

# Approaches to Management of the Handicapped Infant

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A form of management which has proven helpful in a developmental intervention program for handicapped infants is described. The use of ordinal rather than normative assessments when monitoring the infant's development and when teaching families about their infants is advocated. Two cases demonstrate ways to enhance the functioning of the handicapped infant and his family.

The family physician's role in the management of the physically or mentally handicapped child requires that he coordinate the various modalities of care necessary for the child and act as an advocate in the medical care system for the entire family.<sup>1</sup> When a multidisciplinary developmental center is geographically accessible to the child and his family, many of the necessary services may be obtained in one setting. However, many families do not have access to such centers and will continue to rely on their family physician for information and advice about their infant.

The purpose of this paper is to present a frame of reference for intervention in the care of handicapped infants, including approaches to assessment of developmental behaviors and

identification of appropriate parenting activities. Two cases are presented of infants who were followed in a multidisciplinary center. They demonstrate an extension of the traditional counseling role of the physician to include ongoing education of the parents about the following: (1) the behavioral manifestations resulting from the infant's handicap, and (2) parental activities which can enhance the infant's current functioning.

## Background

Society's changing attitudes about physically handicapped and developmentally delayed children, considerations of humanitarian and cost factors in institutional care, and revised concepts about child development have been reflected in the federal funding of a number of intervention programs for handicapped children during the past five years. These developmental programs have not operated for

enough time to permit conclusions to be drawn about their long-range effects on the participating children. However, available data suggest that intervention programs can favorably alter the current functioning of handicapped children.<sup>2-5</sup> It is beyond the scope of this article to compare the pros and cons of programs which rely on behavior modification techniques to train the child with those which use an interactionist approach, prescribing special therapies for the child while assisting the parents in their role as his principal caretakers. The observations presented here reflect the author's experience in a program of the latter type, coordinating the modalities of intervention and providing education and counseling to parents.

## A Frame of Reference for Intervention

Although the complex interrelationships of the genetic and environmental determinants are incompletely understood, there is increasing evidence that both intellectual and emotional development are influenced by a child's interactions with his environment. Two concepts which have affected the design of programs for developmentally delayed infants and toddlers are those of (1) develop-

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mental order, and (2) environmental match.

1. *Levels or stages of development are considered to proceed in a consistent order or sequence.* Although the age at which a behavior is achieved varies with different children, the order of appearance of behaviors within a particular system is predictable. Infants sit before they stand and stand before they walk. Infants attend to sound before they attempt to localize it. If an infant is cooing, he will next repeat his own sounds and then those made by others. Gesell's studies have made it possible to identify whether or not a child is achieving different behaviors at a normal rate. Piaget, while less concerned with specifying the normal time of appearance of stages, has provided evidence that intellectual development proceeds in an orderly, invariant sequence.

For the development of treatment plans and to assist the family in monitoring the handicapped infant's progress, a behavioral checklist (Figure 1) is used. It is constructed to provide a means of identifying the infant's location on a developmental sequence in the motor and the perceptual systems, in communication, and in social development. Progress in each system must be assessed separately, as the handicap may disrupt development and require parenting modifications relative to one aspect of development more than to others.

Normative evaluations inevitably focus attention on how delayed the infant is. With the use of ordinal charting, identification of the behaviors the infant has achieved provides at the same time information about what he can be expected to do next. When he is able to stack two blocks, we can expect that he will next achieve sufficient eye-hand coordination to stack three blocks. When he can put his thumb in his mouth and can grasp an object, he can be expected after this to carry a cracker to his mouth, a step toward feeding himself. The goal of management is not to "catch up" with normality, but rather to facilitate progress toward independent functioning, albeit at a pace which differs from the norm. This approach enables parents and professionals to understand and predict the child's day-to-day behaviors and, thus, to see him and relate to him as a variation in the

category "children" rather than as a tragically different kind of being.

Available data do not permit conclusions as to whether the caretaking responses generated by this kind of monitoring alter the rate of development of a handicapped infant. Clinical observations seem to indicate a related increase in the frequency and quality of mother-child interactions after the program is started. Interactions with the infant are described as more enjoyable for the mother and for other members of the family. This change has potential significance beyond the intrinsic merit of altering the quality of the family's daily experiences.

The importance of the mother, or other principal caretaker, in facilitating early sensory-motor experiences is especially critical with the infant whose functioning is limited by a handicap. However, the mother of the handicapped infant is often bewildered by his developing in a manner different from that of other children she knows. The infant's inability to react and to respond in an expected manner appears to disrupt patterns of mothering<sup>6</sup> and can lead to a secondary deprivation process.<sup>7</sup> In treating all types of developmental delay, one intervention objective is to prevent or decrease this secondary deprivation through enhancing the mother-infant relationship.<sup>8</sup> Even where biological therapies have been introduced, as in phenylketonuria, parental understanding of the disease has been found to be related positively to the behavioral and intellectual status of the child.<sup>9</sup>

2. *Intervention programs also reflect the premise that there should be a correlation between the child's level of development and the environment which he encounters.* Piaget uses the term, "optimal novelty," and Hunt refers to this correlation as a "match." Culturally transmitted patterns of child-rearing express this concept; for example, parents intuitively vary the complexity of their language according to the maturity of the child and select different kinds of toys for children of different ages. Educators use the term "readiness" to describe the child's ability to meet the demands of classroom and curriculum.

A number of infant curricula<sup>10-12</sup> have resulted from efforts to achieve a more precise match between the infant's levels of development and his environment.

Activity cards (Figure 2) suggest parenting activities appropriate to the level at which the child is functioning. Examples shown are from the Portage Guide to Education<sup>12</sup> in which the activity cards are numbered to correspond to the behaviors identified on the behavioral check lists. These specific suggestions have proven particularly helpful to the mother whose child's development is so different that she cannot rely on her intuitive knowledge of child-rearing. They serve as an adjunct to professional conferences with the parents. As the child's environmental challenges approximate his skill levels and interests, he experiences success more often. Although it is premature to predict the effect of this approach on later development, various reports indicate that it can favorably influence current functioning.

## Illustrative Cases

### First Case

P.F., a six-month-old female, was referred to the development center because of findings suggestive of congenital retinal blindness. Visual acuity was reported sufficient for light perception only. The neurological evaluation revealed no other abnormalities and there was no history of seizures. P.F. was a well-developed, well-nourished infant who did not visually attend to objects or to the persons about her. A pendular horizontal nystagmus was present. A bald spot on the occipital area suggested that she had spent considerable time lying in the supine position. She was unable to sit unsupported. No spontaneous engagement of her hands in the midline was observed. She showed minimal interest in manipulating or mouthing objects. She alerted to sounds, but did not smile in response to handling or efforts to communicate with her.

This was the first pregnancy of this 19-year-old mother who had completed the 11th grade, was separated from her husband, and was receiving public assistance. She volunteered that she "didn't know much about raising a

normal child, much less this one." It was felt that the infant's blindness, in combination with maternal uncertainty about her care placed her in a high-risk category and she was accepted into the center. The intervention plan for P.F. centered on involving her with her surroundings using auditory, tactile, and kinesthetic stimuli. No special physical therapy or pre-speech program appeared to be indicated.

The treatment plan for the mother was both educational and supportive. Objectives were to help Mrs. F. to understand the special helplessness of her infant, to understand that because P.F. could not become interested in her world through what she saw, Mrs. F. must interest her through providing objects she could touch and hear. Mrs. F. was encouraged to talk about her feelings, her difficulty in relating to this infant whom she perceived as not responding, since the infant did not look at her. Although the mother had read educational pamphlets about blind children, she appeared to have difficulty in applying what she had read. Suggestions provided in the context of discussions of her own experiences with the child encouraged her to try to play with and talk to the infant.

Mrs. F. learned to recognize the changes in body tone which indicated the infant's responses to sounds and to objects she encountered. Their improving communications reinforced Mrs. F.'s efforts to continue to interact with and to parent this child. When the infant became able to support herself on her hands and knees, but continued to rock rather than move, Mrs. F. became an active participant in the use of bells and rattles to provide an auditory incentive for locomotion. Mr. F.'s interest in what was being done for the child provided part of the motivation for a reconciliation. Both parents have described their enjoyment of P.F.'s emerging use of language. They are pleased that so many people seem to think she is a cute little girl.

P.F.'s development is progressing satisfactorily. At 19 months her expressive vocabulary includes more than 200 words, which she spontaneously combines into two and three-word expressions. On the Denver Developmental Screening Test she scores at or above age level norms in non-visual tasks. She actively explores her

Figure 1. Behavioral Checklist

**LANGUAGE**      Name \_\_\_\_\_

Age Level	Card No.	Behavior	Entry Behavior	Date Achieved
0-1	6	Listens to voice or soft noise		
	7	Responds to voice tone (friendly, angry)		
	8	Laughs, smiles		
	9	Child coos, gurgles		
	10	Responds to own name		
	11	Repeats own sound		
	12	Repeats sound made by others		

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**SOCIALIZATION**      Name \_\_\_\_\_

Age Level	Card No.	Behavior	Entry Behavior	Date Achieved
0-1	1	Responds to another person		
	2	Smiles in response to attention		
	3	Vocalizes when attended		
	4	Nonactive family involvement		
	5	Demands attention		
	6	Smiles in response to facial expression of others		

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Figure 2. Sample Activity Cards

Portage Project                      CARD NO. 9                      LANGUAGE

AGE 0-1

TITLE:

Child coos, gurgles

BEHAVIORAL DESCRIPTION:

The child will coo and gurgle — ie, any sound other than crying, burping, or sounds related to body function.

SUGGESTED ACTIVITIES AND MATERIALS:

1. Present the infant with visual and/or auditory stimulation (mobile, rattle, music box) and reward him by talking to him and patting him when he makes sounds.
2. The parent can coo and gurgle and encourage the child to imitate.
3. Play peek-a-boo and pat-a-cake, or try tickling him.
4. If child makes a sound, the parent should make the same sound as a reward.
5. Provide stuffed musical toys, toys with bells, music, ie, records, radio, voice, to listen to.
6. Sing or hum to the child as you accompany a record or musical instrument.

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Portage Project                      CARD NO. 1                      SOCIALIZATION

AGE 0-1

TITLE:

Responds to another person

BEHAVIORAL DESCRIPTION:

The child will follow a moving person with his eyes, increase body activity or turn his head in response to voices or to movement of people around him.

SUGGESTED ACTIVITIES AND MATERIALS:

1. Play with the child; make feeding, bathing, diapering a fun time — talk to him quietly doing these activities.
2. Attract the child's attention by dangling an object in front of him and talking.
3. Provide bright and noisy objects, toys. Hold and squeak them close to your face to encourage the child to respond to you as well as to the object.
4. See Card No. L4.

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environment but continues to prefer interpersonal interactions to explorations of physical objects. Although initially cautious when she encounters unfamiliar voices, she plays happily with familiar persons. Subsequent studies have confirmed the diagnosis of congenital retinal blindness, and Mr. and Mrs. F. are aware of the hereditary nature of the disorder. The family will continue to be followed in the center until P.F.'s projected entry at age three into a public school early childhood program.

### Second Case

G.S., an infant previously diagnosed as having trisomy 21, entered the program at the age of four months. He was the fourth child of a 39-year-old mother and a 43-year-old father. Both parents were college graduates; Mr. S. was employed as a geologist. The other members of the family, a 6-year-old girl and two boys, ages 9 and 12, were reported to be functioning well.

Initial examination of G.S. revealed physical stigmata associated with Down's syndrome and moderate generalized hypotonus. No evidence of a congenital cardiac abnormality was detected and other physical findings were not significant. The infant was hypoactive but could be stimulated to follow a moving object with his eyes and head through an arc of 90 degrees. Attention to dangling objects was brief and no spontaneous scanning of his environment was observed. He alerted to sounds of moderate intensity. Hand-to-mouth coordination was good, but he did not reach for objects. He was not observed to smile or to vocalize in response to his mother's holding him.

Mrs. S. was self-sufficient and competent, nevertheless, she seemed bewildered and had withdrawn from this infant who was so different from her other three children. She said that she could tell what her other children needed from the way they acted, but this child did not seem to want anything. He would just lie there. Mrs. S. had been told that she should put G.S.

in a good institution but she did not feel that she could do that. She had obtained and read pamphlets about children with problems similar to those of her child, but she had not found them very helpful.

The treatment plan recommended for the infant included an exercise and movement stimulation program designed by the occupational therapist. Later a pre-speech program to facilitate tongue and pharyngeal muscle control was added. The first objective for Mrs. S. was to enable her to recognize that her actions would evoke recognizable responses from G.S., that she was necessary and significant to him. With the recognition that she could understand his early pre-verbal communications, as she had those of her other children, Mrs. S. was able to use the skills she had already acquired as a parent. Appointments with Mrs. S. were used to discuss the progress of G.S. and the activities suggested for him. During these appointments, all elements of the treatment plan as well as the family responses could be monitored.

Family problems became apparent when the formerly cooperative oldest son became sullen and resistant to requests that he assume responsibilities for household chores. He was invited to visit the center to talk with the occupational therapist about G.S.'s exercise program. Mrs. S. was persuaded to locate a "mother's day out" program for G.S., to allow more of her time to be spent in activities with the rest of the family. These changes were followed by a return to more harmonious family interactions. G.S. was enrolled in an infant swimming class so that he could join in family activities in their swimming pool. As G.S. demonstrated increasing motor proficiency, Mr. S's interest and pride in his son increased and he began to spend more time with G.S.

On the Denver Developmental Screening Test, G.S., at the age of 20 months, is functioning within age level norms in gross and fine motor skills and in social development. His receptive language is age appropriate, as is his willingness and ability to follow directions. His expressive language is predominantly gestural. He uses a number of sounds, four of which are recognizable words. He investigates his environment, plays imaginatively with toys, and shows persistent goal-

directed behavior towards the tasks he selects. He is friendly and evokes positive comments from other adults when he accompanies his mother on shopping trips. The current treatment focus is on the development and use of spoken language. He is expected to continue in the program until he enters a public school early childhood program.

## Discussion

Parents of handicapped children have been described as unreliable informants about their children's behavior. Distortions appear to occur on intake histories when the parent may be attempting to prove to staff that the child is acceptable. During the course of the intervention program, when data are being gathered for the purpose of developing treatment plans, parents who are actively participating have been observed to function as reliable observers. At home, a young child will demonstrate behaviors that he does not demonstrate spontaneously in a less familiar setting or perform on request. Thus, a conflicting history is not necessarily evidence of parental unreliability; it may be confirmation of the premise that behavior is partially determined by the setting in which it occurs.

As described in the above cases, parents have been observed to use educational materials more effectively when they are personalized, that is, the information is provided in the context of discussions of the child's current behavior. In addition, in this setting the feasibility of the total treatment plan can be assessed, and professional interest and reassurance provided. A balance of demands and rewards for all participants appears an important factor in program success.

Concurrent with parental success in establishing communication with and providing assistance to the infant, many of the maternal emotional responses associated with the birth of a handicapped child have been observed to subside. Excitement generated in the family by the progress of the handicapped child brings feelings of pleasure and pride in the same way as do the more socially visible achievements of the successful normal child.

Not unexpectedly, the program described above has been less effective with the following: (1) parents with the survival problems and lack of adaptive skills found in some lower socioeconomic families, and (2) principal caretakers with a history of emotional problems which preceded the birth of the handicapped infant. These two conditions are indications for locating supplementary resources for the care of the child and/or support of the family.

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An anatomical illustration of human lungs, showing the bronchial tree in a light tan color against a blue background. A magnifying glass is positioned over the right lung, focusing on the bronchial tree. The magnified view shows the intricate branching of the bronchi and the presence of small, dark, circular structures, likely representing bacteria or inflammation. The overall color palette is dominated by blues and greens, with the magnifying glass frame in a metallic silver tone.

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