Speech and Hearing Association, Chicago, Illinois, April 1980.
5. "Special Kids Have Special Parents - Working with Parents of Handicapped Children", A.G. Bell Association of the Deaf, Houston, Texas, June 1980.
6. "The HI-MAPS Project: A Preventive Mental Health Model", (Enos and Feldman), Illinois Parents of the Hearing-Impaired State Day, Vernon Hills, Illinois, October 1980.
7. "Programming for the At-Risk Infant", (Feldman, Lemmon, Swanson, Morrison), DEC/HCEEP Conference, Washington, D.C., December 1980.
8. "The HI-MAPS Project: A Model Program", (Feldman), Chicago Women's Aid Society, Chicago, Illinois, January 1981.
9. "Language Development in Deaf Infants", (Pien), Siegel Institute MENDAC Grand Rounds, Chicago, Illinois, February 1981.
10. "Parent-Infant Communication: A Supportive Model", (Pien and Feldman), United Cerebral Palsy Birth to Three Symposium, Peoria, Illinois, March 1981.
11. "Communication Issues of Parents with Deaf Infants", (Haight), Siegel Institute MENDAC Grand Rounds, Chicago, Illinois, June 1981.
12. "Counseling Groups for Parents With Deaf Infants", (Clark), Siegel Institute MENDAC Grand Rounds, Chicago, Illinois, March 1982.
13. "What Do Parents Need?", (Clark), MENDAC/HI-MAPS Workshop on Advocacy for Parents of Hearing Impaired Children, Chicago, Illinois, March 1982.

14. "Developmental Aspects of Deafness: The Early Years", (Feldman), Illinois Teachers of the Hearing Impaired, Peoria, Illinois, March 1982.
15. "Apathy or Attachment: The Role of Assessment", (Clark and Feldman), Birth To Three Symposium, Peoria, Illinois, March 1982.
16. "Shame, Sorrow and Apathy in Parents of Deaf Infants", (Clark), INTERACT Conference on Infants, Boston, Massachusetts, June 1982.

APPENDIX 11

### Conferences Attended

1. Chicago Association for the Education of Young Children
2. American Education Research Association
3. Alexander Graham Bell Association for the Deaf
4. Illinois Parents of the Hearing Impaired
5. HCEEP Project Directors Conference
6. DEC/HCEEP Conference
7. Birth To Three Symposium (Illinois First Chance Projects and United Cerebral Palsy)
8. Society for Research in Child Development
9. INTERACT Conferences
10. Illinois Speech and Hearing Association
11. Michigan Association for Infant Mental Health
12. Maternal-Infant Bonding Conference
13. National Center for Clinical Infant Programs Conference
14. Midwest Association for the Education of Young Children
15. Council for Exceptional Children
16. Illinois Council for Exceptional Children
17. Gallaudet College Sociology of Deafness Conference
18. Chicago Institute for Psychoanalysis: Conference on Learning
19. International Infant Conference

APPENDIX 12

IN-SERVICE TRAINING SESSIONS (for HI-MAPS Staff)

1. Auditory Brainstem Response Testing with Deaf Infants
2. Fitting Young Deaf Children with Hearing Aids
3. The Use of the Uzgiris-Hunt Scales with Deaf Children
4. Mahler's Theory of Separation-Individuation
5. Parent Counseling Groups
6. Mental Health Needs of Deaf Children
7. Bayley Scales of Infant Development
8. Genetic Counseling for Families of Deaf Children

APPENDIX 13

221



# Michael Reese Hospital and Medical Center

David T. Siegel Institute for Communicative Disorders  
Dr. Robert Henner Hearing & Speech Center  
29th Street and Ellis Avenue  
Chicago, Illinois 60616  
Tel. (312) 791-2900

## HI-MAPS PROJECT Student Training Program

### Objective

To provide training for one graduate level early childhood and/or deaf education student per school semester, in a supervised student-teaching format which will facilitate the student in learning to work with very young hearing-handicapped children and their families.

### Activities

The student placement will require 15 hours weekly at Siegel Institute. The student will be involved in the following activities as part of his/her training:

1. Direct work with child/parent dyads under supervision of professional staff.
2. Direct work with child/parent groups under supervision of professional staff.
3. In-service training concerning special issues and skills related to serving hearing-handicapped infants and toddlers.
4. Participation in the Siegel Institute sign language/communication class.
5. Attendance at staffings regarding prospective children to be served, case conferences and staff meetings.
6. Assistance with development of curriculum.
7. School visits to become familiar with area preschool classrooms and programs for hearing-handicapped children.
8. Supervisory conferences with the Child Development Specialist who will serve as student training coordinator.

### Evaluation

1. Student will be required to keep a log of teaching/observation experiences. This log will aid review and discussion of student's activities, problems and progress.
2. Student will be observed at work with child/parent dyads and groups. These observational evaluations will be discussed with the student.
3. Student will meet the requirements of their graduate training institutions, including attendance at required seminars, classes and supervisory conferences.
4. At the end of the student teaching experience, student will evaluate the effectiveness and helpfulness of the practicum program provided by Siegel Institute.

To Field Work Supervisors and Students:

The following are guidelines for summary evaluation conferences between Field Work Supervisors and E. I. students. The topics and areas to be covered are intended to be a guide - and only a guide. Please feel free to use these suggestions flexibly. In addition to the conference, field work supervisors are requested to send a written evaluation of the student's learning and performance.

I. Adult-child Relationships.

- A. Ease and quality of relationships with children. (Is the student comfortable with children? Can (s)he talk with them easily? Does (s)he give and receive appropriate physical contact comfortably?)
- B. Sensitivity to individual needs. (Does (s)he vary the approach with different children? Is (s)he able to pick up clues about feelings? Is (s)he able to set limits on individual deviations from group demands?)
- C. Understanding of the process of growth. (Can (s)he accept regressive behavior? Does (s)he have realistic growth expectations? Does (s)he enjoy the "here and now" in the child's development? Is there a tendency to want to hurry or delay development?)
- D. Exceptional children. (Has (s)he been able to cope adequately with children who are handicapped or who present problems-physically, socially, intellectually, emotionally? Can (s)he accept the "whole child" whatever the handicap?)

(2)

## II. Relationships with Adults

### A. Staff

1. Does student interact appropriately and comfortably with staff? Does (s)he communicate effectively with them? Has student been able to learn from staff as well as contribute to the program on a level appropriate to his/her skills? Have any problems been evident in student's behavior or attitudes about staff?
2. Has student been able to make good use of supervision? Is (s)he able to assess his/her own performance? Does student ask appropriate questions about the school functioning and his own participation? Is student able to use help with problems and to put such help into practice? Is student comfortable with the existing lines of authority and can (s)he work well within them?

### B. Parents

1. Does student interact comfortably with parents in an informal setting?
2. Does student prepare and carry out planned/conferences with parents?
3. If student has been assigned any special tasks concerning parents, i.e., parent meetings, work with individual parents, etc., has he performed well?

(3)

### III. Planning and Participation

- A. Has student participated in the planning of group program? Can (s)he plan appropriately for the children in the group? Are the needs of individual children taken into consideration? Are all aspects of development (social, emotional, intellectual, physical) included in plans?
- B. Observation: Can student observe individual children and the group and make use of the observations in an appropriate manner?
- C. Is student able to manage a group of children? Are expectations appropriate, and are they made clear to the children? Does student take into account the vagaries of young children's behavior?
- D. Does student carry through on planned learning activities both for groups and individuals?
- E. Can student use the spontaneous activity of children to enhance their intellectual and emotional development?

### IV. Personal Characteristics and Attitudes

- A. What are personal characteristics that enhance the student's strengths as a teacher?
- B. Are there any characteristics or attitudes that interfere with the student's performance? If so, what are they?

(4)

V. Learning

- A. Has student shown an openness to learning.
- B. What are the areas where the student has made the most progress? Which areas has (s)he made the least gain?

# ERIKSON INSTITUTE

1525 East Fifty-third Street  
Chicago, Illinois 60615  
(312) 493-0200

June 23, 1980

Ms. Valerie Feldman  
Siegel Institute for Communicative Disorders  
Michael Reese Hospital  
3033 South Cottage Grove Avenue  
Chicago, Illinois 60616

Dear Val,

I wanted to let you know how much I appreciated the excellent placement opportunities and excellent supervision you provided for Edie. As you know, she learned a great deal from working with you and from participating in your program at Siegel - and I certainly enjoyed discussing it with her!

Have a good summer.

Sincerely,

Joan

Joan B. McLane  
Faculty Member

JBMCL:bd

BOARD OF TRUSTEES  
Jared Kaplan, Chairman  
Irving B. Harris, President  
Mrs. Abraham W. Brussell  
Mrs. Herbert S. Greenwald  
Gerald L. Gutek, Ph.D.  
Marian S. Harris  
Mrs. Ben W. Heineman  
Anna J. Julian, Ph.D.  
Ellen Klutznick  
Gail Kovler  
Eleanor McGovern

Don P. Nathanson  
Edward Neisser  
Doris Newberger  
Lorraine Parsons  
James J. Pelts  
Maria W. Piers, Ph.D.  
George H. Pollock, M.D., Ph.D.  
Richard Polsky  
Jack L. Rozran  
Norman J. Rubin  
Mitchell A. Seltzer  
William S. Singer

Mrs. Malcolm N. Smith  
Susan Stone  
Michael Tenenbaum  
Harold M. Visotsky, M.D.  
Bernice Weissbourd  
Jack L. Wentz

CONSULTANTS  
Erik H. Erikson  
Anna Freud

# ERIKSON INSTITUTE

Two Illinois Center, 233 North Michigan Avenue  
Suite Twenty Two Hundred  
Chicago, Illinois 60601  
312-565-2970

July 20, 1982

Ms. Valerie Feldman  
Director, HI-MAPS Project  
Siegel Institute for Communicative  
Disorders  
Michael Reese Hospital  
29th Street and Ellis Avenue  
Chicago, Illinois 60616

Dear Valerie,

Thank you very much for your participation in the Erikson Institute Field Work Program and your thoughtful evaluation of Barbara Wright's internship experience. We are grateful for the time and attention you have given so freely and, on behalf of the Institute and myself, want to thank you.

Sincerely yours,

*Barbara ed*  
Barbara T. Bowman  
Director of Graduate  
Studies

BTB:esd