Six presentations and a discussion summary are included from a 1981 symposium on educating handicapped infants. N. Johnson, "Assessment in Infant Education: Paradigms and Problems," notes shortcomings in current assessment approaches and addresses the importance of diagnosis, identification of educational goals, and evaluation of child progress and program effectiveness. K. Jens proposes in "Alternative Strategies for Assessing Development in Young Handicapped Children" to provide a list of developmental markers that are valid, reliable and capable of assessing students for whom traditional measures are inappropriate. Obstacles to staff-parent partnership are identified, and suggestions for enhancing that relationship are given by A. Honig in "Working in Partnership with Parents of Handicapped Infants." L. Phillips provides an administrator's perspective in "Administering Programs for Handicapped Children from Birth through Three," while D. Whitehouse provides a physician's view in "Medical Implications of Early Recognition." Whitehouse covers the neurological examination and lists high risk behavioral patterns. A summary of symposium discussions addresses such issues as program support in times of budgetary problems, transportation, and efforts to identify and follow up at-risk children. A final paper by D. Walker reviews "Trends in Education for Handicapped Children from Birth to Age Five," including increased awareness that collaboration must take place at many levels, and of arrangements for cost sharing at state, local and federal levels. (CL)
PROCEEDINGS

The Infant Symposium: Educating Young Handicapped Children

AUGUST 13 - 14, 1981

SPONSORED BY

Maryland State Department of Education
Division of Special Education
200 W. Baltimore Street
Baltimore, Maryland 21201

The Johns Hopkins University
Division of Education
Evening College and Seminar Session
34th and Charles Street
Baltimore, Maryland 21218
This document was partially funded by the U.S. Education Department, Office of Special Education, under Part C of the Education of Handicapped Act, PL91-230 TitleVI, as amended. Technical assistance was provided by the Mid-Atlantic Regional Resource Center through the Office of Special Education contract OEC300-80-0718. The opinions expressed herein do not necessarily reflect the position or policy of the U.S. Education Department, and no official endorsement by the U.S. Education Department should be inferred.

WITH ASSISTANCE FROM THE MID-ATLANTIC REGIONAL RESOURCE CENTER
FOREWORD

THE INFANT SYMPOSIUM: EDUCATING YOUNG HANDICAPPED CHILDREN.

This symposium was sponsored jointly by the Johns Hopkins University, Division of Education, Evening College and Summer Session, and the Maryland State Department of Education, Division of Special Education, on August 13-14, 1981, in Baltimore, Maryland. The focus was on issues identified by local education agencies in light of present accomplishments and future challenges inherent in providing quality services for the youngest of our handicapped children and their families. Professionals from many disciplines, school systems, and cooperating agencies participated, with distinguished conference leaders.

Three means of exchanging ideas were used during the symposium: presentation of papers by guest speakers; reaction to papers by participants; and round table discussions. This proceedings paper contains the text of the presentations and highlights of the discussions. An additional paper, presented at a previous Maryland State Department of Education conference, is included because of its relevance to the delivery of services for young handicapped children and their families. The information contained in the papers and the discussion summary are distributed so that the responses, opinions, and recommendations of symposium participants can be shared with professionals working in the field of early intervention throughout Maryland.

Funding was provided by the U.S. Department of Education, Special Education Programs through the State Implementation Grant, G008101600. The opinions expressed by the symposium presentors and participants do not necessarily reflect the position or policy of the U.S. Department of Education, the Maryland State Department of Education, or the Johns Hopkins University.
## Members of the Board

<table>
<thead>
<tr>
<th>Name</th>
<th>District</th>
<th>Year Term Ends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joanne T. Goldsmith</td>
<td>District Heights</td>
<td>1985</td>
</tr>
<tr>
<td>President</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lawrence A. Miller</td>
<td>Baltimore</td>
<td>1982</td>
</tr>
<tr>
<td>Vice President</td>
<td></td>
<td></td>
</tr>
<tr>
<td>G. George Asaki</td>
<td>Pasadena</td>
<td>1982</td>
</tr>
<tr>
<td>May B. Bolt</td>
<td>Frostburg</td>
<td>1984</td>
</tr>
<tr>
<td>Mary Elizabeth Ellis</td>
<td>Salisbury</td>
<td>1983</td>
</tr>
<tr>
<td>Verna M. Fletcher</td>
<td>Silver Spring</td>
<td>1984</td>
</tr>
<tr>
<td>Rosetta Kerr</td>
<td>Baltimore</td>
<td>1986</td>
</tr>
<tr>
<td>Albertine T. Lancaster</td>
<td>California</td>
<td>1986</td>
</tr>
<tr>
<td>Frederick K. Schoenbrodt</td>
<td>Ellicott City</td>
<td>1985</td>
</tr>
</tbody>
</table>

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Thursday, August 13, 1981

8:30 - 9:00 a.m. Welcome
Mrs. Joan Maynard, Chief
Program Development & Assistance Branch
Division of Special Education
Maryland State Department of Education

Dr. Elaine Davis, Director
Department of Education
Evening College
The Johns Hopkins University

9:00 - 12:00 noon
"Assessment of Young Handicapped Children"
Nancy M. Johnson, Ph.D.
Acting Section Head, Psychology Section
Division for Disorders of Development and Learning
Biological Services Research Center
University of North Carolina

Kenneth G. Jens, Ph.D.
Head, Special Education Section
Division for Disorders of Development and Learning
Biological Services Research Center
University of North Carolina

12:00 noon.................... Adjourn for Lunch

1:30 - 3:00 p.m.
"Forming Partnerships with Parents and Providing Support"
Alice Honig, Ph.D.
Associate Professor of Child Development
Department of Child Development
Child Development Programs
Syracuse University

Friday, August 14, 1981

9:00 - 11:00 a.m.
"Administering Programs for Handicapped Children From Birth Through Age Three"
Louise Phillips, MA
Former Director of Magnolia Preschool Project
Magnolia Public Schools
Magnolia, Arkansas

11:15 - 12:30 p.m.
"Medical Implications for Early Recognition"
Dennis Whitehouse, M.D.
Director, Diagnostic & Evaluation Center for Handicapped Children
The John F. Kennedy Institute
Baltimore, Maryland

12:30 - 1:00 p.m.
Reaction to Presentations with Discussants:
Dr. Pat Edmister
Montgomery County Public Schools

Mrs. Ruth Reid
Calvert County Public Schools

Dr. Polly Roberts
Department of Health and Mental Hygiene

1:00 - 3:00 p.m.
Lunch and Group Discussion of Approaches to Serving Young Handicapped Children

Group I: Medical Implications of Early Recognition
Facilitator: Ms. June Gallagher
Prince George's County
Consultant: Dr. Dennis Whitehouse

Group II: Administration
Facilitator: Ms. Susan Cassidy Bronson
Cecil County Public Schools
Consultant: Ms. Louise Phillips

Group III: Identification & Assessment
Facilitator: Ms. Sue Toler, Ms. Nancy Bond
Consultant: Dr. Nancy Johnson, Dr. Kenneth Jens

Group IV: Program Planning/Parent-Professional Partnerships
Facilitator: Judy Makolin
Consultant: Dr. Alice Honig

12:30 - 1:00 p.m.
Reaction to Presentations with Discussants:
Dr. Pat Edmister
Montgomery County Public Schools

Mrs. Ruth Reid
Calvert County Public Schools

Dr. Polly Roberts
Department of Health and Mental Hygiene

3:00 - 3:15 p.m.
Evaluation
SYMPOSIUM PARTICIPANTS

Maryland State Department of Education

Joan Maynard, Chief
Program Development & Assistance Branch
Division of Special Education

Lin Leslie, Project Director
State Implementation Grant
Division of Special Education

Sheila Draper, Early Childhood Specialist
Division of Special Education

Kate Kreslie, Early Childhood Specialist
Division of Special Education

Beth Maza, Intern
University of Maryland

Elizabeth Dicembre, Intern
The Johns Hopkins University

The Johns Hopkins University

Dr. Gilbert Schiffman, Professor
Department of Education

Dr. Elaine Davis, Director
Department of Education

Presenters

Alice Sterling Honig, Ph.D
Associate Professor
Department of Child Development
Child Development Programs
Syracuse University
Syracuse, New York

Ken G. Jens, Ph.D.
Head, Special Education Section
Division for Disorders of Development
and Learning
Biological Sciences Research Center
University of North Carolina
Chapel Hill, North Carolina
Nancy M. Johnson, Ph.D
Acting Section Head, Psychology Section
Biological Sciences Research Center
University of North Carolina
Chapel Hill, North Carolina

Louise Phillips, M.A.
Former Director of Magnolia Preschool Projects
Magnolia Public Schools
Magnolia, Arkansas

Dennis Whitehouse, M.D.
Director, Diagnostic and Evaluation Center for Handicapped Children
The John F. Kennedy Institute
Baltimore, Maryland

Discussants

Ms. Carol Barnes
The Johns Hopkins University

Dr. Paula Bell
University of Maryland

Ms. Nancy Bond
Anne Arundel County Public Schools

Ms. Susan Cassidy-Bronson
Cecil County Public Schools

Dr. Pat Edmister
Montgomery County Public Schools

Mr. Edward Reinberg
Anne Arundel County Public Schools

Ms. June Gallagher
Prince George's County

Ms. Jewell Makolin
Carroll County Public Schools

Mrs. Ruth Reid
Calvert County Public Schools

Dr. Polly Roberts
Department of Health & Mental Hygiene

Ms. Sue Toler
Howard County Public Schools
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Author(s)</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foreward</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>I. Assessment in Infant Education: Paradigms and Problems</td>
<td>Nancy M. Johnson, Ph.D.</td>
<td>13</td>
</tr>
<tr>
<td>II. Alternative Strategies for Assessing Development in Young Handicapped Children</td>
<td>Ken G. Jens, Ph.D.</td>
<td>24</td>
</tr>
<tr>
<td>III. Working in Partnership with Parents of Handicapped Infants</td>
<td>Alice Sterling Honig, Ph.D.</td>
<td>41</td>
</tr>
<tr>
<td>IV. Administering Programs for Handicapped Children from Birth to Age Three</td>
<td>Louise Phillips, M.A.</td>
<td>47</td>
</tr>
<tr>
<td>V. Medical Implications of Early Recognition</td>
<td>Dennis Whitehouse, M.D.</td>
<td>76</td>
</tr>
<tr>
<td>VI. Discussion Summaries</td>
<td></td>
<td>89</td>
</tr>
<tr>
<td>VII. Trends in Education for Handicapped Children from Birth to Age Five</td>
<td>Debora Klein Walker, Ed.D.</td>
<td></td>
</tr>
</tbody>
</table>
Assessment has always played a critical role in the provision of educational services; for it is through assessment that we identify students in need of special intervention, determine existing knowledge or skills, evaluate the progress of the student, and examine the effectiveness of our educational procedures. Each time the educational community assumes responsibility for serving a new population, questions are raised as to educational goals for that population and the means by which the skills related to those goals can be assessed. As four and five-year-old youngsters joined the ranks of "school children," many questions were raised as to what should be taught. As these questions were answered, assessment instruments were devised to evaluate "pre-readiness" or "learning to learn" skills: discrimination, matching, problem solving, fine motor coordination, etc.

Now that schools are beginning to take on the task of educating handicapped infants, they are faced with some of their most difficult assessment problems, which are most evident in assessing those skills traditionally associated with the role of the educator, i.e., the language and cognitive skills prerequisite to later academic success. It is widely recognized that assessing these skills in normal youngsters is problematic because of their limited behavioral repertoires. Handicapping conditions further limit the available responses of infants and therefore our understanding of their capabilities.

Traditionally, three basic paradigms have been available for assessing developmental skills in children under three years of age. The first is the use of norm-referenced, standardized, psychological tests that yield one or two scores describing the child's status in terms of deviance from age expectancy or deviance from the mean performance of other children the same age. Most of these tests were developed specifically to measure mental development, although many of the items appear to involve more motor than cognitive skills. They were normed on samples of children deliberately chosen to exclude youngsters with known biological handicaps but are the primary instruments used to assess such populations. When applied to handicapped infants, they are criticized for their single score categorization of youngsters and their limitations in describing specific strengths and weaknesses. Yet they continue to be relied upon both because of the scientific respectability associated with their standardization and because a specific score is often a legal requirement for placement purposes.

Parts of this paper also appear in Johnson, N.M., Assessment Paradigms and Atypical Infants: An Interventionist's Perspective, in D. Bricker (Ed.) Intervention with at-risk and handicapped infants: From Research to Application. University Park Press, in press.
The second paradigm, criterion-referenced assessment, involves the use of instruments containing lists of developmental skills and the criteria defining skill mastery. The lists are usually organized around several areas or domains such as cognition, language, gross motor, fine motor, and personal-social. A child's status is described in terms of the skills mastered in each of the domains. Criterion-referenced instruments were developed, in part, as a reaction against single deviance scores, the rigidity of test administration, and the inappropriateness of many of the items in norm-referenced tests for the handicapped population. Yet, ironically, criterion-referenced tests include primarily (or exclusively) items taken directly from the standardized tests they were designed to replace. Furthermore, in an attempt to draw profiles of strengths and weaknesses in handicapped children, an age level is usually assigned to each skill included in the test. These age levels are also taken from the norm-referenced tests and are based on the mean age of children mastering the skill. Children are once again described in terms of age level or deviance from age expectancy, although with five or six scores instead of one or two. Of more concern is the fact that the scores may be less reliable than those obtained from any one on a different standardization sample.

The third assessment paradigm frequently employed for use with handicapped children is ordinal scales based on Piaget's theory of cognitive development. (For example, Uzgiris and Hunt's Ordinal Scales of Development, 1975; and Escalona and Cormen's Albert Einstein Scales of Sensorimotor Development, no date). These scales have become popular within the last decade as interventionists have become disenchanted with the ability of items from other infant tests to provide an understanding of a child's cognitive capabilities. These instruments are based on a theory of cognitive development and thereby provide a better rationale for selecting intervention goals than simply teaching specific items which have long been included in infant mental tests. The greater flexibility in item administration allows for the description of children's cognitive development along process dimensions rather than only in terms of skill attainment. In practice, however, the ordinal scales are often used as another criterion-referenced assessment with estimated age levels attached to each of the items and children again described in terms of age levels, or deviance from expectancy.

As we evaluate these paradigms, we find that none is adequate to describe the unique development of many of the handicapped children for whom we are responsible. These children do not fit simply on a continuum from profoundly retarded to mildly retarded as scores from norm-referenced tests might suggest. Neither can their cognitive processes be understood by assessment with criterion-referenced tests or ordinal scales where the sensory and/or motor demands of the items are inappropriate to the physical capabilities of the youngsters.

Because of the shortcomings in available instruments, we are constantly searching for new assessment procedures; we often accept new...
procedures as necessarily better without critically evaluating the usefulness of the information they provide. To avoid repeated disappointments with new procedures and premature discarding of traditional ones, it is necessary to recognize that assessment is a complex process, not a single event. To understand the process, assessment must be viewed as serving a variety of purposes or objectives with different objectives—requiring different assessment strategies. Any assessment paradigm, new or old, should be evaluated for the validity of its underlying assumptions and its usefulness for particular objectives or specific times.

In any special educational setting the basic objectives for assessment may be designated as: (a) diagnosis (identification of those in need of specialized services and specifying the nature of their problem); (b) identification of educational goals; and (c) evaluation of child progress and program effectiveness. At any given time, one, two or all of these objectives may be the target of an assessment. Before procedures are chosen, the particular objectives for that assessment should be specified and each procedure evaluated critically against these objectives. The question is not just "What test can I use?", but "What is it I want to know?".

**Diagnosis (identification of those in need of special services and specifying the nature of their problems)**

School age "exceptional" children are generally identified and their needs specified through a two-part process. First, teachers "screen" their classes through observations or tests and identify those children whose characteristics are sufficiently different from the others in the classroom to merit concern. Then these children are assessed by a variety of tests to determine if they are eligible for special services on the basis of specified handicapping conditions. Because infants are not in classrooms where comparisons can readily be made by experienced teachers and because development in infants is markedly variable, the screening step in the identification process is considerably more haphazard than it is for the school-age population.

There are three primary ways in which infant screening occurs. First, when babies are born there is screening by the physicians and other health professionals involved in their care. Severe health problems, known genetic or congenital abnormalities, or abnormal neurological responses may cause a child to be referred for intervention services or further assessment upon hospital discharge. Second, as babies develop, either their caretakers or health care professionals may have concerns about the nature of their development. They screen on the basis of informal observations or, in some cases, with the help of screening tests like the Denver Developmental Screen Test (Frankenburg, et al, 1976) or the Kid Scale (Reuter and Katoff, 1978). Third, children may be screened as part of a "child find" process defined by state laws in compliance with Public Law 94-142.

In each of these screening processes there is a great deal of room for error both in the direction of over-referral and in the direction of
Longitudinal follow-up of infants from neonatal intensive care nurseries indicates that prediction of later handicapping conditions is extremely difficult (Campbell and Wilhelm, in press). Youngsters with seemingly minor problems may develop significant handicaps and others with major problems will appear normal at two years of age. Even among conditions known to be highly correlated with mental retardation (e.g., Down's Syndrome) there are a few youngsters who show no signs of developmental delay in the first two years of life. Screening done on the basis of "risk factors" is apt to lead to considerable over-referral.

The screening which occurs by parents and health care professionals will be influenced both by cultural values (e.g., whether motor or language skills are most valued) and by how well a child's particular pattern of development matches specific expectations. As a general rule, handicaps which produce significantly delayed gross motor milestones lead to referral in the first year of life; those which affect primarily language and cognitive development lead to referral between ages two and three.

The effectiveness of "child find" screening depends on the way the process has been defined—whether all infants in well-baby health care are screened with a good standardized screening test; whether one relies on parent or health care professionals to report suspected problems; or whether one knocks on doors and screens by interview with caretakers or observations of the child.

The second phase of identification, the more formal assessment, is also fraught with many problems. The plasticity of the infant's nervous system, the variability in developmental patterns between infants, and the critical importance of different skills at different stages of development make it difficult to identify the child who is indeed handicapped and even more difficult to specify the nature of the child's problem in order to assign him to one of the exceptionality categories used by public schools. Both medical and psychological diagnoses are apt to change frequently during the infancy period. For example, many infants diagnosed as "cortically blind" are not blind at all but are too retarded to make use of visual information. Similarly, some infants appear hearing impaired because their motor or cognitive development is too delayed for them to give normal responses to sounds.

A critical question in psychological and educational diagnosis is whether or not the infant is retarded, i.e., has significant cognitive impairment. Historically, interest in infant assessment in this country was based primarily on a desire to predict future intellectual or achievement status; to identify the mentally retarded, the normal and the gifted. It is recognized that only norm-referenced, standardized assessment paradigms are appropriate to this objective. Such tests were constructed to reflect the emergence of developmental skills in the infancy period. Items were selected that discriminated between normal children of different ages and that were believed to be relatively unaffected by environmental experiences. These items were arranged either in a sequence determined by the mean age at which normal children passed them (e.g., the Bayley Scales) or in groups of items reflecting the typical skills.
developed by children at different ages (e.g., the Cattell Infant Intelligence Scale). Because of the limited behavioral repertoire of infants, the tests are composed almost entirely of items based on sensorimotor behaviors at the earlier ages with language items gradually being added after the 10-month level and contributing significantly to the scores after the 24-month level.

Using these tests to predict later intellectual status or to diagnose mental retardation appears to be based on the underlying assumptions that: (a) the rate of acquiring sensorimotor skills in infancy is the same as or similar to the rate of later cognitive development, (b) retarded and other atypical children will develop the same skills as normal youngsters but at a slower rate, and (c) the rate of development is relatively constant over time.

That such "mental" tests correlate only between .30 and .50 with later I.Q. measures suggests these assumptions may be questioned (Thomas, 1970). Among others, Kagan (1978), Zelazo (1977), and Kopp and Shaperman (1971) have effectively pointed out the limitations of the assumption that particular sensorimotor skills are necessary for subsequent cognitive development or that sensorimotor skills necessarily accurately reflect underlying cognitive development. They cite evidence for the development of adequate and even superior intellectual abilities in individuals with limited sensory and/or motor skills.

In addition, McColl (1979) cites evidence from longitudinal studies to support the proposition that the predominant structure of mental performance changes from one developmental stage to another, making untenable the assumption of a relatively constant rate of cognitive development across stages. He and other stage theorists (e.g., Uzgiris and Hunt, 1975) suggest that an infant mental test can accurately describe an infant's current standing relative to his peers within a particular developmental stage but cannot be expected to describe the child's relative position on the different mental skills that will be assessed as he progresses to another developmental stage.

Before standardized mental tests are discarded as being of little use in predicting future status, however, it is important to recognize that while they are inadequate predictors of later I.Q., they do predict developmental outcomes remarkably well for clearly deviant populations (Erickson, 1968; Illingworth and Birch, 1959; Knobloch et al., 1956). For example, VanderVeer and Schweid (1974) report that of infants and toddlers identified as borderline, mildly, or moderately-profoundly retarded on the basis of Bayley scores, all continued to fall in the retarded range one to three years later (on the basis of Stanford Binet or Bayley scores). In a study involving prediction over a longer time period, Werner, Honzik, and Smith (1968) found that 89 percent of the 20-month infants who scored below 80 on the Cattell demonstrated a variety of significant school problems at age 10. What this may suggest is that infant tests identify which children are handicapped and, therefore, in need of services, but are not sufficiently comprehensive to define the nature of the handicap. The handicap may be a learning disability, emotional disturbance, mental retardation, or some form of sensory or motor impairment.
Considering the nature of infant development, it may be inappropriate to try to define their handicapping conditions according to the categories usually used for older children. The critical issues for the educator are that development is significantly delayed or atypical, that it is unlikely that the problem will "go away" without intervention although its form may change, and that the test has clearly designated those tasks the child has and has not mastered. It may be necessary to develop arbitrary rules for assigning youngsters to categories until it is possible to convince the bureaucrats that such categories are relatively meaningless for infants.

Identification of Intervention Goals

In most infant education programs standardized tests are not used as the primary assessment for planning intervention although they can certainly be used to write educational objectives based on the items the child passed and failed. Bagnato (1981) has pointed out that considerable assessment time could be saved if standardized tests were used for planning at least initial educational goals.

More often criterion-referenced assessment tools like the Learning Accomplishment Profile (Sanford, 1976), the Hawaii Early Learning Profile (Furuno, et. al., 1979), and the Early Intervention Developmental Profile (Rogers, et. al., 1979) are used for describing developmental status and setting intervention objectives. These instruments divide developmental tasks into domains: gross motor, fine motor, language, cognition (or sensorimotor), social, and self-help. The tests which a child has mastered in each domain are checked off and the easiest items he has failed become the objectives for intervention. These instruments, used as a basis for planning treatment, are problematic in that they are primarily amalgamations of items taken from a variety of standardized developmental tests. They are an improvement over a standardized test only in that more items are included and the items are divided into developmental domains, making it easier to identify the strengths and weaknesses of the child. However, they suffer the same limitations as the standardized tests in that sensorimotor skills pervade the items in the cognitive and language areas, making it difficult to develop reasonable intervention goals for youngsters with significant sensory and/or motor problems.

In addition, the way that some of these instruments have been developed and used can be criticized because of the assumptions underlying such development and use. Four examples are illustrative. First, in many criterion-referenced tests the sequence of the skills in a particular domain is determined by the mean ages at which these skills are observed in normal children. Many interventionists use the sequence to determine the order in which skills are to be taught. Assuming that skills should be taught to handicapped infants in the order determined by the mean ages at which normal children master the skills is questionable since most normal children do not develop all skills in the order they appear on the Gesell, Cattell or Bayley tests. Furthermore, such an ordering does not necessarily provide a logical teaching sequence in which recently learned skills are practiced as a more difficult skill is learned. In the cognitive area particularly, the items adjacent to one another often have
little in common. For example, a sequence of skills may read: recovers rattle dropped on chest, makes gestural response to familiar gesture, looks for dropped object, finds partially hidden object. It is difficult to ascertain either a common cognitive basis for this sequence of common sensory or motor prerequisites.

Second, if standardized test items become criterion-referenced items there is a danger that teaching will become situation specific, altering the significance of accomplishing the item. For example, on almost every standardized infant test and on almost every criterion-referenced assessment there is the item, “places three blocks in a cup.” If a child can put three blocks into a cup after 30 training trials, it may represent something different in terms of cognitive development than if a child does it spontaneously or after only one demonstration and few past experiences with combining cups and blocks. The latter child could be expected to be able to put a variety of objectives into a variety of containers and, perhaps, to imitate a variety of simple motor tasks. The same could not be expected of the child who needed extensive training unless efforts had been made to build in generalization of the skill.

Third, when a standardized test item becomes a criterion-referenced test item, there is an assumption that the skill represented can be taught using reasonable educational and behavioral methods. Yet, an item which was selected for the standardized test because it discriminated between children of different ages may represent a skill that is primarily dependent on neurological maturation rather than on learning per se. Educational intervention to develop such skills may be relatively fruitless. Examples of such skills might be the visual search for sounds exhibited by blind as well as sighted children and the pincer grasp which facilitates the child’s ability to pick up small objects. Even in relatively motor-free areas it remains quite unclear which developmental tasks can readily be taught using a behavioral paradigm, which are primarily dependent on physiological maturation, and which are triggered by maturation but can be facilitated by appropriate teaching.

Finally, if the criterion-referenced test is entirely made up of items which occur on norm-referenced, standardized tests, there is an assumption that the items on these tests represent the most important or the only skills that should be taught. With such an assumption skills that are important to later learning but have never been included in standardized tests because they are not age specific may be neglected. For example, simple contingency learning (moving to make a mobile move) is rarely assessed on norm-referenced tests but has been demonstrated to be important for learning later, more complex contingencies (Watson and Ramey, 1972). Furthermore, skills may be ignored which are not “normal” but which allow handicapped individuals to make adaptations to the world around them, for example, manual signing or manipulating a switch or pedal that could later be used to operate a communication board.

One alternative to using amalgamations of items from standardized tests for program planning in the cognitive domain has been to use scales based on Piaget’s stage theory such as the Uzgiris and Hunt Ordinal Scales.
of Psychological Development (1975). These scales were designed to assess and describe a child's development in each of six domains of cognitive functioning. Since the ordering of items in each domain provides a logical sequence for teaching and since there is flexibility in the materials used for assessment, interventionists have used the scales as a criterion-referenced instrument for intervention planning. However, using the scales in this way involves some of the same assumptions questioned above, that is, that a trained-in skill has the same generalizability across situations and materials as one developing through a variety of natural experiences and that the assessed skills can, in fact, be taught. Furthermore, the items on these scales are as dependent on visual and motor skills as items on all other infant tests, making them equally inappropriate for planning intervention for children impaired in these areas.

A second alternative to using items taken primarily from standardized tests has been the development of instruments specifically designed for handicapped youngsters with items carefully sequenced to provide logical teaching sequences and items included to address compensatory skills that would not be included on standardized tests for normal children. Two of these instruments are the Adaptive Performance Inventory (CAPE, 1979) and the assessment tool accompanying the Carolina Curriculum for Handicapped Infants (Johnson, et al. 1979).

Evaluation of Child Progress

Ongoing assessment of handicapped children is an essential part of educational accountability. Yet, for infants there are major roadblocks to the development of good assessment procedures for this purpose. While it is simple to check off items a child has mastered between two assessments and thereby indicate his developmental progression, it is by no means simple to demonstrate that the mastery of any of the items is a direct function of educational procedures. Progress attributable to intervention in infancy is usually defined as development which is greater than one would expect if no intervention had taken place. Since experimental and control groups are neither ethically nor practically available to educators, the search is for assessment procedures that will identify changes in the rate of development in individual children after intervention is begun.

Standardized, norm-referenced tests have often been selected to demonstrate rate changes because the quotients they provide purportedly reflect developmental rate. With some regularity these tests suggest that intervention is more effective with mildly handicapped than severely handicapped children. In the National Collaborative Project, for example, progress as measured by Bayley or Denver scores was more related to degree of handicap than to any program characteristics that could be defined (Meisel, 1976). The most severely handicapped children made practically no measurable progress even after 24 months of intervention. Considering the shortcomings of such norm-referenced standardized tests already described, these findings are not surprising. Most severely handicapped children have sensory and motor impairments that prevent appropriate responses to the test demands. Moreover, the predictive power of standardized tests for the moderately and severely handicapped populations suggests that these tests are unlikely to be sensitive to intervention effects.
Some proponents of criterion-referenced assessments (e.g., Sanford, 1976) have attempted to monitor rate changes more effectively by treating each area of development (gross motor, fine motor, cognitive, etc.) separately. An age level is assigned to each item in the assessment based on the age at which normal children are expected to pass the item. The assessment is treated as a norm-referenced test, and developmental ratios (Developmental Age/Chronological Age) are computed for each section of the test. The five or six ratios obtained each time the child is assessed purportedly increase the likelihood of monitoring rate changes in some skill areas even if they are not present in all.

Such a procedure is highly questionable both because the age levels for items in the test are estimates based on a variety of samples of normal children and because ratios based on developmental and chronological age are notably unreliable (hence, the preference for deviation I.Q.'s over ratio I.Q.'s). Furthermore, one must question the validity of statements about rate changes on the basis of McCall's (1979) discussion of the discontinuous nature of development across developmental stages. Other proponents of criterion-referenced instruments (e.g., White and Haring, 1979) have suggested that developmental progress be evaluated by computing the percentage of items passed in an assessment instrument at each assessment point. These percentage changes can be compared with changes expected on the basis of the development of normal children, some specific handicapped population, or a control group. Percentage changes in developmental domains where intervention has occurred may also be compared with those in domains where intervention has not occurred. While these procedures eliminate the problem of unreliable age levels and unreliable developmental/chronological age ratios, they introduce yet another source of variability; that is, the percentages are based on items of unequal difficulty. Wherever there is a grouping of relatively easy items, progress will appear to be rapid just as it will appear to be slow when there is a grouping of relatively difficult items. Before percentage changes can be used as adequate indicators of progress it will be necessary to scale items to produce intervals of equal difficulty. This is no easy task since intervals made equal for task difficulty in normal children may not be equal for children who are blind, motor-impaired, or multiply handicapped.

In conclusion, it is evident that we are a long way from solving the problems of assessing handicapped youngsters. Simeonsson, et al., (1980) are undoubtedly correct in insisting that a variety of assessment procedures will be necessary for most handicapped youngsters because each provides only a partial picture and is useful for only limited objectives.

In spite of the problems involved in adequate assessment, optimism is warranted. Research expertise has been growing among interventionists and an increasing number of those involved in normal developmental research have become interested in the questions raised by the atypical development of handicapped children. A merger of the knowledge and skills of these two groups of professionals should contribute significantly to solving assessment problems. As the merger takes place it will be apparent that
The "normal model" is not always applicable to many handicapped youngsters. Assessment procedures that focus only on the skills that appear important in normal growth and development may miss skills that are of particular importance to the adaptation of groups of handicapped youngsters. To be most helpful to the handicapped, future research will need to focus on questions raised by the assessment and treatment of handicapped youngsters, not only the questions raised by observations of normal children. This will involve not only collecting extensive longitudinal data on handicapped youngsters but asking different questions in the study of normal children. The assessment issue is less one of finding the one best assessment paradigm than one of approaching each assessment with the questions: 1) what specific information needs to be gained from this assessment? and 2) what collection of procedures is most likely to produce that information? With these questions in mind the interventionist can be creative with assessment techniques, serve children more effectively, and, with careful documentation of his/her procedures, contribute data and ideas for further exploration of assessment issues by those involved in laboratory research.
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ALTERNATIVE STRATEGIES FOR ASSESSING DEVELOPMENT IN YOUNG HANDICAPPED CHILDREN

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It is a fairly well accepted principle that persons search for new methods of doing things because they find reason to be dissatisfied with existing methodologies. This is precisely what has been happening for some time now in the area of infant assessment. There is an abundance of evidence suggesting that the predictive validity of developmental tests used with normal infants is not very good (Stott & Ball, 1965; Bayley, 1966; Honzik, 1973) and many explanations have been offered regarding these predictive difficulties. Only within the last half decade, though, has it been suggested that this problem may in large part be a function of the fact that indices of cognitive development utilized with infants are heavily loaded with motor-dependent items (Zelazo, 1976). Zelazo has pointed out that when traditionally used infant tests are analyzed for content their items tend to fall into three categories -- those which measure gross and fine motor performance, indices of imitative behavior which are directly affected by one's motoric abilities, and the production and comprehension of language -- with language production also being directly affected by one's motor development. This tie, wherein the assessment of cognitive behavior is implied through motor and language-laden test items is problematic to say the least. While age-appropriate motor and language responses on traditional tests may well reflect age-appropriate cognitive development, a lack of such performance cannot be assumed to indicate delayed cognitive development.

The aforementioned problems, along with the fact that we are primarily involved in trying to identify useful ways of assessing development in moderately/severely/multiply handicapped young children, has led us to the search for non-traditional assessment techniques. We are especially interested in techniques and strategies for assessing cognitive ability exclusive of, or minimizing, the need for verbal and motoric responses. This need has forced us to acknowledge the restricted utility of standardized instruments with very young moderately/severely/multiply handicapped children and has forced us to seek heretofore little used information regarding developmental markers from the professional literature of child development.

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We are primarily interested in the utility of affective responses as indices of cognitive development. This is certainly not a new idea, though, as Piaget suggested as early as 1952 that affect and cognition are complimentary and develop in a parallel fashion. It has also become a relatively well accepted fact that affect and cognition develop interactively and that affective responses are, in fact, behavioral indicators of cognitive information processing in both social and non-social situations (Lewis and Rosenbloom, 1978; Kagan, 1978; Zelazo and Komer, 1971). There appears to be relatively extensive evidence in the literature that four affective behaviors—smiling, laughing, fear, and surprise—have been logically related to cognition, either theoretically or empirically. We have been attempting to use each of these to increase our understanding of both individual cognitive responses and the course of cognitive development in handicapped infants. Three of these behaviors—smiling, laughing, and surprise—appear to be useful in the assessment process at this time.

More than a half century ago, Washburn (1929) observed that the age at which laughing first occurred in response to a variety of stimuli varied amongst children. These age-related variations were hypothesized to stem from maturational differences in children, and more recent studies (Sroufe and Wunsch, 1972) have substantiated the fact that increasing amounts of laughter to specific stimuli are, in fact, associated with increasing chronological age. Sroufe and Wunsch (1972) also found that older infants laughed in response to different types of stimuli than those which elicited laughter in younger children.

In an extension of that work, Cicchetti and Sroufe (1976) developed a battery of stimuli which utilized tactile, auditory, visual, or social stimulation in an attempt to elicit smiling and laughter on the part of young children. They found that young normal infants smile and laugh primarily to intrusive stimuli such as being tickled or bounced or upon hearing unusual sounds. Older infants were more likely to smile and laugh in response to more cognitively complex items of a visual and social nature such as game playing or the recognition of discrepant events (e.g., mother waddling like a duck or sucking on a baby bottle). They found that, in general, the affective response of children with Down's Syndrome progressed in the same developmental fashion as non-handicapped infants and that both the onset of laughter and the total amount of laughter shown were positively correlated with later performance on infant intelligence scales.

A similar developmental progression has been demonstrated and shown to be related to mental age in a mixed group of severely/multiply handicapped infants by Gallagher (1979). Thus, while the number of developmental markers provided is extremely limited, the assessment of the development of affect may provide an indication of cognitive development in infants who are unable to produce the motor responses pre-requisite to more traditional assessment.
Kaga, Kearsley and Zelazo (1978) reported the development of a procedure for assessing perceptual-cognitive information processing on the part of young children with impaired motor or verbal abilities. They utilized an expectancy paradigm which makes use of surprise and associated changes in heart rate and observable behaviors to indicate cognitive processing of sequential visual and auditory events. While a youngster's heart rate is being monitored and he or she is being observed for behavioral responses, a standard series of events (a car running down a ramp and knocking down a snowman) is presented; this is followed by a shorter series of discrepant events (the car runs down the ramp but the snowman does not fall), and there is then once again a series of the original standard trials wherein the car runs down the ramp and the snowman falls. Youngsters' responses to these stimuli are developmental, with changes in heart rate and observable behavior associated with the various trials changing predictably from 6 through 30 months of age. These procedures appear to be measuring children's increasing speed of information processing through the first three years of life.

Johnson (1981) has pointed out that with the use of these alternative assessment paradigms it may be possible to show that some youngsters who are likely to be labeled mentally retarded on the basis of their inability to respond to norm-referenced tests may avoid the attachment of that label because of their ability to smile and laugh in response to age-appropriate stimulation or to demonstrate assimilation of sequential visual and auditory events. Johnson (1981) has also suggested that these alternative assessment procedures may be used to increase the reliability of prediction within an assessment process, but that they do not, by themselves, offer a better alternative to existing assessment strategies. She indicated that while alternative procedures may suggest that the problem is not mental retardation, they do not tell you what the problem is. A discrepancy between performance on the two assessment procedures does not negate the value of one, whether it be a standardized test or a non-traditional assessment technique; it may simply rule out one possible cause of poor performance and identify a need for still further assessment to improve the specificity of diagnosis.

Persons responsible for implementing intervention programs are then presented with the following problem: "How can I use the existing knowledge regarding the development of affective behavior to assist me in making decisions regarding the current developmental status and/or the intervention needs of a particular child?" Hopefully, the psychologist and infant educator will have in their repertoire knowledge of the various landmarks of affective development (e.g.):

A child smiles to a human face at 6 weeks;

A child shows surprise when a covered object is found to be missing upon uncovering it at 16 weeks;
By 4-6 months children laugh in response to "intrusive", auditory and tactile stimuli;

Between 7 and 9 months children begin to laugh in response to social and visual stimuli;

The first instances of stranger and separation anxieties occur at about 8 months of age;

Laughing in response to incongruities such as a mother sucking a bottle or walking like a duck occurs at approximately 10-12 months;

And, fear of perceived depth, the visual cliff, has been found to occur between 7 and 12 months and to be closely related to the development of locomotion in normal children.

The interventionist's task, then, is to apply this kind of information to particular children who are not developing according to normative expectations and to make use of research findings which, in most cases, come from a sample of children who are developing normally. In addition, the practitioner will have to deal with inconsistencies in the theoretical and experimental work on affective development.

The multiplicity of landmarks and shifts in theoretical foci over time present what O'Donnell and I have referred to as the practitioner's dilemma ( Jens & O'Donnell, 1981). Educators and psychologists who are trying to be responsive to new developments in the field frequently find themselves in a bind; they want to integrate the latest research information into assessment and programming, but the utility and application of new constructs and strategies (e.g., smile stimuli, habituation or surprise paradigm) is neither obvious nor direct. Usability is constantly being evaluated by the practitioner and applications are made on the basis of that evaluation.

For example, Panabecker and Emde (1980) and their colleagues have been studying the perceived onset of emotions including easily identifiable ones such as interest, joy, surprise, and anger as well as some which are less easily identified in the infant -- sadness, disgust, contempt, and guilt. This data may make a major contribution to our understanding of the development of, or the child's communication of, discrete emotions. Most practitioners, however, would have difficulty perceiving infants as capable of reflecting disgust, contempt, or guilt; they would have even more difficulty attempting to use the onset of these emotions in the assessment/intervention task.

How then does the interventionist approach the literature provided by theoreticians and researchers when attempting to gather information for day-to-day problem solving? O'Donnell and I have
proposed the adoption of an "as if" model to bring resolution to this dilemma, wherein one deals with current views and literature "as if" they are in fact true. This "as if" approach is primarily based on the conceptual work of Kuhn (1970) who suggested that within any area of professional development there are paradigms which compete for viability in determining the course that professional intervention, treatment, and research models follow. As any given paradigm gathers advocates on the basis of its apparent validity, it may offer strong competition to paradigms in use and change the course of intervention and research for a period of time. Such shifts are not unusual and they are most frequently seen as signs of progress. The shifts are not absolute either; a new paradigm may have greater face validity and thus credibility for immediate practice than the one which it replaces. But elements of the latter may still be maintained long into the future.

Examples of such paradigmatic shifts are obvious within several areas of special education. One of the most obvious is that which saw the shift from self-contained classrooms to "mainstreaming" within regular education as the expected way of providing educational programs for mildly handicapped children within the public schools. Another conceptual shift brought us to the realization that infants are very capable of learning -- that they perceive, respond to, show preferences for, and generally interact with their environments in a meaningful and purposeful manner.

Over the years, models for intervention have continued to compete for credibility. As such, groups of practitioners have utilized them "as if" each were representative of truth. This phenomenon allows intervention to occur on the basis of a given model, providing direction to the efforts of practitioners while not ignoring the possibility that other models might, at the same time or in the future, provide a more logical basis for intervention. A shift in perspective for either intervention or research emphasis is seen as acceptable for the moment on the basis of consensus if it is seen as useful in application, but it is always subject to rejection by a changing consensus.

Using an "as if" approach seems to meet a twofold need of the interventionist. It allows the comfort and structure offered by a currently acceptable framework for explaining development in children. This can provide the practitioner a model from which to formulate the assessment and intervention needs of a particular child. Second, the interventionist, especially one dealing with handicapped children, needs freedom and flexibility within a model. The "as if" approach gives the interventionist permission not to throw out the model or the child when current theory and research fail to be useful clinically. One is also allowed to be creative when using a model in an "as if" way, rather than holding to more inflexible rules when a model is seen as representing a universal truth.
Using Research Finding in Clinical/Educational Settings

Individuals working with at-risk or handicapped infants have at least four recognized tasks. These include (1) assessment -- identifying infants in need of service and specifying the nature of their problems, (2) identifying intervention goals and associated intervention strategies, (3) monitoring and evaluating developmental progress and intervention effectiveness, and (4) becoming involved in the interactive process going on between parents and children. These tasks are not mutually exclusive; one does not facilitate intervention without assessment and one cannot assess a child without intervening in at least some small way.

Child Assessment - What is it that we want to know as a result of assessing a child's affective development? In all likelihood, we are trying to gather information in three areas. First, we are trying to gather information about the child's information-processing abilities so as to facilitate developmental/educational planning and to select appropriate intervention strategies. Second, and this is probably part of the first point, we are trying to predict sets of stimuli that will be attractive to a particular infant and which will maximize his or her responding. Third, we are making hypotheses about the probable course of development for a given child. This prognosis will, in turn, affect both short and long term goals selected for intervention.

As an example of the use of affective information in the assessment of a child, consider the case of Kristin, a young girl with cerebral palsy of a spastic-quadraplegic nature. She demonstrated few responses besides eye movement and smiling upon entering our intervention program at 10 months of age. While a traditional assessment was impossible because of her severe psychomotor impairment, her mother was able to provide the following information when questioned: at 3 months Kristin appeared to be exhibiting a social smile, at 8 months she was attempting to attract others' attention through smiling and, at 9 months she was showing obvious discrimination of her mother from other persons as well as showing real distress when being left with others. On the basis of the information provided, and recalling the literature which suggests that cognitive and social-emotional aspects of development are inseparable, our first hypothesis was that Kristen appeared to be showing normal cognitive development despite her very severe physical handicap. While the amount of data utilized as a basis for this hypothesis may be minimal, we were relying on our "as if" model because of the lack of a better basis for decision-making. We assumed, for example, that the statement by Cicchetti and Sroufe (1976) that the chronological age when infants first laugh appears highly predictive of performance on the Bayley Mental Scales at 16 months and the Uzgaris-Hunt Operational Causality Scales at 13 months is a useful truth. We assumed the same for the studies of Bell (1970) and Lester, et.al. (1974) which demonstrated that the development of person permanence is closely related to the development of object permanence and that both relate to the expression of separation distress.
In this case, our assumptions paid off. By the time Kristen was two years old other measures of her cognitive abilities (e.g., receptive language) appeared well within normal limits for her age.

Identifying Intervention Goals. Intervention, of course, follows very naturally from assessment. If, in fact, assessment has explored strengths and weaknesses and noted them, then it has also set forth hypotheses with regard to the way infants process information and the nature of appropriate intervention. Because both very young and severely/multiply handicapped children are unable to provide us with the verbal and motoric responses required in traditional assessment paradigms, we are likely to underestimate their information-processing skills. This frequently leads to a situation which we have seen all too frequently -- children being taught very low level, rudimentary skills with the realization sometime later that they were undoubtedly capable of processing information and thus learning at a much higher level.

Utilizing the developmental markers provided by researchers in affective development has helped alleviate this situation somewhat. It was apparent with Kristen, for example, that there was a considerable discrepancy between her level of affective responding and her ability to demonstrate her cognitive abilities in other ways. Using the aforementioned information, her teachers and parents were able to structure intervention experiences geared to a higher cognitive level than they would have otherwise. Without considering the affective information, we might have focused on an entirely inappropriate developmental level.

Demonstrating Developmental Progress. Parents are generally overwhelmed following the birth of a youngster who has been identified as having disabilities which may result in a handicapping condition. At a time in one's life which is supposed to be filled with excitement about the future, they are having to deal with a series of traumatic events, all of which have repeatedly pointed out that their youngster is different. This frequently results in their having a great many questions, such as: "Is it okay to handle him like other normal babies?", "How should I interact with him?", "What should I expect from him as he's developing?". At the same time, though, most of these questions go unasked because of the potential that unwanted answers might serve only to confirm that a youngster is, in fact, handicapped.

Because of these questions and because parents do not know what to expect with regard to the development of their youngsters once they have been told that they are developing differently, they have intense needs to see early signs of developmental progress.

Andy, a youngster with Down's Syndrome, was 3 months old when he entered the Infant Treatment Group. At that time, his mother demonstrated extreme anxiety with regard to his developmental progress. She observed the administration of the auditory and tactile sections of the "Smile Scale" to Andy. While 85 percent of Andy's responses were neutral and another 10 percent indicated distress, the
situation still provided a setting wherein it could be pointed out that Andy was attending to some of the stimuli and there did appear to be an emerging smile at times. While this was not much useful information, it was comforting to Andy's mother to know that there were first signs of an emerging smile at 3 months and also to know that Andy's development in this area appeared similar to that of other babies with Down's Syndrome who were now older and whom Andy's mother perceived as making reasonable developmental progress.

Re-administration of the Smile Scale at 5 1/2 months not only showed Andy's mother that he was smiling to a significantly larger number of items, but she was also able to notice and point out to us that Andy was showing much better visual attention and that his visual tracking skills had increased noticeably since the last administration of the stimulus items.

At this time, we were also able to tell Andy's mother that he was smiling in response to a number of items which normal children generally begin to smile at when they are 3 to 4 months of age. This provided her with a developmental reference point, and perhaps more importantly, it provided her with a hypothesis regarding intervention. That hypothesis was "If I provide Andy with more auditory and tactile stimulation, he will probably learn some important behaviors." Thus, she began to attend to the frequency and type of stimulation that she was providing for Andy, and much more reciprocal play involving the two of them ensued.

Entering into the Parent-Child Relationship. The use of affective information, as described by the current literature, is perhaps the best medium for entry into the parent-child relationship. The importance of assessment and intervention in the relationship between the child and his or her caregivers has been highlighted repeatedly in the child development literature of the past decade (Samaroff and Chandler, 1975; Bell, 1970; Brazelton, 1979; and Parke, 1979). Brazelton (1979), for example, suggested that the primary task of the interventionist is to enter into the process between the child and the parent, thereby increasing the plasticity in the child's subsequent development. He calls attention to the processes whereby the mother captures the child's attention and engages the child in communicative acts. He also points to the importance of the child's ability to engage the mother, to elicit care and contact from her, and thus to reinforce interactions that will ultimately facilitate development in other areas as well. Similarly, Emde (1980) refers to the importance of "emotional reciprocity" in parent-child relationships if they are to be maintained. His concern with "emotional availability" seems to parallel Sroufe's description of parent and child "capacity for emotional involvement," and at issue in both cases is the need for clarity of emotional signaling on the part of both parent and child.
Clinical experiences have shown that severely/multiply handicapped children have much greater problems than normal children providing signals that are readily understandable by their caregivers. For illustrative purposes, consider the case of Ann. Ann is 3 years old and severely handicapped with athetoid cerebral palsy. For some time, her teachers have been concerned about her seeming lack of any affective signals and the effect this might have on her relationship with her mother and other members of her family. Through ongoing observations of her responses in the pre-school classroom and through repeated administrations of the Smile stimuli, her teacher was able to share this problem with her mother and to explore with her the possibility that Ann does respond, but in ways not readily translatable. With these clinical observations and with information provided by Ann’s mother about her response in other situations, we were able to arrive at a joint conclusion that an unusual facial grimace (which her mother called Ann’s “fish face”) was, indeed, Ann’s smile! Not only has this hypothesis facilitated her development in the classroom, but we feel it has had a significant effect on Ann’s affective relationship with her parents. At least one of her emotional signals is clarified, and it is likely that more will be identified. Her mother sees her as emotionally available and able to respond to emotional signals. This has quite probably resulted in increased maternal accessibility which is seen as an important factor in developing and maintaining essential social interactions.

Limitations and Problems Association with the Use of Non-Traditional Assessment Strategies. There appears to be little doubt about the fact that strategies for assessing development which, until recently, were relegated primarily to research laboratories can be very useful in clinical and intervention settings. It is entirely possible that by combining information available to us from a variety of assessment paradigms that we may assemble a list of developmental markers which are valid, reliable, and allow assessment of those youngsters who do not have the verbal and motoric responses necessary for responding within more traditional assessment paradigms. Studies of visual preference and the development of affect, information processing, and social competence are all providing us with developmental markers which are useful for both diagnosis and the development of intervention programs.

While the introduction of experimental data and strategies regarding development can be very useful in psychoeducational interactions with young handicapped children, applications of this data as well as the “as if” approach to using it do have limitations.

First, few of the developmental markers which are suggested come with directions for use of data regarding their previous use, such as that supplied with standardized test instruments. Thus, utilizing them in an “as if” manner is appropriate; the knowledge and understanding of the person using these markers will in large part determine their usefulness.

21

30
References


Three ideas about handicapped children have come to be challenged radically in the past decade. One was the notion that nothing much could be done for educating a handicapped or retarded child before the school years. Current knowledge about the importance of building later skills on earlier infant learning is coupled with current sensitivity to the early prevention of the development of more severe disabilities in later life. Such new understandings have led to efforts to begin work with infants as soon as possible after a disability or risk condition has been detected.

A second idea from the past was that handicapped youngsters always had to be educated in a special, protected, separate environment. Today we know that while this may still be true for some children, others can best learn in a mainstreamed environment if there are proper supports and education of teachers, parents, and classmates. The Brickers (1972) have successfully mainstreamed Down's Syndrome preschoolers with normal toddlers in a program that counts heavily on parent participation for carrying out systematically prescribed learning exercises with the children.

A third idea was that only professionals could either diagnose or remediate handicapping or delayed developmental conditions. They were the experts. Often the first person to be troubled that development is not proceeding normally is the parent. The parent may feel strongly that coping with this baby is very difficult, that worries are frequent, that help is needed. Sometimes professionals will reassure an anxious parent that a baby will "grow out of" a problem or that the baby is "too young to tell" just yet if there is really something wrong. Efforts to downgrade a parent's concern or dismiss a parent's fears can lead only to alienation of parents and lack of trust in professionals. Helping persons need to value parents as sources of special information about an infant's development. Valuing parents helps them counteract their own feelings of self-doubt at the crisis of birth of a handicapped infant. We need to respect the parent as a prime observer of infant characteristics that can give clues for appropriate remedial efforts. As Karnes (1979) advised, "Think of parents as teaching resources who can contribute knowledge about and insight into their children, helping you to enhance educational programs." (p. 38)

Thus, the third notion has been replaced with the realization that parents are the first and most loved and most available teachers of their infants. They are an important and crucial component in the front-line preventative and remedial work done with handicapped children.
Obstacles To Staff-Parent Partnership

Despite the new awareness and appreciation of the role of families as educators of their young handicapped children, cooperation between helping staff and parents may not be easily obtained. Staff desire to help the infants has not always been accompanied by sensitive efforts to build trust with parents, so that, for example, parents understood the reasons for certain stimulation exercises or curricular interventions urged by the staff. What are some of the aspects of parent involvement in the development of handicapped infants that can work against a cooperative partnership between parent and practitioner?

Knowledge of Child Development

One of the difficulties that sometimes prevents communication between practitioners and parents lies in the different views of the infant and differential knowledge about child growth and development that parents may have in contrast to professionals. De Lissovoy (1973) surveyed rural, adolescent parents of infants to find out at what age most parents think babies can accomplish a variety of developmental tasks, such as sitting alone, social smiling, toilet training, saying first words, and being obedient to "no-no." Parental estimates in weeks of when children were able to complete developmental milestones or were able to recognize and be held responsible for behaviors considered wrong by the parent were totally out of line with developmental norms. Fathers, for example, believed that babies could sit alone at 6 weeks; the norm is 28 weeks for normally developing infants. Both parents believed that toilet training should be accomplished by 6 months, whereas neurological maturation that permits voluntary sphincter control may not be completed until after the second year for many toddlers. Most of the parents expected very little crying from their babies. During visits, Dr. De Lissovoy often witnessed excessive physical punishment of very young babies. Parents explained that the baby "had been asking for it all day" or that the slapped baby had already been told to stop crying and had disobeyed. Poverty and very low tolerance for frustration seemed to increase parents' perception of infant care as a very trying experience. Very few of the parents spontaneously cuddled or played with their child just for the "sheer joy of it." (p. 24)

Epstein (1978) has also found that teen-age mothers seem to be unaware of the developmental meaning of observed infant behaviors and parent-child interactions. Therefore, some parents may be unresponsive to the developmental needs of their babies for supportive stimulation, verbalization, and interactions. Thus, a thorough knowledge of normal and delayed infant development stages and processes can help a provider help parents. Parents have a basic civic right to child development knowledge (Honig, 1979).
Grief and Anger

Most parents are prepared for the birth of a normally endowed, perhaps even an ideally endowed, baby. The birth of a handicapped infant or an infant at risk poses a massive threat to the parent's inner picture of a "good parent." Feelings of denial of the reality of the handicapping condition may arise. All is well. Nothing is really wrong with their baby. They resent the professional who is suggesting terrible, threatening ideas of defect or danger. They may ignore professional advice and suggestions.

Feelings of rage and of grief often mix together and flood a parent with emotional distress. Numb, unreal feelings about the actual existence of the handicapped baby and wishes that the baby might die may arise. The hurt feeling that a particular baby will never grow up to be the son or daughter dreamed about may interfere with early ability to focus on the real baby whose needs for special care may be so urgent. Emotions of panic and irritability may be augmented by physical exhaustion if a parent is caring for a baby who has difficulties with breathing, feeding, or sleeping.

Neediness and Anxiety

Insecure and depressive feelings may accompany even normal pregnancy and delivery. Usually, hopeful and positive feelings surge up as the newborn is held and beheld by the parent. Loss of the dream of a normal baby is a real deprivation. Like other deprivations, such as financial struggle or abandonment by a loved partner, deprivation of the normal baby that the parents expected can lead to hopelessness or resentment about ability to fulfill the parenting role. Since the handicapped neonate was so much a part of the mother's body, the newborn can come to stand for "bad," unwanted parts of the mother. Kaplan (1978) suggests that even before birth "the baby-to-be has been an angel and a monster" (p. 66). The birth of handicapped neonates may precipitate feelings of self-hate and of maternal alienation from the "monster" aspect of the baby that the handicap represents. When the baby has been born to a mother who has herself been poorly parented in the past, the guilt at having produced a "bad" baby literally, coupled with having been the "bad baby" psychologically, may awaken ancient angers and hatreds, toward self and the new baby.

Sometimes a series of deprivations coincide, as when an unwed, young mother bears a handicapped infant. Professionals need to be aware of the ambivalent feelings, especially of insecure feelings toward the baby, and also of great anxiety about whether the baby "loves" her. The author was once present in a therapeutic day care center for at-risk infants. A teen-age mother thrust her baby suddenly into the arms of another young mother. The baby screamed. The mother smiled triumphantly, snatched back her baby and repeated the thrusting away of baby to another person's arms. Again the infant
cried out terrified. Turning to the author, the young mother said defiantly "See, that proves she loves me best and I'm a good mother, 'cause she cries when she's in their arms!" Kaplan has noted that in some mothers, deprivations can lead to "awakening of the unloved self" (p.65) possibly followed by anxiety, depression, and panic.

Further, some parents, particularly fathers, may be "so out of touch with memories of neediness that they find it impossible to empathize with neediness in others. They resent being needed and resent those who are in need (Kaplan, 1978 67-68). Since newborns with handicaps often need special care and attention for long periods after birth, parents may come to see their babies as being totally needy and dependent on them. This can awaken old anxieties about dependence and neediness. An important antidote may be to allow fathers to participate in the birth process and in holding the newborn so that emotional openness to nurture and empathize with the baby can be enhanced.

Attachment Status and Early Learning

During the past decade, intensive research on securely attached versus insecurely attached infants has revealed the critical importance of the attachment bond as an organizing force which permits the infant to learn. Sroufe (1981) and his colleagues have found that year-old babies who were securely attached are, as toddlers, able to persist longer at tool-using tasks than those who had been insecurely attached. The securely attached tots were more prone to enlist the parent as helper when the problem-solving tasks were quite difficult and they exhibited far fewer tantrums than insecure infants in the face of frustration.

Ainsworth and her colleagues (Bell & Ainsworth, 1972) have demonstrated that securely attached infants can be more easily comforted by caregivers. Such infants can also use the parent as a "homebase" from which to go forth and explore toys and environment. The importance of this enablement lies in the fact that it is "the (baby's) active, coordinated alert engagement with the environment which sets in motion early learning" (Escalona, 1981). Thus, the parent as the primary infant caregiver has come to assume new importance as a force for learning in the life of the handicapped infant. Handicapped infants who are well-attached to their parents will be more able to utilize environmental encounters as grist for early learnings. Professionals need to nurture and encourage bonding and attachment of program infants and parents. Some program personnel overemphasize lessons and exercises and do little to nurture the emotional relationship between parent and child which supports learning.
Secure attachment is also important because of its relation to compliance. Research on securely attached infants has revealed how closely attachment and cooperation with parental demands are related (Stayton, Hogan and Ainsworth, 1971). Mothers who used warmer voices in giving commands and gentler physical handling with their 12 month olds had 21 month olds who were more compliant and cooperative not only with their mothers but with an adult woman playmate and with an infant test examiner (Londerville & Main, 1981). Handicapped infants will often have to struggle harder to accomplish developmental tasks. Frustration may be sharper than for normal babies. Certain handicapping conditions may require persistent efforts at therapeutic exercises or even at simple self-care tasks. Professional encouragement and support for maternal-infant emotional closeness may well enhance the cooperation of toddlers with prescriptive procedures necessary for remediation efforts.

Provider Attitudes That May Interfere With Effective Partnership

Disillusionment

Sometimes providers of services to handicapped children begin their efforts with a missionary zeal. They may feel frustrated and indignant that parents do not carry out all the prescriptives delivered with such good will. They may not be sensitive enough to parent resentment that the professional seems to be "taking over" the baby while demonstrating or giving suggestions about work to be done. Also, if the infant progresses slowly, some of the provider's zeal may evaporate. The provider may secretly believe that the parent is not cooperating well enough between home visits. Disillusionment may lead a provider to "give up" on a parent as not caring or not trying hard enough. More patience and awareness of realistic expectations for growth processes may help bring worker and parent into a less adversarial and more cooperative effort.

Rigidity

Some trainers in work with handicapped persons perceive that they must use special materials or procedures in certain ways only. Rigid use of training materials without sensitivity to the home circumstances, to parent feelings, or to infant level of ability or interest may lead to discouraged feelings on the part of a provider. Honig (1981) has suggested the concept of "dancing the developmental ladder." Tasks and games and processes of interaction should be so tailored that the small child is lured forward to try tasks just a tiny bit more difficult or more novel. Conversely, the task may be made less demanding so that the baby can be emboldened to try. Flexibility in making task presentations or requirements more difficult or easier so that babies are helped to engage in efforts is preferable to rote presentation of prescribed items where the baby is not actively engaged in the learning interaction.
Value Conflicts

Some professionals disapprove of the life-style of parents and allow this feeling to color their perceptions of the parent-infant relationship. Parents can be positively encouraged into loving, facilitative interactions with infants in circumstances that may be messy, dirty, or even "immoral" to the worker. What is important is the process of the intimate relation between parent and child. One worker reported with shock that she found the baby sleeping on the floor on a blanket in a cold empty room when she came to the home visit. The baby was in no physical danger, nor was she otherwise neglected. Poverty of furnishings is not necessarily coupled with poverty of caring. Of course, if there are physical dangers or poor nutritional practices, then child development information can be communicated in a manner that conveys how much the parent and the worker both care for and about the welfare of this baby.

Suggestions For Building and Maintaining Parent-Professional Partnership

Given the difficulties of emotional adjustment that so many parents of handicapped infants undergo before the processes of reconciliation and getting on with the work of loving and rearing can come into play, what can a service provider do to improve communications with parents and improve the partnership process?

1. Start a relationship as early as possible post-partum with the parent(s).

Parents, right after birth, need support and are likely to be more willing to be recruited into a program that offers support. If a partnership between parent and professional is formed early on, efforts to encourage the optimal development of the at-risk infant are increased. The biggest payoff for neonatal enrichment programs may be the parent's continued commitment to, and participation in, their child's educational program.

2. Meet the parent's needs whenever possible for a reliable support system.

Building trust takes time and often involves a "show me" attitude on the part of parents. Such a trusting relationship can serve to buffer the parent against frustrations and angers with institutions and systems that do not seem to be responsive to his or her or the needs of the handicapped baby. For example, last year, a visiting nurse reported that as the months after birth went by, during which she continued visiting a mother, the doctors kept demanding that the baby be brought in for more and more tests and procedures. Gradually toward the end of the year, medical staff suggested that the baby might indeed not only be developmentally delayed but also deaf and possibly blind. The mother felt crushed. She felt that the truth had been kept from her. She had not been advised at each point about what was suspected or being tested. She had been given no inkling after...
birth of the possibly massive nature of the deficits now being
mentioned. The parent poured out her anxiety and despair during
visits and on telephone calls. The professional listened
empathetically. Grief can be even more overwhelming when there is
nobody who seems to care. Bromwich (1981), in her program for at-risk
infants gives primary emphasis to empathetic listening:

"our approach to intervention required that we
first listen to the parent carefully, that we
acknowledge her feelings, that we be empathetic
with her by trying to see things from her
perspective, and that we try to understand her
perceptions of her child and of herself as
parent.... While we listened empathetically, we
communicated to the parent that we valued her talk about what was preoccupying her and that
we tried to hear what she had to say in a
non-judgemental manner, i.e. that we accepted her
regardless of the feelings she might express. We
helped her realize that most parents feel
frustrated, ambivalent or angry. Our acceptance
and the parents' realization of the universality
of their feelings often provided them considerable
relief. (p. 175)

3. Share knowledge about normal and delayed child development.

Parents depend on providers to bring a professional understanding
about infants. Sometimes what looks like inappropriate, deliberate
mismangement on mother's part results from a lack of understanding
of infant comfort, anatomy, or activity. A mother in the pediatric
waiting room was trying to dress her infant who had a cold and a
stuffy nose. Mother laid the baby with head dangling down on her lap.
He fretted and cried as mucus clogged his breathing. The mother, to
quiet him, popped a pacifier into baby's mouth. The baby's struggles
grew wilder and more frantic. A parent worker came over and asked
permission of the mother to help in dressing the baby. The mother
with relief watched as the worker held the baby so that his head was
above body level. The child quieted and was able to be dressed. The
worker matter-of-factly explained how babies breathe and how scared
they feel when they can't seem to breathe well. Simple, calm,
explanations increase parent competence rather than leave parents
feeling inadequate or incompetent with their baby.

4. Build your own and the parent's observation skills.

Child-watching is an art and a skill. The more we can learn to
watch a child with the parent and be able to point out tiny advances
or changes in behavior, the more we can help a parent to become a
better observer of his or her own baby. Bromwich (1981) has reflected
that
"the kinds of comments that accompanied our observations of the child's play, language, affective cues, social responses, and motor behavior called the parent's attention to the details of behavior that revealed important developmental changes in the child, no matter how small. Observing with the parent meant that parent and staff shared with each other what each had observed. The discussions that ensued from the observations were motivating to the parent to continue to observe, and they gave her additional ideas about what was important to look for in order to help her interact more pleasurably and effectively with her child. Observations and the accompanying discussions also made the parents more interested in investing more time and energy in providing the kinds of play opportunities that the child seemed ready for." (pp. 176-177)

Observation skills can be brought into play to encourage staff and parents when progress seems discouragingly slow with a severely handicapped infant. A parent, for example, can notice that the baby's hand is no longer so tightly clenched, but that the fist sometimes opens now in response to stimulation.

In a hospital room, a mother reported feeling upset about trying to bottle feed her newborn. The carefully observant parent worker noticed that the mother held the baby's head so that the cheek opposite to the mother's body was stroked. In response to the rooting reflex, the infant naturally turned his head away from mother. When mother was helped to notice this and to understand the rooting reflex, she was better able to feed her baby without feeling rejected.

Observation skills can attenuate staff burnout. If a profoundly retarded toddler is able to perform only, for example, at a Piagetian stage 3 sensorimotor level, then limited activities can be introduced. Nevertheless, the observant worker, using Piaget's principle of "horizontal decalage," will use different materials or modes of arousal to elicit any behavior of which the infant is capable. These skills can be taught to parents. Can a baby who can visually track a flashlight beam 180 degrees, now also learn to track daddy's keys that jangle, or a pop-it bead necklace slowly moved across her field of vision?

5. Discuss child behaviors and interactions with parents.

It may be difficult at times to know when professional observation should be used to begin discussion with a parent about inappropriate adult behavior or missed opportunities for enhancing the infant's responses. If professionals show off their skills too much, they may make parents feel inadequate. If they consistently ignore inappropriate behaviors of parents, this may be inimical to the infant's best interests. Choices are not always easy. A mother had
brought her poorly thriving baby into the clinic for evaluation. Mother sat in a chair quite near the high chair where testing toys and items were being presented to the infant. At one point the infant threw a toy from the table and started to lift himself upward a bit in order to peer over the edge of the table to recover the toy with his eyes. "No-no!" the mother said, very sharply. Baby looked scared and started to cry. This was a good time to explain easily about what "no-no" means to a 9-month old infant. How can a baby figure out precisely what is forbidden or bad? If he reaches toward something hot and we say "no-no" and take the hand away and say "hot!" in a serious tone, then the baby may learn in that interaction what "no-no" means. If too often we use generalized sharp warning prohibitions, then the baby may simply come to feel that she is the "no-no"--the base creature. This mother had been afraid perhaps that the infant could lift himself out of the high chair into which he had been securely strapped. We need to reserve sharp negatives for serious situations where babies can better understand our meaning.

Helping a parent to see that situation from the viewpoint of the baby can promote increased sensitivity to infant needs and infant levels of understanding. For example, if a parent is dragging a screaming two-year old down the hallway of a respite care center, a worker might comment, "It sure is tough to try to walk as fast as a grown-up when you have little legs. It makes you feel all upset to try to walk so fast when a person is so little." Some parents simply have not learned how to look at the world from a tiny person's point of view, especially a tiny person with handicaps. Warning: Some parents are so needy themselves that this method may simply call forth the rejoinder, "He can so do it. He's just trying to irritate me today!"

In discussion times, professionals may get more attention and interest if parents initiate topics. Behaviors that the parent perceives as worrisome or aggravating often provide good opportunities for staff to introduce new ways to think about infant behaviors, new ideas about why tots carry out actions that adults might find messy or naughty. Most parents have little idea of the deep need of toddlers to be active, to roam, to explore, to search for, to take apart, to pour in and out. Helping parents see the meanings of behaviors for the child can sometimes lessen the parent's anger at what is considered deliberate defiance. Such a view of the developing child may lead to discussions of more appropriate ways to protect family possessions from toddler curiosity. Staff can support parents' search for ways to promote toddler exploration through activities the parent may choose as more acceptable than "messing" with food, for example.

Dialogues with parents slowly build new ways of seeing what a tiny person is like. Dialogues with parents slowly give them an opportunity to feel free to try alternatives to some of the unthinking punitive ways some adults use in dealing with "naughtiness" in small children.
Encourage parents to try alternative ways to solve their problems with their children. Research has shown that the more alternative solutions children and adults can generate to solve their own interpersonal problems, the more successful they will be in their encounters with problems (Shure & Spivack, 1978).

6. **Encourage parents to think about the consequences of their behaviors.**

Sometimes in discussions new ideas or behaviors are introduced, but there may be little parent follow-through. Encourage parents to take the "What will happen if...." attitude. If we read daily and engage happily in language activities with a speech-delayed child, then vocalizations and increased interest in language may result. If a parent habitually presents a hemiplegic baby with a toy in the hand that does not function rather than the hand that can function, what is likely to happen to the goal of encouraging infant advances in reaching for and obtaining toys?

7. **Encourage parents to accentuate the positive.**

Many parents of handicapped youngsters become preoccupied with what the infant cannot do. Staff need to help the parent find ways to encourage what the infant can do. For example, a blind five-month-old cannot see the visual mobile over a crib. In order to encourage infants' circular reactions of kicking the mobile, getting a pleasurable feedback from their own actions and then resetting this process in motion, parents of blind infants can be encouraged to use mobiles that produce noise or music on being set into motion. The infant can respond to auditory feedback with the same delight that a sighted baby brings to experiences in playing with gaily swinging toys (Bower, 1977).

Sometimes parents of handicapped youngsters act overprotective. They worry about falls and dangers. Instead of yelling "Don't run, you'll get hurt," a parent can be encouraged to call out "Walk slowly, Johnny," or, "Swing gently." Parents may find it a relief to be able to state what they do want rather than what they don't want from their children.

Sometimes parents of slow-learning children feel upset and threatened by the child's slowness. They may feel a need to push their little ones into giving rote responses. In one program for disadvantaged small children, the mothers' "usual pattern was to present a difficult problem and then to punish error or silence-with-nagging threats. They told the child to sit up, to pay attention; they informed him that they knew he knew the answer, so he better say it" (Risley, 1970, p. 145). Mothers in this behavior-modification program were taught how to recognize child behaviors that could be praised and how to use positive reinforcement to give their children attention and praise for behaviors that they wanted the children to continue.
8. Share your joy at small developmental advances made by infants.

Telling parents what we see as professionals may not be as useful as helping parents to "see" the child with new eyes. The author was working during a second visit with an iron-deficient, solemn-faced infant who lagged developmentally. As the baby picked up two blocks and tentatively brought them toward the midline, I remarked, sharing my delight with the mother: "You remember last week that Leroy could only use one block at a time. Today he is picking up two blocks and even trying to move them toward each other a bit! He isn't able to patty-cake with the blocks yet, but just see how hard he is trying to get those blocks together. He is working so hard. It is so exciting to watch a baby trying!" The mother looked radiant. She said that she did remember that the baby could not use more than one block to "go bang-bang" on the testing table the week before. She became excited at her own ability to observe and appreciate small steps forward. The tester's delight with the baby came across also as a delight in the mother of such a child who could learn, who could try. The mother later volunteered things she had noticed after the first assessment session with the baby. "Assessment sessions provide a fine opportunity to build a mother's pride in her observation skills and appreciation for her baby's early learnings."

9. Praise specific achievements of both parent and child.

While demonstrating a new task, the skilled professional often asks a parent to try the game or to model the task for the baby. This gives the parent a chance to practice a skill and to be in the position of "expert." It also gives the worker a chance to praise a parent warmly for specific work or for perceptive and positive ways of interacting with the child. Be sure to use specific praise, such as:

"Bobby really stretches his hand up to reach when it is you, his very own papa, who is getting him to reach just a bit more with those little hands."

"Lianne comforts so nicely when you pick her up and cuddle her if she needs some hugging. You are so good at comforting her."

"He really listens when you are trying to talk with him. Mama is an important person to listen to. Babies love to hear mothers talk with them."

10. Treat the parent as expert about details of the child's experiences.

Ask questions to build a parent's observation skills. Using the parent as informant will enhance self-esteem. "What kinds of sounds have you heard Andrea making? Have you heard her try to put a vowel and a consonant together yet...as in buh-buh? What kinds of things seem to set off Daryl's tremors and stiffening of the arms? What do you try when that happens?"
11. Use a variety of parent involvement techniques depending on family needs.

No one way to reach parents succeeds with all families. A variety of program models are available for parent involvers to choose from (Honig, 1980). Some programs mix and match methods to serve parents better. They may carry out home visits. Yet, in addition, parents and toddlers may be bussed to a center several days a week so that special group activities can occur (Jew, 1974). Trained teachers can serve as expert models for parents during these sessions. Also, parents get a chance to meet with one another.

Some programs add a weekend half-day session for fathers. Some programs mix practical guidance in child management with therapeutic counseling for parents still struggling with distress and difficulty in recognizing and accepting the child's problems. Parents actively involved in therapeutic techniques with their own infant often gain more acceptance of the handicap and more assurance in the role of parent, teacher, and therapist.

Special program "extras" may make all the difference. Some programs have a "retreat house" where fathers, mothers, and children can spend a weekend. Family get-togethers, sports, and child-development discussions in a homey, friendly atmosphere give program goals a boost. Some programs have a 24-hour psychiatric "hot line" service for parents in crisis. Provision of a variety of extra services may increase the motivation of some parents to become more actively involved.

Parent-to-parent models have been particularly successful in helping parents cope with some of the agonizing personal problems that may arise after the birth of a handicapped infant. How shall relatives be told? Many such problems can best be helped by enlisting the support of parents who have already coped with having a developmentally disabled newborn in order to help those who are first facing the problems (Bassin and Drovetta, 1976). Training parents as providers for other parents may be an important and helpful aspect of your parent involvement program.

Not only may different modalities of service provision be used, but priorities may need to be set concerning the level of involvement that can be expected of a particular parent. It may be of little impact to hold an enthusiastic session on making mobiles for a crib with a mother who avoids eye contact with her infant and is reluctant to handle or cuddle him. Bromwich (1981) suggests that parents can be helped to progress from lower levels of involvement to active, self-initiated participation in enriching activities with their infants. The "Parent Behavior Progression," devised by Bromwich, provides examples of parent behaviors that reflect increasing involvement from level I to VI.
Level I: The parent enjoys her infant.

Level II: The parent is a sensitive observer of her infant, reads his behavioral cues accurately, and is responsive to them.

Level III: The parent engages in a quality of interaction with her infant that is mutually satisfying and that provides opportunity for the development of attachment.

Level IV: The parent demonstrates an awareness of materials, activities, and experiences suitable for her infant's current stage of development.

Level V: The parent initiates new play activities and experiences based on principles that she has internalized from her own experiences, or on the same principles as activities suggested to or modeled for her.

Level VI: The parent independently generates a wide range of developmentally appropriate activities and experiences, interesting to the infant, in familiar and in new situations, and at new levels of the infant's development.

It could be very discouraging for a worker who expects a mother not yet successful at Level I to participate in program efforts that demand Level VI skills and engagement. The partnership between worker and parent must be sensitive to the "match" or "mismatch" between the level at which a parent is functioning in her or his role and the program expectations of where the parent "should" be functioning. Partnership will work best if the level at which the parent is functioning is nurtured and appropriate activities and trusting interactions are engaged in so that the parent can progress slowly toward the next higher level of functioning.

12. Marshal community resources to serve parents.

Provide a respite center for parents of handicapped young children. One of the best ways to get parents to cooperate with program goals is to cooperate with parent needs and goals. Most parents with severely-disabled small children need some form of respite care so that they can attend to their own personal needs as human beings. Erikson long ago taught us that the young child can grow up to be a giving person if he or she has been generously given unto during infancy and the early years. Parents need the giving acceptance and encouragement of staff in order to feel ready to give of their efforts to carry out staff suggestions. Provide a free subscription to the magazine "The Exceptional Parent", which is filled with good ideas for practical guidance for parents of handicapped youngsters of all ages.
A literature and audiovisual library may help parents feel free to browse among materials to learn and understand more not only about the particular handicapping condition of their infant, but about infant development in all children. Parent's Magazine and others have produced useful film strip series on parenting handicapped children. Subscriptions to publications of the 'Council for Exceptional Children' and the 'National Center for Clinical Infant Programs' will be useful. Parents as well need access to materials on quality infant caregiving and how to nurture growth and development. (For example, see: Honig & Lally, Infant Caregiving: A Design for Training, 1981.)

Research materials may be of interest to some parents: For example, Carew (1980), in her research report, reveals that regardless of whether infants were home-reared or day-care reared, the intellectual experience that most powerfully predicted IQ and intellective competence by 3 years of age was the situation where an interactive caregiver taught the toddler new words and created language-mastery experiences for the little one.

13. Provide support for parent involvers

Workers who face daily the difficult problems of families in crisis after the birth of a handicapped infant need support systems too. Reaching out to parents and encouraging them to become loving, effective teachers of their infants requires extraordinary commitment, stamina (particularly for home visitors in snowy cities with infrequent bus service), tolerance, flexibility, and patience as personal skills. Additionally, the worker needs people-helping skills to work with adults in crises and needs child-development knowledge, particularly focused on the tasks and gains of the sensorimotor and early preoperational period.

A supportive supervisor is a boon to parent involvement personnel. They can express their worries, concerns, ask for counsel, turn to the supervisor for community resources and literature suggestions when a family's needs require additional aids. When a supervisor meets regularly with family workers, these problems and possible ways to handle them can be shared in the group. Staff training that provides rich opportunities for mutual feedback can help workers weather some of the storms of families in crisis.

Conclusion

None of us can help all people all of the time. But much can be done to increase the chances of families for supporting the growth and development of their handicapped infants and toddlers. Such efforts require personal skills and professional knowledge that may encompass several disciplines. Effective parent involvers need to be learners—forever increasing their areas of competence which, in turn, may increase their effectiveness with families. A parent involver needs to be able to coordinate services, to move from one intervention model (such as home visitation) to another (group meetings) as family needs and strengths dictate. A parent involver needs to be an advocate for the family and for the child. Concern for the needs of adults and children will require sensitive efforts to encourage adult
development, and yet remain alert to the needs of infants. A
well-functioning program will nurture the needs of workers for support
and for extra knowledge in order to increase the effectiveness of
staff for helping parents nourish the development of their handicapped
babies.
References


The case for providing instruction for handicapped children from birth to three years has been generally accepted by service providers in the past five years. Research has indicated the value of early intervention. Practice has begun to develop effective and workable models. The advent of models developed through the Handicapped Children's Early Education Programs gives reality to the efficacy of early intervention. The development of assessment tools, curriculum materials, and evaluation instruments have made possible the development of teaching programs that can be moved from one locale to another. Acceptable training methods have been developed, validated, and funded. Successful models have been funded as outreach projects to begin a broadening process of spreading methods to other agencies. The state implementation grants have begun to further expand the accumulated knowledge gained from research and experimentation.

The major problem remaining is how to best fund and administer programs so that adequate and efficient service and instruction are made available for all handicapped children.

Public Schools as Administrators of Preschool Handicapped Programs

One of the issues that must be resolved is the selection of one agency to develop, plan, and administer an instructional program for the young handicapped child. One agency must be held accountable for educational programming from birth to adulthood. This does not mean that one agency must do everything. It means that one agency must be held accountable for seeing that proper assessment, educational instruction, and support services are made equally available to all children in need of them. This tends to prevent over servicing of one child and under servicing of another. It is especially important that adequate and accurate records be kept on the handicapped child from the entry of the child into services.

A multidisciplinary team should determine the total program of the child and parent, but a single agency should coordinate and direct so that all resources are used to the best advantage. When a high risk or handicapped child is found, the continuous assessment and planning of the team should continue.

The chief reason for the public school to serve as administrator is continuity. The educational aspect of planning constructive remediation for the handicapped child should be continued without break. Secondly, the public school is established by law to provide educational activities for children. It maintains regular terms and, since it is tax supported, it provides stability of buildings, supervision, materials, and other
program facilities. The third reason for the public school to serve as administrator is the fact that all children by law must go to school. Public schools serve the greatest number of children and have a direct link with parents.

If the local education agency is responsible for the development of the individual education plan (IEP), it must be responsible for setting up an acceptable pattern for coordinating all agencies which contribute to the welfare of the child. Whether the Local Education Agency provides services directly or contracts for them, it must develop a plan for total involvement of all community resources as they affect the child. To develop such a plan and to establish communication among the agencies, it is helpful to start with a community survey which would search out all medical, social, educational, and community organizations which offer services to families--parent or child. It is imperative that duplication of services be avoided and that all possible coordination be achieved. The high cost of providing services necessitates cooperation, not competition among agencies.

Types of Program

The primary teacher for the infant is the parent. Hence, provision of training for the parent or parent surrogate becomes a number one objective. Services and training may be provided by a home based program or a combination of both home and center. A combination offers the most flexible approach. The parent is with the child for extended periods and can observe and work with the child as the need arises. Daily teaching service by professionals is not considered necessary for the most efficient use of time. The professionals may work with the parent one or two times weekly and help sustain a regular instructional pattern. The professional does not want to assume the parents natural teaching and care giving role. Teaching activities need to be built into the routine of daily living. For the younger child training of the parent in the home is more likely to produce desirable results. As the child progresses, some opportunity to be part of a group for a few hours each week becomes more important. If possible, such group activities should also include some nonhandicapped children.

Great care should be taken to see that the child and parent have access to medical services, social services, and counseling. Be willing to adjust time schedules so that workers may visit daily, weekly, or twice weekly when needed. There are times when more frequent visits are needed to teach a routine. Later less frequent visits may be sufficient.

Cost Effective Service Delivery

In establishing support for early education programs the collection of data about benefits and costs is essential. Benefit data should include outcome data related directly to program objectives. It should show the number of children served, the progress they have made and other child or parent changes that have been targeted.
Data should show the costs of service input from all sources—school funds, contributions of cash or in-kind services. The most frequent question administrators are asked when confronted with financial support for a new program is, "How much will it cost?" It is important to have realistic cost appraisals packaged in simple form to clearly show the receiving audience what is needed. The information in such a package should include data from other projects. Data is available from model projects throughout the nation. Most of this data has been assembled by TADS (Technical Assistance Development System) and WESTAR (Western States Technical Assistance Resource). A clearcut presentation of costs and benefits at the state and local level is essential to establish credibility. The target should be to show local taxpayers that the support of early intervention programs for young handicapped children can pay off in dollars and cents as well as human satisfaction.

In these budget cutting times we tend to forget about assessing the long term pay-off. Pay-off comes in many forms. For young handicapped children, the pay-off may come when failure to intervene early enough causes the child's problem to become insolvable. Failure to act early may mean higher costs at a future date. As educators and professionals with a deep concern for your handicapped children, we not only have the right to speak, but we also have an obligation to speak effectively to decision makers.

**Simple Formula for Figuring Costs of Program**

**With Buildings (as a school or other free space)**

<table>
<thead>
<tr>
<th>Personnel</th>
<th>Fixed Charges (FICA, Retirement, etc.)</th>
<th>Travel</th>
<th>Equipment</th>
<th>Supplies</th>
<th>Miscellaneous</th>
<th>Total</th>
</tr>
</thead>
</table>

**Without Building**

<table>
<thead>
<tr>
<th>Rent - Leasing</th>
<th>Personnel</th>
<th>Equipment</th>
<th>Supplies</th>
<th>Travel</th>
<th>Fixed Charges</th>
<th>Miscellaneous</th>
<th>Total</th>
</tr>
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-43-
Staffing Patterns

Lack of qualified personnel is a common cause of ineffectiveness and inefficiency in many early childhood programs. Two problems exist in major proportions: recruitment and cost. Whether staff members are part time or full time does not matter. We must have access to highly skilled medical personnel, psychologists, therapists, and other diagnosticians. When the assessment of the child's problem is completed, highly skilled teachers are needed to work with parent and child. The quality of training that can be developed to help parent and child depends on the quality of the staff. In many areas (e.g., small rural communities) the creative search for and use of personnel becomes critical. Sometimes this requires traveling professionals. Search through local agencies (social service, hospitals, clinics) for possible part-time help or shared time. Work toward state-wide plans for regional training workshops. Volunteers can offer tremendous help, but they must be trained by competent professionals.

Combination of Resources

We no longer have the option of allowing every separate agency to act on its own initiative independent of all others. We must reach out and develop cooperative patterns to share the segments of a parent and child training program. The need to develop working patterns among medical, health, and education professionals is essential. None of us can do it all. When you consider that the plan for the training of a handicapped child requires medical evaluation and treatment, the need to build better working relations with the medical community becomes obvious. When you consider that the plan for a child will require a wide range of diagnostic skills, you must find ways to secure these services. When you consider that the family may be in need of social resources (money, housing, counseling) you need to look at ways to give the family support. When you consider that the parent will need training to work with the child, you need educators who can directly teach both parent and child skills which minimize the effects of handicapping condition.

One agency must tie all these professionals together to develop a coordinated plan and then direct its operation.

Supplemental Funding Sources

In addition to funds allocated by state law for specific services, the LEA will be searching for additional funds to enrich the program. Since most federal grants are quickly being eliminated, state and local funding, foundations, and private agencies must be tapped.

As in all educational programs voluntary contributions of services become a valuable asset. This symposium is directed toward the coordination of assessment services, research, educational management, and evaluation. Consultants in all of these areas should be sought from the beginning to be involved in possible volunteer services.

Civic clubs, church organizations, and professional organizations often select projects to help. Provide them with choices in your plan. Private agencies (such as United Way, United Cerebral Palsy, Association for Retarded Citizens) may be able to loan personnel or supply funds.
Foundations are a source of funds; there are many small ones which tend to serve local areas. Talk to industrial organizations in your area. They can sometimes offer materials or money.

Your largest pool of supplemental funding is going to come from the adroit use of volunteers. People hours can be used to perform innumerable pieces of chore work that you can't buy. Develop creative jobs and times to fit the leisure hours of workers. Go for the volunteer skills of the teens and the seniors.

Building Public Awareness

In these days of budget cutting we must convince the taxpaying public of the value of making handicapped children future participating members of society. We must be able to carry our story to all citizens—those who have normal children as well as those who have handicapped children.

The prime target to influence is, of necessity, the legislators—local, state, and national. You have to sell your program to the ones who control the money. To reach legislators you have to sell the need for your program to the people (taxpayers).

If you accept the premise that early childhood education is of critical importance to children who are at risk for handicapping conditions, then you must accept the obligation to work to secure the necessary financial and program support. To do this you must venture into the world of policy makers and budget makers. You must meet the decision makers on their own grounds. We have good, sound models developed with methods and techniques that work, but who knows about them? Tremendous efforts can be made to protect the environment, millions can be spent for clean air, and Congress can devote major time to speed limits, why can we not mount a program that speaks to the needs of handicapped children? This type of program has started and has been effective for school-aged children. Now, we must speak for preschool handicapped children.

Nothing beats parent advocates! To get parents beating the drums, you must have an effective program that really works. Generate enthusiasm for your program by being thoroughly knowledgeable. Know what you are doing, how you are doing it, and practice saying it. Do some practice sessions with your own staff in how best to say it. Don't be reluctant to brag about your work. Who else knows what wonderful things you are doing? If you want a future for young handicapped children, stop apologizing and sell! You are educators. You know what needs to be done. Don't be bashful! Speak up and out!

Organize letter writing campaigns to your state legislators and to your congressional delegation. Grass roots opinions do affect the legislators. In these letters preach the doctrine of "every child deserves a chance." Your best approach to the decision-makers or money-minders is by way of local voters.

Every person in every program should become a walking-encyclopedia of information on the advantages of early intervention for young handicapped children. Don't forget that "all" of your staff "show case" your program.
Be sure that your volunteers, cooks, custodians, bus drivers, and secretaries know what the purpose of the program is and know how to describe it to the communities. As practicing professionals, we must know the facts and make opportunities to present them. Who will know of your deep concern for young handicapped children if you do not learn to speak effectively to others? You not only have the right but the obligation to speak.

All the techniques you have developed need to be called into play. Invite influential citizens to visit your programs. Try for spots in radio and TV programs. Speak to any club that invites you. Use your affiliations to get invitations. Seek out opportunities to speak to church groups. Work with your local papers. Write letters to the editor.

The imperative activity for the eighties must be to get the attention of decision makers. It is absolutely essential that you develop quality programs and that you be prepared to speak confidently with facts, but now is the time to speak for handicapped children. Build the sound for this need to a loud roar that can not be ignored! Add your voice! You can make a difference!
MEDICAL IMPLICATIONS OF EARLY RECOGNITION

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Introduction

Educational philosophies have progressed remarkably over the past fifteen years. Kindergarten, once considered unimportant by many school systems, is now regarded as a most important phase in a child's education. In the mid-1960s, one large Maryland school system had a policy of not enrolling mildly intellectually limited children into an appropriate program until the age of eight. Prior to that time, such children usually repeated first grade once or even twice.

The medical profession has also seen progress in its approach to handling children. Pediatricians have always been taught the importance of mothers to the child under five years, and previously considered any intervention from the outside world to be detrimental to the child. Nursery schools were recommended only under very special circumstances.

At the same time, research into the behavior of the young child has revealed previously unthought-of latent potential, down even to the neonatal period. Lorenz described prenatal influences in the form of imprinting animals; the extent to which this is relevant to the human fetus is still under investigation. Fantz (1963) and others have studied neonatal visual processes and found that they have a remarkable capacity to discriminate the mother’s face from random patterns. This facility has even been shown in the pre-term infant (Hack, et al., 1981).

The sensitivity of the developing child to environmental sensory deprivation has also been recognized more fully. The classic case is that of amblyopia, whereby suppression by the brain of a non-fixating eye in the presence of strabismus can lead to permanent irreversible loss of vision before the age of five if not treated. In earlier years, this had been considered merely a cosmetic problem, to be treated at leisure. Now we are able to demonstrate the converse, by which increased activity in a system can apparently permanently increase function in that system, whether the system is deficient or not.

During this time, there has necessarily been a change in the relationship between the medical profession and education over diagnosis. Initially, the responsibility for early recognition and diagnosis of handicapping conditions in the early years was almost totally that of parents and health services. No educational remedies were available except in certain isolated private sectors. Now, with the extension of public educational facilities down to birth, medical professionals must not only pursue their own search for better ways to diagnose early but join in a cooperative venture with the school system to improve techniques for recognition.
This paper is such a venture and seeks both to explore ways to jointly identify handicapping conditions early and also to point out some of the pitfalls of such attempts. It is only possible to point out certain key areas and impossible to be exhaustive. Each stage in diagnosis can be expanded to considerable length.

Genetic Factors

A logical place to start would seem to be at the beginning, and the beginning of the child is conception; but in fact, one can start even before this beginning. Based upon a steadily increasing awareness of the fact that many handicapping conditions are genetically determined, the prior existence of similar problems in older siblings, parents, or other relatives is a likely fact. Genetic factors were suspected as early as 1905 by Thomas (1905). And despite the historical background of first identifying learning disabilities and behavioral syndromes in adults following brain damage, experience and research has suggested that more of these disabilities may be inherited than acquired. A careful family medical history can often pick up previous problems in the family, and it has been our experience that many teachers have been in a position to remember such problems in other members of the family who have passed through their schools. Such inherited factors are not likely to affect all members of the family but can involve varying percentages, according to the type of inheritance. The presence of such a history should make one look at all members of the family more carefully.

Unfortunately, only a very few of the disorders producing handicapping conditions can be identified by characteristic laboratory tests. The most certain tests are those measuring genetic material, namely DNA. Figure 1 shows a normal chromosomal pattern with the chromosomes rearranged to show the different groups. Figure 2 shows a child with Down's Syndrome whereby there is a translocation of material with extra material at the 21 chromosome. This is called Trisomy 21. The third figure shows the opposite pattern, whereby material (an X chromosome) has been lost. This is characteristic of Turner's Syndrome, and the absence of a Y chromosome means that the child must be a girl. Interestingly enough, the extra genetic material in the child with Down's Syndrome is accompanied by much greater deficiency in learning than the missing material in the child with Turner's Syndrome, who, nevertheless, has a characteristic pattern of learning disability affecting spatial perception more than language.

Unfortunately, it is rare to find genetic proof in this form, and we can more often recognize such syndromes by characteristic body morphology or clinical examination than we can by microscopic examination. The more severe the body dysmorphism, the more chance there is of nervous system involvement.

There is another way in which we can identify certain potential handicapping conditions in the laboratory, and this is by the recognition of certain biochemical disorders. Many of these result in excessive amount of material toxic to the body and the brain. They can be identified by either the abnormal chemical products in the tissues or by measuring the...
enzymatic defect in the cells which produce them. Phenylketonuria, one such biochemical disorder, produces toxic materials that are so potent that the developing infant may be damaged by the mother's toxic products in utero, even though the infant is born without the biochemical disorder. Much current research is being devoted to recognizing these defects in utero before the birth of the child.

Clearly, this type of diagnosis remains totally in the hands of specialized medical personnel, although an occasional child with a low-grade enzymatic defect may enroll in a school program without being diagnosed and may show intellectual deterioration as the first evidence of a progressive process.

**Prenatal Factors**

The next crucial stage of the child's development occurs during the 9-month period of gestation. Here we see the combination of the contributions of the genes, and the effect of the intrauterine environment. The latter depends on many factors ranging from the maternal state of well-being to the physiology and nutritional capability of the placenta.

Historically, much of our early knowledge of both learning and behavioral abnormality stems from reports of adults who lost function because of brain damage. A natural consequence of this has been to concentrate on potential causes of brain damage to the developing infant, during the prenatal period, as well as during the perinatal and immediate postnatal phases. The association of pregnancy complications with later handicaps is undoubted and well documented. Pasamanick and others (1956) devised the concept of a "spectrum of reproductive casualty", in which surviving infants showed a spectrum of conditions from severe handicaps to the absence of handicaps as a result of a spectrum of prenatal complications.

As a direct consequence of this, the concept of the High Risk Infant evolved some 20 years ago as a means of aiding early recognition of handicapping conditions. Figure 4 shows examples of typical factors which have a potential for producing handicapping conditions in the pre-, peri- and postnatal periods of life.

The National Collaborative Cerebral Palsy Project was set up by the Perinatal Research Branch of the National Institutes for Neurological Diseases and Blindness in 1958 to study the epidemiology of 60,000 pregnancies, and the outcome of the child up until the age of eight years. We followed 3,000 of these children at Johns Hopkins. Observations resulting from the study are still coming forth.

One of the more impressive observations was that individual children could be quite normal even after severe medical complications of pregnancy and/or delivery. This means that a number of children can be over-diagnosed by using an etiological approach and some will be missed. The data must be used only as a reason to increase alertness to possible developmental problems in the future.
One other important fact learned was that causation is often multiple, not single. Similarly, the resulting handicap could also be multiple, with one disability predominating and others less obvious.

**Delivery**

At birth we have our first chance to observe the infant directly. From this time on we are engaged in measuring behavior and looking for significant deviations from the theoretical mean.

Two major problems persist through the early years of life. The first is that because of the uniqueness of each child, it is difficult to decide what is normal with regards to behavior. The second is that we are attempting to measure the whole from an organism that is only partially formed. By five years of age, the child is only just over a third developed, and at one year of age the brain has only about one-tenth of its future functions developed. In addition, the development is not linear, nor even curved, but consists of quantum jumps and plateaus. All these factors make predicting development and projecting it ahead to future handicapping conditions more difficult. Figure 5 shows some of the observations that we are attempting to make on the infant at different stages.

In newborn infants we can recognize only severe conditions with any degree of certainty, but we can still watch those with more minor deviations more closely. A neonatal behavior scale such as that of Brazelton (1973) is useful in this observation. Initially we are mostly identifying innate reflex behaviors but higher centers are maturing rapidly, and at the same time the environment is flooding the developing brain with information.

By the fourth month of life we are seeing suppression of the innate reflexes by the developing voluntary centers. The next phase of evaluation is, therefore, watching for the normal suppression of the inborn reflexes by the developing "voluntary" activities. If these reflexes persist for a longer period than usual, there is a presumption that the higher centers are delayed in their development. Occasionally, as in walking, the reflex pattern may cease before the voluntary pattern is established, and an infant may show neither pattern and cease stepping movements until they resume under voluntary control.

Some of these patterns are quite elegant in their evolution. One of the most elegant is that of the development of prehension in the first year of life. Figure 6 shows some of the stages from mere observation of an object by a newborn to the more accurate finger-thumb control in the one-year-old.

Again, there are pitfalls. Figure 7 shows the normal progression of locomotive development, indicating that crawling normally occurs before walking. Some children do not crawl before they walk and some do not crawl at all. One group in this country has used this as a cornerstone for therapy and has made older children with the diagnosis of brain damage get
down on the floor to learn to crawl all over again. However, we have neither documented that not crawling is abnormal nor that it is harmful, and no one has demonstrated that going back to crawling at the age of 12 years is in any way therapeutic. I can personally vouch for the fact that in some children it can be emotionally harmful.

**Visual and Auditory Perception**

So far we have been discussing development largely in the motor area. At the same time, visual and auditory perceptual processes are evolving as a result of both innate maturation and environmental stimulation. While central visual and auditory associations are occurring separately, these two streams are also forming cross associations. The result of this is increasing modification of the infant's gestures which are destined to become visual output, as well as changing vocalizations which will become speech or language output. Initially the visuomotor output is largely total body language, but later it will focus on the hands as the most flexible motor unit with the widest range of expressive capacity, unless affected by the handicapping condition. As these more sophisticated and more final processes occur, we can more accurately assess the handicapped child's potential, with less margin for error but still with need for caution. In measuring the different aspects of neurological function in the handicapped child, it is as important to measure strengths as it is weaknesses, because the basic rule of education still applies across the board, namely, learning through strengths and remediating weaknesses.

There comes to mind the case of a bright child in a bright family who was slow in evolving a single-word vocabulary because he could manipulate the world, and the world could comprehend his needs so that language was not initially necessary. He later suddenly came out with long sentences, once he discovered that such communication was much more effective in communicating his needs. At the same time, another bright child in another bright family had a similar problem of language delay but was not a cause of concern to the family. Total communication sufficed for the child's needs and the fact that the child had a profound sensorineural hearing loss was missed for some time. In this case, the family had used total communication and had not realized that anything was amiss. The child herself was a accomplished lip reader by the age of three years. Incidentally, this case shows the value of using total communication with the young child in the presence of certain specific handicaps.

**Early Recognition**

It is clear that these early developmental changes are seen mostly by the immediate family and are not going to come readily to the attention of professionals. The paradox here is that an abnormal developmental process must be suspected first to bring the child to the attention of someone who can recognize it. This means that the education of the parents is an essential component of early recognition. However, the statement that only the parents are seeing this developmental process unfold is not totally true, because the whole concept of preventive medicine for the young child
involves well baby care, both in the pediatrician's office and in the health department. Here, too, education is needed. Too often have we heard a good pediatrician reassure an anxious mother whose two year old child is not 'saying any words that he will "grow out of it." He does, and passes straight on to delay in the next stage of language development and often finally into a reading disability.

The child with developmental delays can be recognized either by the composite process of looking at all the different aspects of the child's development that we have mentioned so far, or by actual measurement at the time he is seen. The Denver Developmental Screening Scale is a useful test to help measure the child's current developmental status. In fact, a recent proposal to use a telephone interview for developmental screening (TIDS) clearly showed that parents can be excellent identifiers if asked the right questions. The TIDS suggested by Morse (1980) could be a useful tool to screen certain parts of the population who do not necessarily attend an office interview or examination.

The Medical Evaluation

An important part of early recognition at any age must be the collection of all the preceding data on a longitudinal basis with interpretation. The past developmental pattern can suggest or even negate the presence of a current developmental deviation, depending on factors such as accuracy of history and the degree of the disturbance. Nevertheless, the most important part of identification is that of recognizing the current factors in the child's life. Only the current actual status can begin to give accurate information as to the nature of the child's developmental level. Again, we need caution, because an evaluation at the end of a developmental plateau can make the child appear to function worse than he really is, just as an evaluation following a developmental spurt may make him look better.

Be that as it may, the most vital component of the evaluation is a holistic approach. It is a medical axiom to look, not at the disease, nor at the organ, but at the patient. The same applies to developmental processes. We must look beyond the system whose processing seems to be faulty, and look beyond the total brain, towards the whole child. In fact, it becomes important to look at the whole family. One reason for this is the iceberg principle by which a particular developmental abnormality in learning or behavior may be so obvious as to detract attention from recognizing lesser but still important disabilities. The classical example of this is the child with minimal brain dysfunction, as shown in Figure 8, whose hyperactivity overwhelms both parents and school and leads to a concentration on behavior and not learning. Even more serious is the possibility that the other components such as learning difficulty and clumsiness may be blamed on the behavior and not even examined in their own right. This is a model for a holistic approach to evaluation of the nervous system because the three components of behavior, learning and other neurological signs are found in almost every handicapped child at all ages.
The holistic approach must extend even beyond this. Figure 9 shows some of the factors affecting learning. The central channel is the developmental one, and other diagnostic terms can be substituted for the word "learning." On the right-hand side are abnormalities outside the nervous system which are organic, medical or whatever physical label one wishes to use for them. Visual deficits (in the eyes) or hearing deficits (in the ears) must clearly interfere with the learning of the developing child, but they do not necessarily involve an abnormality of development in their own right. Likewise, chronic disease processes such as asthma or congenital heart disease may well reduce the child's capacity to learn and even impair developmental processes through organic means. It is clear that the child's general health status must be part of this evaluation. Correction of such defects are an important part of the therapeutic process.

On the left-hand side there are the effects of environment to be considered. Deficits here, in visual, auditory or haptic, sensory input, can limit the child's learning, whether there is a handicapping condition present or not. Here also is a channel through which we can modify the handicapping process to the child's benefit by judicious increase in such stimulation. The word "judicious" is used here deliberately because it is important to design a therapeutic program carefully. There is, again, a medical principle that too much medical treatment can be as harmful as too little. There is also a potential for stress being produced in the young child by over-enthusiastic treatment, and although this paper is primarily concerned with recognition processes, it seems appropriate to be concerned with over-treatment as well as over-diagnosis.

From this concept of the holistic approach to diagnostic processes comes the obvious principle of multiple criteria for recognition. The pattern in Figure 10 is one developed for use in Baltimore City some years ago and corresponds to the previous description.

The first set of criteria is that of general health and specific medical problems.

The next four levels represent different processing systems actually used in the course of learning. You will notice that motor function is classified here as a learning process, because this, in fact, underlies the Piagetian principle of learning through activity. The behaviors listed here also directly offer learning through an organic mechanism.

The sixth level consists of some of those behaviors which have an environmental origin and are not part of the organic developmental behaviors in the category above. An attempt was made to divide behavior into that which is due to organic brain dysfunction and that produced by environmental, functional, or truly emotional disturbance.

The last set of criteria simply measure the child's actual achievements in the classroom and these should depend largely, but not totally, on the factors above. This category is far from satisfactory, because it should measure the child's classroom action in each of the...
evaluation functions above, including motor, visuomotor, language and behavioral areas.

Though the system was designed for a school-aged child and not the preschool child, the same principles apply to young children. Academic levels become difficult and then impossible to measure as the age is reduced, but our examinations are designed to recognize the basic functions of the child in categories II through V, as well as any problem in level I or VI.

One of the principal factors interfering with accurate measurement in younger children is behavioral dysfunction, which can significantly interfere with carrying out adequate examinations and also invalidate data obtained. Parents and professionals frequently express the view that because of this interference, which can clearly make a child appear to be more handicapped than he really is, such measurements should not be obtained. We disagree with this in our clinic and prefer to obtain the measurement, but at the same time carefully pointing out the qualifying behaviors and using the final product as representative of minimal abilities, not maximal. The very existence of the qualifying behaviors is a vital part of the evaluation. Furthermore, if the child does not function well in the evaluation situation, he may not function well in the educational situation, and this, as well as the behaviors leading to it, must be known.

Future evaluations may then be used to monitor progress in behavior as well as in learning. Later on, one can more accurately measure the real deficit. We feel that educational strategies may be planned using this approach.

The Neurological Evaluation

This discussion applies particularly to psychological testing, but the developmental neurological examination uses the same principles and is fraught with the same difficulty. The traditional neurological evaluation uses a technique designed to test systems for adequate function and to detect abnormalities in the system. The order of testing, the way in which the tests are carried out, and the relationship with the child can be varied to fit the behavioral situation.

In fact, the standard medical and neurological examination only has the capacity to identify or exclude disease. As most of the handicapping disabilities to which we are referring are either genetically-determined or, at the most, the result of past disease processes, such an evaluation is not often rewarding. It is, in fact, essential to carry it out as part of the total evaluation, but more is needed. As this was the only form of neurological examination up until the 1960s it is to the credit of Strauss and his co-workers (1940, 1947, 1955), who pioneered the concept of the child with minimal brain dysfunction, that so much dysfunction was identified with such poor tests.
Soft Neurological Signs

In 1962 Clements and Peters pioneered a new approach to the examination of children with what was then called minimal brain dysfunction. As part of this examination, they referred to the previous use of "equivocal" signs, which usually meant that one was not sure whether this was a sign or not, and referred to these signs as "soft" signs. The original concept probably meant a more subtle neurological sign, but in succeeding years it has been recognized that these are signs of developmental immaturity and therefore rank along side the signs elicited during developmental testing by psychologists or educators. The important corollary is that any evidence of the developmental status of the child, however obtained, can be regarded as a neurological sign and could be called a soft sign. Most of the signs elicited by the medical profession were in motor and sensory areas without reference to visual and auditory processes. Nevertheless, evidence of auditory and visual processing difficulty can be regarded as just as much a neurological sign as the others.

It is in the administration of these tests that the physician may experience some difficulty in terms of behavioral interference, because these signs require very careful attention to detail, careful standardization of administration, and more cooperation from the child.

Figure 11 shows the concept of soft signs as distinct from hard signs. The lower half of the right-hand column indicates the traditional areas of soft signs, because most of them have been described by physicians in the motor and haptic sensory areas. Nevertheless, the developmental concept applies to all items. The soft signs elicited by the physician do have a slightly different set of references because, on the one hand, they are harder to elicit in the child under three years of age, and on the other hand, they appear to mature in such a way that many of them are hard to find beyond the age of 12.

One reason for the difficulties under age three is cooperation. The other may be that the child's motor system has not yet reached a high enough level of integration to measure hemispheral motor and sensory signs, just as it is hard to measure language in the pre-verbal infant. Another reason may simply be that we have not yet developed a technique sufficiently delicate to elicit the signs. The ideal age to elicit these signs is probably between four and six years of age, but they can be observed as early as age three.

In case the foregoing remarks suggest that these signs are a prerogative of the medical profession only, it should be pointed out that Clements was a psychologist and Peters a psychiatrist, and that teachers can equally excel in observing differences in fine and gross motor function in the classroom. They not only see the child in many different activities but also see him for a longer period of the day.

For physicians to go beyond the traditional soft neurological signs is to take them into the realm of psychological and language testing, and even further into the educational field. This is exactly the situation that makes the interdisciplinary approach so valuable because each member of the team proceeds from one discipline to look at the whole child and overlap.
only into adjacent disciplines. Only one absolute prohibition exists, and that is for professionals in one discipline to use the exact instrument used by their colleagues in other disciplines. Although there is debate over this question, test-retest problems may exist, and the risk of interference should, and can, be avoided.

Physicians should not use the Bender Gestalt test, and when we were examining our own 3,000 children from the National Collaborative Study, we adopted the Gesell drawings as our visuo-motor test. Figures 12 and 13 show the patterns used. These turned out to be an excellent alternative as they can give a lot of information similar to but, in fact, sometimes better than the Bender Gestalt test, so that our own psychologists no longer use the latter as often as they did before.

Language is the most demanding of the developmental systems in terms of testing and is the most difficult for physicians to evaluate with their tools, unless they borrow liberally from colleagues. Even the psychological testing may give insufficient data in this area, and this is why we have our speech and language colleagues to help us. Nevertheless, a tremendous amount of information is generated by observing the child's response to each instruction throughout the examination as well as by listening to his or her responses. Speech is readily observed, but speech is the phonology of language and has much more of a motor base than language. Expressive language must be measured by the language clinician.

The significance of right-left orientation in terms of learning disability was recognized as long ago as 1925 by Orton (1925, 1928). He even proposed using the term "strephosymbolia" (meaning "twisted symbols") for children with reading problems. Despite this, there has been little data on the developmental hierarchy of right-left organization, and it is rarely used in a clinical setting. In fact, it is an important neurological sign in association with handicapping conditions, as it does reflect one example of the brain's spatial orientation, although the same disorientation will also involve up and down, back and front, and even before and after. This was studied at Johns Hopkins (Whitehouse, 1980) and we established a developmental hierarchy as shown in Figure 14, suggesting that most children should identify right and left by the age of five years cross the midline by six years, and reverse right and left for the examiner who is facing them by eight years. This test has importance but is only useful in the older preschool child.

Using all of these techniques and using them as a highly standardized and ordered investigation of the child's response to the various applied stimuli it is possible to obtain an extremely accurate measurement of the child's developmental levels. This measurement is not one that easily applies itself to mathematical quantitation, and much of it must be admitted to be judgmental, based upon comparison with other children. Nevertheless, this degree of judgment can be acquired by physicians working in this area and a number of studies have suggested that the accuracy of such pediatric examinations can approach those of psychological testing.
Behavioral problems can also interfere with the neurological examination. However, if it is structured by starting with obvious games that interest the child, such as measuring the motor state, dominance, and reactivity by playing ball with the child, one can usually obtain full cooperation. Throughout the examination the child's behavior is observed and measured, recognizing that each test may have multiple consequences and that simultaneous measurements of different functions are going on all the time.

The Interdisciplinary Approach

It is clear that no one professional can measure all dimensions of the child's developmental behavior, and for this reason the team approach is essential. Figure 15 shows a model that includes most of the persons who could be involved with such an evaluation.

In reviewing it, you may notice that the pediatrician is not named here. This is because the pediatrician is, in fact, functioning as both neurologist and psychiatrist. In fact, these two terms could be replaced by the term "developmental physician," leaving it open for any medical specialist to enter this area. It is important, however, that the specialist recognize the need for a different approach than that derived from a formal training in medical school.

If I was asked which member of this team is the most important, I would have some difficulty. In general, I would have to list the parent as the most important person. But in terms of formal evaluation, it is hard to put one professional above the other. Probably one might say that the psychologist has the best overall technique for measuring developmental status, although such evaluation may not be predictive of the child's response to the task of academic learning at a later age. The educational specialist can more readily measure a child's educational level at a later age but may not have data to compare this with the child's potential.

I must be honest and say that physicians are doing their best to catch up with psychologists and teachers in terms of measurement. Perhaps their only claim to importance here is that they are generalists and can cover information in quite a wide range of neurological dysfunction. They are also the only members of the team who can use medication in those cases where this may have relevant bearing on a developmental process. This is a topic for a total discussion in its own right. But it is important to point out that the stimulant drugs, which can be used as young as two to two and a half years have an effect in improving learning behaviors and are not just used for controlling undesirable behaviors. The most marked benefit is on that important dimension of attention span.

This team would be beneficial for every developmentally disabled child, of every degree; but the demands of time, the number of professionals available, and certainly the cost, make this prohibitive. I would consider that the ideal minimal team includes a teacher, psychologist, physician, parent, and child. Other professionals should be consulted as needed. Not all children need a language evaluation, although
statistically it is probable that a considerable number of our preschoolers with problems come to us after an observed language delay simply because this is something that parents are more likely to pick up and bring to our attention. What is important is that the language clinician does not concentrate totally on language and recognizes that the child may have other problems as well.
SUMMARY

1) An attempt has been made to point out the various factors affecting the child’s development, starting with the genetic endowment of the child as shown by evidence from other members of the family, and ranging through the genetic mutations that may take place, the various intrauterine processes that may affect the developing child and change his or her endowment, as well as peri-and post-natal events.

2) It was also shown that at different levels of neurological organization, different information became available to observers, ranging from the basic reflex activity of the newborn infant to suppression of this activity by increasing maturation of higher functions, and then to increasing levels of organization that can be measured by examiners.

3) There are problems and pitfalls of over-diagnosis as well as limitations of early examinations in this area, but increasing accuracy can be achieved as the child gets older. At the same time, our own techniques have improved considerably and, it is hoped, will go on improving.

4) What is most important in this area from the physician’s point of view is that his or her part in medical assessment should be made as a member of the team and not in isolation. The interdisciplinary team cannot only check each other’s results but can provide feedback into the system and, in fact, can learn from each other in their technology and the handling of data.

5) This involvement of education with the younger child is a relatively new phase in public school education and it is clear that all members of the team have a lot to learn from each other in this on-going cooperative venture.

6) A word of caution has been added, to the effect that not only can overdiagnosis be a problem, but we must avoid over-treatment and overstressing the young child, although so far, the data has shown that pediatricians, at least, have totally underestimated the ability of the infant and the young child to tolerate such procedures. The interest shown by children under two in infant stimulation programs in public schools may be one of the best demonstrations that children like to learn and do not have to be taught.

7) Finally, I would like to congratulate the Maryland State Department of Education for the way in which they have spearheaded these programs and for sponsoring this symposium jointly with Dr. Gilbert Schiffman, from the Johns Hopkins Department of Education, who has espoused this cause for many years.
References


Karyotype of a Normal Female. The paired autosomes are not recognizably different from those of the male. There is, however, no Y chromosome. Instead there are two X chromosomes which appear in the upper right hand corner of the karyotype.

FIGURE 1
Trisomy 21. Meiotic non-disjunction has resulted in a patient with three chromosomes number 21. This extra chromosome in an otherwise normal karyotype is responsible for the set of symptoms known as Down’s Syndrome.
Turner's Syndrome. Karyotype of a patient with Turner's Syndrome. The only deviation from normal is the complete absence of a second sex chromosome. With only one X chromosome and no Y, a person is essentially female, although lacking in secondary sex characteristics.
"HIGH RISK" ETIOLOGICAL FACTORS

A) Pre-Natal
   1) Genetic
   2) Social
   3) Maternal Health
   4) 1st Trimester
      - Bleeding
      - Excessive weight gain or weight loss
      - Excessive swelling
      - Elevated Blood Pressure
      - Medical Condition
        (Diabetes, Thyroid, Alcoholism,
         Chronic Diseases, Medications,
         x-rays, etc.)
   2nd Trimester
   3rd Trimester

B) Peri-Natal
   Labor and Delivery
   - Prematurity
   - Twin Birth
   - Breech Delivery
   - Cesarean Section
   - Placenta Praevia
   - Etc.

C) Post-Natal Events
   - Jaundice
   - Cyanosis
   - Edema
   - Seizures
   - Low Blood Sugar
   - Tetanus
   - Etc.
   - Later Illnesses
     (Meningitis, Head Injury, etc).

FIGURE 4
HIGH RISK BEHAVIORAL PATTERNS

A) Abnormal signs
   CNS - Seizures, Jitteriness
   Alimentary - Vomiting
   Respiratory - Breathing Difficulties
   Cardiac - Cyanosis

B) Absent or Poor Innate Reflexes
   Sucking
   Rooting
   Grasp
   Gallant

C) Persistent Primitive Reflexes
   Moro (after 4/12)
   T.N.R. (after 4/12)
   Landau (after 1 to 2 years)

D) Hard Neurological Signs
   Asymmetry of Functions
   Abnormalities of Tone
   Abnormal Reflexes
   Abnormal Visual Responses
   Abnormal Hearing Responses

E) Developmental Delays
   Fine Motor
   Gross Motor
   V / Co-motor
   Language
   Behavioral

FIGURE 5
THE DEVELOPMENT OF PREHENSION

1) No visual regard for object

2) Transient regard for object

3) Prolonged and definite fixation with slight postural changes (16 weeks)

4) Visual fixation with crude bilateral or unilateral hand approach (20 weeks)

5) Unilateral pronated hand approach with scratching at object (24 weeks)

6) Pronated approach with raking flexion and palmar prehension

7) Pronated hand approach with index finger extended and partial suppression of other digits = poking

8) Rotation of wrist with pincer-like prehension of index finger and thumb (40 weeks)

9) Perfection and further delimitation of pincer-like response (48 weeks)

FIGURE 6
FIGURE 7
MINIMAL BRAIN DYSFUNCTION  The Hyperactivity Iceburg

FIGURE 8
CAUSES OF LEARNING PROBLEMS

Acquired

Genetic

ENVIRONMENTAL DEPRIVATION

CNS DYSFUNCTION

FUNCTIONAL

Organic

Vision

Hearing

Chronic Disease

OTHER DISORDERS

LEARNING

FIGURE 9

-69-
### Function

<table>
<thead>
<tr>
<th>Description</th>
<th>Instrumentation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical and Health Status</strong></td>
<td>Standard Medical Procedures, Audiology test, Ophthalmological test, Optometric test</td>
</tr>
<tr>
<td><strong>Developmental Physical</strong></td>
<td>Frostig Test of Motor Perception and Abilities, Motor Skills Inventory, General Aptitude Test Battery, Ayres Handwriting Scale</td>
</tr>
<tr>
<td><strong>Developmental Language</strong></td>
<td>WISC Verbal, Goldman, Fristoe, Woodcock Johnson</td>
</tr>
<tr>
<td><strong>Visual Motor</strong></td>
<td>WISC Performance, Bender Gestalt, Benton Visual Memory Tests</td>
</tr>
<tr>
<td><strong>Developmental Behavior</strong></td>
<td>School and Home History, Psychological Observations</td>
</tr>
<tr>
<td><strong>Social and Emotional Development</strong></td>
<td>School History, Home History, Vineland (I.Q. less than 56), Psychologist's Observations, Projective Testing</td>
</tr>
<tr>
<td><strong>Academic Achievement</strong></td>
<td>Wide Range Achievement Test, Gates Reading Comprehension Test, Gray Oral Reading</td>
</tr>
</tbody>
</table>

**FIGURE 10**
NEUROLOGICAL SIGNS IN MINIMAL BRAIN DYSFUNCTION

"Hard" Neurological Signs

- Sensation
- Power
- Tone
- Deep tendon reflexes
- Superficial Cutaneous Reflexes
- Coordination (Finger-Nose Test, Gaits, etc.)

"Soft" Neurological Signs

- Language: Receptive, Expressive
- Visuo-motor (Gessell)
- Right-left orientation, etc.
- (Mixed dominance)
- Fine Motor (Speech, Finger Movements)
- Gross Motor (Ball Throwing, Hopping)

Dysdiadochokinesia (Impairment of the power to perform alternating movements in rapid, smooth and rhythmic succession)

Dysdiadochokinesia

FIGURE 11
THE DIAGNOSTIC AND EVALUATION CENTER
VISUAL-MOTOR TESTS

Name ____________________________
Date of Examination ________________
Date of Birth ______________________

Patient Identification

FIGURE 12

PED OPD 1/69 (1000)
-72-
FIGURE 13

CHILD'S SIGNATURE

Name of Child
Date of Examination
Date of Birth

Patient Identification
**RIGHT-LEFT DISCRIMINATION TEST**

1. Show me your **LEFT** hand. | ![ ]
2. Show me your **RIGHT** eye. |

3. Put your **LEFT** hand on your **LEFT** eye. | ![ ]
4. Put your **RIGHT** hand on your **RIGHT** ear. |

5. Put your **LEFT** hand on your **RIGHT** knee. | ![ ]
6. Put your **RIGHT** hand on your **LEFT** eye. |

7. Touch my **RIGHT** hand. | ![ ]
8. Touch my **LEFT** knee. |

9. Put your **LEFT** hand on my **RIGHT** hand. | ![ ]
10. Put your **RIGHT** hand on my **LEFT** knee. |

11. Put your **LEFT** hand on my **LEFT** knee. | ![ ]
12. Put your **RIGHT** hand on my **RIGHT** hand. |

**COMMENTS:**

**FIGURE 14**
THE INTERDISCIPLINARY TEAM

- Parents
- Teacher
- Social Worker
- Patient
- Psychologist
- Psychiatrist
- Counselor
- Neurologist
- Physical Therapist
- Occupational Therapist
- Ophthalmologist
- Orthopedician
- Etc.

FIGURE 15
Supporting Programs in Times of Shrinking Dollars

Comprehensive services to handicapped infants and their parents are costly. Infant program enrollment is expanding during a period of budget constraint. Many infants identified have multiple handicaps with needs best met by a multidisciplinary team. How can Boards of Education and other funding authorities and the public at large be convinced that these programs are worth the price?

- Personnel at state and local levels need to collect and present data on child progress which supports the efficacy of early intervention programs.
- The taxpaying public needs to be aware that early intervention programs save tax dollars in the long run, as many children served will need fewer and less expensive services in later years.
- Decision makers need to see programs in action to learn first-hand what handicapped infants need and are receiving through special programs.
- Parents as advocates are influential in securing and maintaining funding for their special needs children. Organized parents can help convince Boards of Education and legislators that existing services are appreciated and that there is a need for expanding services.
- Advisory council members can disslove community resistance to special needs programs. Members can act as information bearers to influential persons responsible for funding decisions.
- In times of budget constraint, presenting a two or three level budget, offering alternative levels of services, may help a county phase in needed services over a span of several years.
- Because of shrinking resources, school systems may be unable to provide funds for summer month services. In some areas, educational agencies collaborate with other agencies such as Departments of Parks and Recreation to provide summer recreational programs for special students.
Mediating Parent/System Conflicts

School systems, operating with limited resources, have difficulty accommodating some parents who want intensive services in all areas for their child. Requests for daily physical, occupational and/or speech therapy are often supported by a private physician's prescription for these services. What are some of the issues confronting administrators in these situations?

- Professionals should strive to develop good patterns of communication with parents, building a spirit of cooperation and emotional rapport early in their relationship. This may prevent conflicts later.

- As professionals convince parents that what they are doing is worthwhile, it is difficult to demonstrate that doing twice as much isn't twice as good. However, overstimulation can have possibly stressful effects in children.

- No physician should decide alone how much speech therapy, how much physical therapy, or how much occupational therapy is needed for a child. The individual professionals working on the ARD team should be the experts recommending the appropriate level of therapy in each situation.

- Professionals working in partnership with parents within a team should come to agreement on appropriate levels of service. No one should feel pressured into decisions or stifled in expressing their opinions.

- An important role of the therapist is showing parents, teachers and others how to do things for individual children. Therapists should be able to assign some activities to assistants. This increases their overall effectiveness because they cannot do everything that needs to be done by themselves.
Transportation

Transportation continues to be a complex challenge for special education programs. What are some ways that administrators in other areas cope with transportation needs for very young children?

- In some programs parents are reimbursed at a reasonable rate for bringing their children in for services. For families that don't have a car available, the reimbursement can be made to neighbors or relatives who transport the child and parent to the center.
- Some school systems contract with taxi companies for transportation.
- Program Managers have arranged to share vans to transport the handicapped population in the morning and afternoon and to transport the elderly for senior citizens' projects in between times.
- Program aides or custodial workers have been trained as bus drivers, transporting children in a system's "spare bus" that is left at the special center when it is not needed.
- In most circumstances, program staff and volunteers should not be expected to transport children in their vehicles because of the possibility of personal liability in case of an accident.

Parent and Family Participation

What are some issues concerning parent participation and family support in early intervention programs? What are some benefits of parents acting as consultants to each other and to professionals?

- In some areas professionals organize a network of parents who reach out to parents of newly identified handicapped children. Parents are trained in active listening and are knowledgeable about the resources in the area. They are often matched with parents of children with similar disabilities.
- Parents can help each other sort out a myriad of feelings because of similar, first hand experiences. Examples of shared issues are: telling relatives, friends and neighbors about the infant's problems; fears during subsequent pregnancies; anger towards insensitive professionals; and feelings encountered when comparing their children to normal children.
Programs have bolstered parent meeting participation by providing babysitting for handicapped children and siblings through respite care workers and community volunteers. Parents respond well to centers that have special features for them, such as a coffee room or media viewing room. These centers communicate that the parents are valued as well as their children.

Parents have been well utilized as guest speakers or panel members for inservice and preservice training. In addition to being "expert" information givers, they benefit from increased feelings of confidence.

Evening and weekend parent meetings accommodate the schedules of fathers and working mothers. Special sessions for fathers may help them become more involved and provide an outlet for discussing their concerns.

Divorce is more common in families with a handicapped child. Programs that can provide or access counseling for marriage stress can aid the handicapped child by helping to keep the family together.

Providing counseling for siblings is another level of support to the family. Siblings of handicapped children may have special needs, jealousies and fears.

There is concern that some parents are unwilling or unable to follow through with any home-based activities. At what point does it become justifiable to withdraw or modify intervention to the child because of the parent's lack of concern or interest?

We must acknowledge that some parents who do not serve their children are ones whose own needs are so intense that the child's problems seem small by comparison. The process of building trust and commitment between parent and professional may be difficult, frustrating and long term. Creativity in serving these parents has to enter into the process. Some rural programs have shown that child progress occurs almost incidentally as the critical economic, social and emotional needs of families are met.

In Maryland, alternatives to the home-based model are the center-based or combination home-center program. These alternatives may be necessary because of differing needs of families with different child characteristics.

We need to recognize that each staff person has different skills with families. The staff needs to come together frequently enough to discuss problem children and families and get help from one another. They may need to trade parts of caseloads. Often we have solutions within our own teams that we need to unlock.

In hopefully rare cases, if the child's development is at risk, ethical decisions leading to legal problems must be faced. We can never withdraw our interest in small, vulnerable handicapped children.
Improving Communication Between Educators and the Medical Community

There need to be more open communication among the educator and physician and parents. Exchange of information is necessary for coordination of efforts in work with children. How can this be better accomplished?

- Educators are often unable to interpret medical reports. Physicians and teachers need to talk directly with each other, to ask questions and discuss the reports. Alerting the physician's office as to the nature of your call allows the physician to return your call after locating the pertinent data.
- In writing reports to physicians, descriptive data on the child's behavior, social adjustment in the classroom, and progress in the learning modalities helps the physician determine how well the treatment or therapy is working.
- Professionals who take time to carefully explain diagnostic information and etiology may relieve parents of feelings of inadequacy and guilt and lessen their need to shop for other opinions.

Concerning the At Risk Children

In Maryland, approximately 2,000 intensive care newborns are identified each year. Efforts to systematically track this population are being initiated. What kinds of follow-up measures are important?

- Regular developmental evaluations, provided by private physicians or well baby clinics are critical for this group. However, all children should go through this process because of the high probability that handicaps will be identified here. Many parents recognize developmental delays, but may not get the child to the right professionals at an early age.
- At present, the Health Department has the edge over the private sector in doing this job because of well organized well baby clinics and the public health nurses' activity in the community. Funding cuts are diminishing the number of public health nurses available to monitor the progress of at risk infants. Educational agencies need to become political allies with social and health programs to support their needs for adequate funding.

What are some indicators from a medical standpoint that infants born very prematurely are in need of early intervention services?
Typical neurological sign such as asymmetry, abnormal muscle tone and abnormal reflex patterns are important to the diagnostician and probably are more useful indicators than developmental signs. The child's adaptive functions are important also, but data shows that the normal premature baby is going to be developmentally delayed during the first year of life.

The cut-off point, in terms of enrollment is difficult to know. This population represents a spectrum of disability. At the lower end of the spectrum, services are probably not needed. Measuring development at two points in time is a better indicator of need than a single measurement. Professionals have to be assured that these children are not going to be irreparably harmed if they are not served for a little while.

We cannot afford, the cost of putting children in services for possible disability. We need to wait to determine whether there are definite disabilities.

There are social, environmental and parental factors which enter into the premature infant's development. There are also risk factors related to pregnancy, labor, delivery and the postnatal period to help determine which children may have a handicap. But prediction based on risk factors is not always possible.

Professionals can help the family adjust to an infant born at risk and hospitalized for extended periods.

Parent educators and social workers can reassure parents about feelings and stimulation activities. Because the premature baby's responses are not at the same level as those of a full term baby, maternal responses may not be triggered. Parents may need to put in a bit more effort and not be put off by an unresponsive baby.

Physical and occupational therapists have skills in assessing early motor and reflex behaviors and can monitor the progress of the infant.

Referrals concerning children who are functioning broadly within normal limits have been increasing. The quality, spontaneity or frequency of the skills demonstrated in testing suggest that these children may be at risk for later learning problems. How can diagnosticians attempt to define qualitative delays while using quantitatively oriented test instruments?

Certain test items may assume particular significance as being indicative of developmental delay, even though the total test score is within normal limits. Examples of important developmental phenomena in infancy, as cited by Dr. Honig are: 1) ability to delay mouth gratification in order to do examining behavior and 2) ability to use two hands in a "hold-operate procedure".
An issue of paramount importance concerns how resources are allocated. In the best of all possible worlds we could be able to serve all children that we were concerned about, regardless of what those concerns are. But we are not allowed by law to serve all children from birth to three. We can only serve children who are handicapped. The "at risk" category is a mystery category. If we choose to define it by qualitative differences, we are guessing, on the basis of our perhaps very good experience, which children are going to have trouble.

Within the decision-making process for including infants in special programs, just as with any other decision making process, we can't avoid some error. We have to decide whether we are going to overinclude children, incurring greater expense through serving children who might survive without inclusion in our programs or underinclude children and risk not serving some children who need services.

A complex socio-cultural problem is: Are precious resources to be allocated to mildly handicapped children where their chances to achieve independence are much greater? Or are resources to be allocated to more severely handicapped children where their chances for independent functioning are very small, but where our chances are fairly great for helping families to cope and for changing the whole families' quality of life as a result of intervention?

Referrals for behavioral problems in preschool age children are increasing. Is a behavior problem a handicapping condition in a preschool aged child and what are some opinions as to proper management of this population?

In some cases, preschool special education programs may be helpful to children presenting behavioral problems of an suspected organic basis, notable for distractibility and short attention span. However, educational programs at this age are not as important to this population as to other populations of handicapped children.

Proper medication, such as Ritalin, is effective with many of these children. There continues to be controversy concerning the effects of food additives and the benefits of special diets on the problem behavior of some children. Because research studies have not supplied consistent data that this diet works, parents are told to try it if they want to. Many parents find diet management effective and report that this is more helpful than Ritalin or that the diet increases the benefits of medication.
Improving Assessment Skills

How should a battery of tests be selected to include both traditional and non-traditional (alternative) assessment measurements?

- In the past decade, traditional assessment instruments have been produced very rapidly. Where there once were few instruments available, there now are well over a hundred. These instruments generally include almost the same items, varying primarily in quantity and quality. Combining selections of one or two traditional assessment measures with Uzgiris and Hunt's Ordinal Scales of Psychological Development will yeild the desired information.

What about the usefulness of non-traditional assessment measures for programming?

- Information derived from Uzgiris and Hunt's Piagetian tasks are very useful for determining the stage of cognitive development at which an infant is operating. This information is used in teaching so that tasks are neither too high nor too low on the developmental ladder. The Piagetian tasks have the same limitations as traditional tasks in terms of motor demands on the child. However, the tasks may be modified and alternative ways found for a child to demonstrate the skills. This is done in the curriculum tentatively titled "The Carolina Curriculum for Handicapped Infants" developed by Drs. Jens and Johnson.

- Information derived from the Smile Stimuli is probably more useful for diagnostic purposes than program planning purposes. If a child's responses suggest that he/she is brighter than was thought, it signals the need for further assessment, such as looking at the child's visual responses to language input.

- Use of this measure has yielded rhythmic information with implications for programming. Certain children, e.g., hypotonic Downs' Syndrome children, tend to take longer to build up a smile response to stimuli. Mothers have changed their entire tempo of interacting with their babies when the scale is interpreted for them.

- Different disciplines have different perspectives on what the ideal instrument is or what is necessary to assess. There will probably never be one instrument to meet all of the needs of the handicapped population.

The Learning Accomplishment profile (LAP) is widely used as an assessment tool in Maryland. What are some of the appropriate uses and possible misuses of this instrument?
The LAP was one of the first instruments designed to assist the teacher in planning programs for individual children. It is considerably more useful for mildly handicapped children who are going to show delayed but normal developmental sequences than for more severely handicapped or very atypical children.

Some people assume that the LAP is standardized. It is not and there are no norms that accompany it. The age levels given are not reliable. Consequently, the test should not be used as a basis for determining that a child is handicapped.

A newer version of the LAP, entitled the Diagnostic LAP was standardized, but only on a small group of Head Start children. Persons using the Diagnostic LAP should recognize the limitations of its norms.

Although there have been some item changes in the different editions of the LAP, the most widely used LAP still contains a basic set of items that were developed because they offered discrete developmental markers. That set of items was never meant to be an ideal set of instructional objectives. Teachers need to be aware of this limitation and not construct a child's IEP solely on the sequence of items presented on the LAP or any other similar instrument.

In addition to the teacher, the OT, PT, psychologist and speech therapist should contribute to the development of the child's IEP. The team can pool test results and observational data in developing goals and objectives. The team, including parents, translates that information in ways that are functional and meaningful to the child in the everyday environment.

What are some of the difficulties incurred in developing IEP's for infants and also for severely and profoundly handicapped children?

Specifying IEP goals and objectives for a full year is extremely difficult because of the problems of predicting the growth rate of a handicapped infant. Rather than a year-long plan, a series of three-month plans may be a more realistic process for staff and parents.

In working with children functioning below six months of age, it is important to select an assessment instrument that has many small discrete steps at this low functioning level. Some instruments have very little to show parents that growth is occurring, even though in small increments.

In some cases, children may be so profoundly handicapped as to be functioning at a pre-birth level with abnormal reflex patterns which interfere with learning. Because they are not yet responding to stimuli, they are beyond the scope of available assessment or curriculum measures.
Some infants suffer repeated trauma in intervention programs and lose skills previously attained. They need to recover lost ground, working back up to the level at which they started the program.

New criterion-referenced materials, such as Drs. Jens and Johnson's "Carolina Curriculum for Handicapped Infants" (in press) may fill a need for quality materials offering a more discrete assessment instrument with logical sequences for teaching the items. The program incorporates skills normally found on criterion-referenced tests plus Piagetian based tasks into an organization of twenty or more different instructional areas. This program also has received good feedback from professionals involved in field testing.

Where does parent involvement and parent interaction enter into the assessment process? Should formal assessments which look at parent-child interaction be part of the evaluation process in early intervention programs?

If parent-child interaction is ignored, important variables will be missed which enter into predicting the outcome of any given child. There is a need to develop and revise scales to help us look clinically at parent interactions. There is a need for a scale that can measure the kind of contingency relationship between parent and child that is critical for learning.

Professionals need to be cautious in measuring parent-child interaction with handicapped children, especially those that are severely handicapped and nonresponsive. Sensitivity is necessary so that the mother's sense of failure is not increased when she is unable to get the child to respond to her.

Babies who have had long hospital stays after birth often show deficits in social interactions as well as other delays. "Attachment" can begin at any time and the disruption caused by separation of parent and child can be remediated, but the attachment process takes time.

Some handicapped infants do not issue the kinds of responses that reward caregivers. Professionals can help parents identify subtle infant behaviors which are clues that the infant is responding to the parents.

Sometimes initial attachment may be made not with the parent but with another caregiver or professional. As the infant develops more responding skills, the attachment between parent and child may strengthen.
Meeting Teacher Training Needs

What are some important training needs for teachers preparing to work with very young handicapped children?

- Understanding of both normal and abnormal development is critical. Teachers need not only good task analysis skills, but the ability to know why teaching particular skills is important to individual children.

- Acquiring skills from other disciplines helps teachers and others move towards transdisciplinary teamwork. This training can take place through coursework in complimentary disciplines (i.e., child development, motor development) and through informal and/or structured inservice training. Occupational and physical therapists are valued consultants as they teach educators handling, positioning, and relaxation techniques to employ with certain children.

- Courses dealing with characteristics of exceptional populations generally fail to examine the effects of the characteristics on learning and interactions. Methods courses generally are limited to surveying materials that are available for teaching.

- Understanding learning theories and models is necessary for educators. Education results from the intermix of learning and development. Piaget is a good example of a theorist who assists teachers to look at a child so that learning activities are matched to the child's capabilities and needs.

How can the right kind of early intervention professional be found? Should it be someone who knows early childhood education; who knows exceptional children; or who knows parent training?

- Look for flexible, adaptable persons who are warm and open, and who want fiercely to learn more about doing well the job that is required.

- Look for persons that have been motivated to learn from other disciplines.

- Recognize the need for ongoing inservice training to meet specific needs. If possible, send the teacher to learn from others with expertise in the ages and handicapping conditions that he/she is working with. As an alternative, have the "experts" come to your program to share special skills.

- Recognize that adult education is very different from early childhood education. Select inservice instructors who can model warmth, openness and an appreciation for adults.

- Direct teachers toward courses on parenting, such as Parent Effectiveness Training (PET), Systematic Training for Effective Parenting (STEP), or Interpersonal Covenant of Problem Solving, often given in the evening through local universities.
Provide team members with the time and structure to learn from one another. Weekly full-day child staffings and teaching/therapy demonstration sessions are provided in one large county program to coordinate team efforts and strengthen skills of individual members.

Develop regional forums within the state so that program staff can meet on an informal basis to discuss their concerns, problems, and strategies.

Develop an early intervention newsletter to share information on new instruments, teaching methods, research funding, parent involvement ideas and general ideas to help one another.

Secure new information in the field by subscribing to journals, such as Child Development and getting on mailing lists of major research centers to avoid "publication lag."

Providing direct service to handicapped infants and children is often stressful, frustrating, and difficult. What are some morale issues and coping mechanisms for early intervention professionals?

- Professionals working in early intervention do become involved in a personal way with families. We need to recognize that this attachment is normal and necessary.
- Professionals need to develop objectivity so that they are not immobilized by a family's problems. Their primary role is to act in ways that will benefit the child.
- Professionals need to realize that the grieving process of parents is a normal and healthy one. They need to be trained to recognize the stages of grief and to use active listening skills appropriate to adult needs.
- Professionals often have feelings of frustration and guilt when intense efforts to help a child and family yield slow results or none at all.
- Professionals sometimes bear the brunt of a parent's anger. Their reactions to parent hostility may be guilt, defensiveness or resentment. They need support systems of colleagues and supervisors so that they don't pull away from the parent.

Team members need to be supportive of each other. Active listening skills can be therapeutic to professionals as well as parents.
Principals and program coordinators need to be accessible to staff and cultivate good listening skills. They need to be sympathetic to discomforts inherent in working with this population.

Supervisors have initiated flexible staffing patterns to diminish stress. Part-time hours meet staff and budget needs in some programs.

Administrators and supervisors need support from state personnel to help them cope with their own morale problems. Regional administrators and staff specialists help by lending noncritical ears to their problems.
The Education for All Handicapped Children Act (P.L. 94-142) requires that all children ages 3-21 be identified, evaluated and placed in appropriate programs by this month -- September, 1980. States with more comprehensive mandates such as Maryland and Michigan require special education services from birth on. Thus, school systems across the United States which traditionally have not been delivering services to young children under age 5 have been given the responsibility to implement a law even though there are many other players in every community. It's quite clear from this mandate that schools are to be in charge; schools must take the lead in every community. In most cases, especially for younger children, programming will involve effective collaboration, interagency agreements and transdisciplinary teaming with health and social service providers and agencies.

Historically, it was ten years ago that the federal government began to provide legislation and financial support for the education of handicapped preschoolers. The first step came through the creation of The Handicapped Children's Early Education Assistance Act in 1968, which established experimental programs as models for state and local educational agencies. The program is still in operation today with over 200 projects — many of which are models of comprehensive services for young children (Cohen et al., 1979; Swan, 1980).

The educational amendments of 1974 (P.L. 93-380) communicated a philosophy of commitment to provide special education services from birth on with no demands to do it; other programs in support of early special education are the State Implementation Grant Program under the Handicapped Children's Early Education Assistance Act and the Preschool Incentive Grant Program.

Where are we then with these mandates? Of 50 states, about 20 are not mandated to serve any preschool children; of those remaining, about 30 serve some children ages 5 and under, 7 are mandated to serve 3 to 5 year olds, and 5 serve children from birth on (Cohen et al., 1979). Thus, Maryland is in the minority and at the forefront of a trend in the field.

I applaud Maryland for taking the lead and having such a progressive law. In states where special education begins at age 3, there is much discussion about what to do for the younger children and a strong push to lower the mandate. From experiences in other states across the country, I feel there must be a lead agency assigned for providing the services to young handicapped children. Even though this doesn't always produce successful programming, it at least gives one a place to go to exert pressure. Personally, I feel education is an appropriate leader for these services given its past history and role in delivering services to children, for it is the only system by tradition which has been universally accessible to all children. The field of Early Childhood Education also
has more of a tradition of training professionals to look at the total
development of a child in context as opposed to the more narrow training
focus of other professionals currently delivering services to young
handicapped children.

The most difficult of all the young ages to deal with in implementing
this new law are the ages from birth through 2 years. This is also the age
group which is least familiar to schools, since some schools have been
delivering preschool programs via Title I of Head Start for the past 15
years. In my own state of Massachusetts, the Department of Public Health
and the Department of Mental Health are contending for the lead in
delivering services to this age group. Instead of unified programming for
all children who need services, there are lots of gaps and fragmentation in
services. I hope that Massachusetts follows Maryland's step and mandates
that schools be the lead agency in developing and delivering comprehensive
services which include the medical, health and social welfare systems.

Traditionally, where were these children who are currently being
served under your special education mandate? Where are they in service in
states without such mandate? In the past these states there were very
few services for children with a variety of problems. The services which
existed for special needs young children were limited in scope,
crisis-oriented, medically-focused, and categorical in nature -- meaning
that they were dependent on a child's disability or the socioeconomic
status of the child. Traditionally, visits by the public health nurse or
enrollment in a medically-based program operated through a Crippled
Children's Title V program were the only services for young handicapped
children in a community. Furthermore, the limited existing services were
fragmented and uncoordinated. The intent of P.L. 94-142 and Maryland's
Bylaw is to go beyond this parochial limited view of the service world for
this population and to provide comprehensive service models which have
ecological validity and impact on many domains of the child's development
and his/her family functioning.

Comprehensive program models, which have been slowly evolving during
the past 10 years across the nation to meet these mandates, offer
illustrative examples of programs, options, and services for young
handicapped children that a state such as yours can use in this new area of
programming. I might add that there is also evidence that these programs
are cost efficient (administrators take note) as well as beneficial to the
child and his or her family and to society as a whole.

The good news today is that there is exciting evidence to back up the
mandates for early comprehensive programs for this population. Recent
data especially that of Lazar and his colleagues show long-term effects
of programs (Comptroller General, 1979; Darlington et al., 1980). As
leader of a Consortium of Longitudinal Studies, Lazar reported last year on
the follow-up data of 14 separate longitudinal studies of low-income
children in experimental infant and preschool research projects begun in
the 1960's during the War on Poverty era. The median grade for the
subjects in the follow-up was seventh; the range of ages in 1977 when the
follow-up was completed was 9 to 18 years. Projects evaluated in the
long-term impact study were the experimental interventions
of leaders such as Kuno Beller in Philadelphia, Susan Gray's Early Training Project in Tennessee, Phillis Levenstein's Mother-Child Home Project in New York, and David Weikart in Ypsilanti, Michigan. The programs evaluated included a variety of ages of children and types of programs -- home and/or family based. These findings provide the best evidence available for positive effects of early childhood and family development programs.

First, children in these programs required special education less often; in other words, children in early programs were placed in remedial special education significantly less often after entering school than their controls who were not in these programs. Special education was defined as being placed in a class for remedial work, placed in a learning disabilities class, or classified as an educable or trainable mentally retarded or emotionally disturbed youth. There were more positive results for the children who were in programs before the age of three and programs with high parent involvement. Specifically, 17% of those in early developmental programs, compared to 38% of those who were not, were placed in special education programs after school entry. Cost implications of these results are clear.

Second, children in these early programs also were held back in grade less often than their controls. For two programs, the number who were held back was reduced at least 50%.

Third, children in these programs scored consistently higher on intelligence tests than their controls; this finding is in contrast to the earlier predictions of Bronfenbrenner and his colleagues who analyzed data on the same children only two to three years after the preschool interventions. For example, Bronfenbrenner (1974) found that, even though there were some short-term gains after the programs, they seemed to be fading away after three to four years in elementary school. These long-term studies show that in fact these gains-- albeit statistically small in difference--do remain and hold up even ten to fifteen years after the original programs.

The final findings of the longitudinal study was that the parents who were involved with these programs also express positive feelings. There were also no interaction effects by sex, race or any other differences within programs in these longitudinal findings. Thus, these findings--even with problems in assessment, attrition, and methodological design--show that the early intervention programs are successful on a long-term basis.

In addition, we have studies of early intervention on more impaired populations of children such as those who are deaf, blind, and/or mentally retarded children. Even though we do not have a longitudinal study (similar to that of Lazar and his associates) on more impaired populations, we do have results which show the existence of positive short term gains. We also have studies which show that secondary problems also can be prevented by intervention. For example, Northcott (1971) found that hearing impaired youngsters showed less excessive body contacts and other stereotypic behavior if they were placed in early intervention programs. In addition, Fraiberg (1977) in her monumental work with blind children found there were many successes to be attributable to early interventions with young blind children.
In the areas of infancy research, we know from longitudinal studies that the quality of transactions between the care-giver and the infant can facilitate or retard development. Such work comes from the studies of Thomas, Chess, and Birch (1968) and from Werner, Bierman, and French (1971). In sum, there is evidence that the environment is very influential to the behavior and development of young children with all types of special needs. As Hunt (1961) concludes, "a major share of early losses can be made up if the development-fostering quality of experience improves, and a great deal of early gain can be lost if the quality of experience depreciates."

In addition to the impact of early intervention programs, research studies provide strong support for maternal/parental involvements in programming. In most studies during the past decade maternal intelligence has been found to be the single best predictor of intellectual development in children. Studies show that the more one involves parents, the more gains are made by children. Thus, the thrust of many programs to educate and involve parents is a trend for the 1980's. Presently, there are more home-based programs available for young children from infancy to two years of age and more center-based programs available for the three to five year old.

In addition to the intervention studies, developmental research during the past ten years have shown the importance of the early years in the optimal development of a child. For example, White and his colleagues (1979) in the Harvard Preschool Project, through ecologically valid research methods, made observations of mothers and children in their home settings for the first three years of life. They found from this descriptive work that the basic development during this period was crucial in four areas: language, social attachment, learning to learn skills, and curiosity. White has concluded from his research that the eight to eighteen month period makes the crucial difference in a child's development, that performance and competence in an individual is basically developed by the age of three, and that there is little one can do after to undo the basic competence developed. For example, he found that well-developed three-year olds were twice as socially experienced as other three year olds. He attributed this development largely to the quality of the care-giver. He describes optimal parents as organizers and designers of the child's environment, disciplinarians who are capable of showing affection, and expert personal consultants to the child. It was the quality of the interaction with the child rather than the quantity that made the difference. Based on these results, the Brookline Public School System began a major intervention for all children who were born in the town of Brookline in the early 1970's. The data from this program, called the Brookline Early Education Program, is currently being analyzed.

Thus, all of this research points out that the earlier one intervenes and the more the family is involved in the intervention, the more the positive growth and developmental gains for the child. In fact, the evidence from experimental and developmental research studies is so overwhelming about the necessity of early intervention, it is sometimes surprising to me that more states and federal initiatives have not been
targeted on early programming for all young children. The main message is that one does not have to be skeptical anymore about the value of early intervention; the evidence is slowly mounting to support the efficiency of early programming with special needs children.

Next, I would like to discuss what states are doing to meet these unique preschool mandates. What are the characteristics of programs and services for young children? What are the trends across the country as states begin to implement these programs? What are the issues for the 1980's with respect to education for young handicapped children?

1. One trend I have seen across the country as states have struggled to implement these mandates for any preschool age is the increasing recognition by all involved that young children are indeed different from the school-aged population. This means that the services delivered to this population cannot essentially be tailored and modified after elementary services or those for secondary school children. Furthermore, the needs of children within the period from birth to five years of age vary widely. For example, programs for infants are quite different than programs for two year olds or programs for four to five year olds. Some states are beginning to recognize a need for a new set of regulations which focus on these early ages only. In other words, those regulations which have been developed for the school-aged population cannot be always directly applied to younger children. Examples of this come in the requirements for screening, assessment and individual education plans. Because these children are different and are not part of the traditional school structures, the outreach component of the regulation must often be changed. I feel that regulations should be written to specify that those involved in screening, assessment, and programs for this age group should have special training and experience with young children.

In addition, some states are considering legislation changes on issues like the definition of handicapped children and the levels of services included. For example, the categories developed for use with older children do not necessarily apply to this young age range. In many instances, it is not until a child is much older that a specific label or disability category can be assigned to a child. Thus, I support legislation which allows children in these earlier ages to be eligible for special education by being categorized as "under evaluation," "at risk," and "developmental delay."

States are also grappling with the issue of how many of these children they should expect to find for services. The problem of determining how many young children there are with a variety of handicaps is difficult for many of the reasons cited above relating to services. From experience in those states where there has been some work placed on locating or identifying the number of young handicapped children, it seems appropriate to assume that at least six percent of the age range from birth to five years would have a handicapping condition in some stage of development which would need some type of attention and special education services (Jacobs, 1979).
Another trend which is evident across the country is that collaboration at many levels must take place in order to effectively deliver comprehensive programming for the early age periods. No longer can schools or other institutions use the "ostrich" approach which simply means putting one's head in the sand and waiting for everyone else to do their thing. In many ways the old education and old health ways of doing business don't work anymore. The services which are necessary require active collaboration and multidisciplinary or transdisciplinary teaming. In other words, many professionals must be involved and must collaborate; however, this collaboration must involve the respect of others' perspectives and training as well as take account of the fact that each has an appropriate role in the early intervention process. Let me make it very clear that I support and see the need for collaboration, but only support collaboration which is on an equal basis with all parties involved. I further believe that equal basis collaboration should also involve equal pay for participation.

It is very clear in a state like Maryland that the schools are responsible for taking the lead to facilitate this collaboration. Thus, each district should have an early childhood educational specialist with enough time to administer and coordinate all collaborative efforts within a district and from the district out to community resources. This early childhood special educator should act as the leader and be the case coordinator/advocate for the child and the system.

Another type of collaboration which is growing across the country with the implementation of early childhood mandates is collaboration within the school system. For example, the health services, pupil personnel services, and special educational services should be administratively organized so that they can effectively work with each other within a school district. In addition, all of these services should be linked to compensatory education services which are also available for handicapped children.

Another type of collaboration is that among school districts. Models of this exist in the midwest through the intermediate school districts and through collaboratives in states like Massachusetts. In essence, these types of arrangements provide for shared programming and resources. They are especially good for rural areas where it is difficult for a school system to provide services for low incidence needs children. In some cases, the school collaborative will provide a classroom for hearing-impaired youngsters and/or will hire a physical therapist or a teacher for the visually impaired who will be shared by children in several districts.

Another type of collaboration which is growing is that between schools and other agencies. In order to collaborate with other community agencies, the school must know about the services and how to use them. Key elements in community collaboration are linkages between the schools and the public health department, through the Early Periodic Screening, Diagnosis and Treatment (EPSDT) Program; the public health nurses who hold well-child clinics and/or make visits to newborns and their families; Title V Crippled Children's Services; Developmental Disabilities activities;
Welfare and Social Security assistance; and/or other private or volunteer activities for handicapped children. Another possible collaborator in the community is Head Start which is mandated to include ten to thirteen percent handicapped children. Let me point out, however, that even though collaborative arrangements should be made with Head Start, these services should not be the only services for handicapped preschoolers available in a community. Another set of services with which collaboration should be sought is schools in the day care community, since day-care facilities offer many options for program placements as well as serve as a source of referrals and identification of children with problems. A new focus of collaboration for the 1980's, I believe, will be adolescent pregnancy programs since many of the mothers themselves as well as their children have special needs.

Finally, another area for collaboration is that with the individual providers in a community. These individual providers include physicians, psychologists, social workers, and all who contact children and their families. Usually the primary physician or a health provider at a health center is the best source of collaboration for referrals since the health care system in theory does contact most young children before they reach school age. However, I must emphasize again that this kind of collaboration should be kept on an equal basis or it is in fact not effective collaboration from the child's perspective. Finally, collaboration should occur during all steps in the early childhood intervention process (identification, screening, assessment, educational programming plans, and evaluation). Collaboration will help school systems to carry out the intent of the law and provide the most effective set of services for a child.

3. Another trend that I see across the country is cost-sharing and other arrangements being made at the state, local, and federal levels. For example, right now there are more than ten major pieces of legislation which affect children and their families (see Table 1). Agreements made at the state and federal levels facilitate collaboration at the local level. The basic problem today is “who is the payer of last resort?” In some instances, schools are mandated by P.L. 94-142 and state codes to do what other agencies and providers have also been mandated to do. However, it appears across the country that most of the other service agencies have been backing off and saying to schools, “it’s all yours,” when there are other sources of legislation and sources of funds which could cover some of the same services.

One example of a trend for the 1980's is that schools will become or consider becoming Medicaid vendors. If schools were allowed to become Medicaid vendors, portions of the costs for screening, assessment, and program treatments, such as speech and physical therapies, could be paid out of Medicaid for children who are eligible by the guidelines. Of course, there are many pros and cons concerning schools becoming Medicaid vendors. On the one hand, it would allow for more community-based and integrated services since the schools would be the site for many services. On the other hand, it raises the issue concerning what types of experts would be allowed to deliver these services in schools as well as issues
| A. | The Education of All Handicapped Children’s Act of 1975 (P.L. 94-142) |
| B. | Elementary and Secondary Education Act - Title I - Compensatory Education Programs |
| C. | Elementary and Secondary Education Act - Title VII - Bilingual Programs |
| D. | Social Security Act - Title XIX - Medicaid/EPsDT |
| E. | Social Security Act - Title V - Maternal and Child Health/Crippled Children’s Program |
| F. | Social Security Act - Title XVI - Supplemental Security Income (SSI) |
| G. | Social Security Act - Title XX - Aid to Families with Dependent Children (AFDC) |
| H. | Rehabilitation Act of 1973 - Section 504 |
| I. | Developmental Disabilities Act |
| J. | Head Start |
concerning the identification, and thus labeling, of children who are eligible for Medicaid through schools. School officials, of course, tell the local community that the services would be cheaper since the local property taxes would not be the source of payment for these mandated services; however, in the end, all taxpayers are involved with the payment of these services through Medicaid. In addition, private insurance premiums would probably also go up if Medicaid became available through schools.

Thus, the wave of the future is towards more and more cost-sharing and other arrangements among policy-makers who implement legislation and the institutions which deliver services to these children. Even though the overall amount of dollars available for these services is not nearly what it should be, given the legislative mandates, schools in fact probably have more resources for collecting payment for some services than many are currently aware of.

4. Another trend of the future concerns changes in training and credentialing of all professionals dealing with children. I feel that anyone involved in delivering early childhood special education services needs specialized training both in special education and in early childhood. This means that any other professionals who would be dealing with this particular area of services, whether it be the pediatricians, nurses or teachers, are going to need some kind of specialized training in these two fields. Professionals who have worked with normal children exclusively, or who have worked with older children, cannot automatically extend those credentials into this new area. Therefore, I think that schools must hire experts with the appropriate skills to deliver these services and that state regulations for personnel should reflect this trend.

In addition, there needs to be technical assistance and training available to providers in this field throughout the states in the country. Massachusetts has a model program for delivering such services through the Early Childhood Project which deserves consideration. In this model an early childhood specialist is hired for each of the six educational regions across the state to provide technical assistance and training to any school system in the region which needs and requests special help in the early childhood area.

Another area in which all professionals are going to need extra training concerns the involvement with families, family counseling, and family systems. Today none of the professionals, with the exception of specially trained family therapists who are working in the field, have training and expertise for interacting with families.

The issues surrounding training and credentialing will intensify during the 1980's since there will be a relatively larger group of professionals working with fewer children. At the present time there are big battles between the various professions about who should be delivering these services. In the 1980's I feel these battles will accelerate into an all-out war.
5. Another trend in special early childhood programming across the country concerns the inclusion of parents and family involvement in programming. This is a positive step and consistent with the research literature as suggested before; it should be encouraged at all levels. Since the parent is the child's number one educator and consultant, it makes sense that parents be involved from the very beginning in their children's education. In fact, I think the screening process or any contact with the parent is a way of educating the parent about the system in which the child will be and how to be an advocate for his or her own child in that system. Often that is more important than the results of the screening or assessment itself. It is also clear that programs should involve parents and families since the home is the most natural environment for the child. Thus, programming which involves parents and families is ecologically valid in Bronfenbrenner's terms (Bronfenbrenner, 1979).

6. Another trend for the 1980's is that programs will be more and more community-based. In addition to community-based programs having ecological integrity, they meet the requirements of the mandates that children be placed in the least restrictive environment. Remember, however, that the program for the child is the best program for the child's needs and not necessarily the best existing program available.

7. Another feature of the early childhood program efforts across the country is their wide variability and flexibility. There is no one model program that is good for all children at any one age or any one type of disability. Programming should be tailored to an individual child's needs; and will thus vary according to the type of child, the locality, the dollars available, and the various professionals involved. For example, a cerebral palsied child might be involved in a program which is center-based, has a physical therapist home visitor, and/or provides some kind of psychological counseling. Model programs which have become available through the resources of the Handicapped Children's Early Education Project during the last ten years are available throughout the country.

8. Another trend which I see evolving in the 1980's is the realization that advertising and outreach to providers of services as well as to parents are needed in every community. For example, in our study of child health services in Flint, Michigan, where we surveyed primary care physicians and early childhood educators about their knowledge of special education mandates, Jacobs (1979) found that, even though Michigan had had a special education mandate for service from birth on since 1971, both sets of professionals were indeed ignorant about the law and what services were available in the community. More specifically, we found that 31% of the primary care physicians (N = 51) knew about P.L. 94-142 as compared to 65% of the early childhood educators (N = 71); with reference to the state mandate which had been around longer, we found that 56% of the primary care physicians and 74% of the early childhood educators in 1978 had heard of this state mandate. With respect to the state mandate's applicability to preschoolers, we found that only 37% of the primary care physicians and 48% of the other childhood educators knew of this provision. Finally, only 11%
of the primary care physicians and 18% of early childhood educators knew about Child Find. Similarly, there was low acknowledgment of Crippled Children's Services, the Women Infant and Children program, EPSDT, Protective Services, and the Intermediate School District's special programs (Gortmaher et al., 1980). This has shown our group of researchers that there is a great deal that must be done to inform providers in the various sectors about services available. One cannot assume that a provider of children's services in one sector knows about services in other sectors. In-depth knowledge of services at a community level is necessary for comprehensive programming. Interagency councils or similar mechanisms at the local level might be formed to facilitate this type of programming or networking.

In summary, I see several trends which are evolving and will become more prominent in the 1980's concerning early childhood special education programs. (1) States will recognize that early childhood education is a special field and that various regulations and programs must be uniquely provided for this age period; (2) Collaboration at all levels within school systems and districts and with other community agencies will be necessary for providing comprehensive services; (3) Cost-sharing and other arrangements at the state, local, and federal level will also be needed; (4) Issues in training and credentialing will accentuate during the next decade as more and more professionals become involved with serving this young age period; (5) Parent and family involvement is a must and has been proved effective; (6) Community-based services will also be more prominent as communities strive to be in compliance with the intent of the various deinstitutionalization laws; (7) Variety and flexibility will categorize program efforts; and (8) Outreach and advertising to providers as well as to parents is necessary.

Finally, the task of the 1980's is the implementation of the knowledge we already have into programs for young handicapped children in all the states across the country. Although the knowledge-base available is clear and supportive of special education legislation, it is apparent to me that strong advocacy efforts are going to be needed from all of us in order to accomplish the actual delivery of effective programming for this age range in today's society. The costs of preventing future societal problems via these program efforts are indeed cheap when compared to the cost of an MX missile system or the other defense expenditures we are now considering which in fact we do not need. I hope advocates for children in the 1980's will work hard to insure that our number one resource—the young children of this country—receive the quality services they deserve and they need. I wish you good luck as you embark upon this challenge of delivering full programming for the young handicapped children during this month. I look forward in the future to watching your state as it progresses in implementing this mandate. Thank you.
References


