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ABSTRACT

Presented in the monograph are current or proposed methods for screening and assessing children, from birth to 5 years of age, who have diverse developmental disorders or who are at risk, and whose mental and physical development will benefit from early identification and intervention. Considered in relation to general screening are a screening analogy; physical, environmental, and cultural factors; at risk registers and populations; and societal, ethnic, ethical, and legal aspects. Described are the physical factors involved in streamlining physical examinations and laboratory procedures, genetics and amniocentesis, biochemical and metabolic indicators, nutrition, gestational age, at risk indicators, vision screening, hearing, neurological screening, and abused or battered children. Examined among intellectual and cognitive factors are the infant's attention to discrepancies, ordinal scales of cognitive development, and aspects of assessing infants' intelligence and predicting later cognitive development. Language factors discussed include receptive language development, diagnostic significance of an infant's cry, expressive development, language tests and scales, and interdisciplinary screening. Examined among social and emotional factors are mother-infant attachment dynamics, social adaptation ratings, childhood psychosis prediction, and functional analysis for intervention. Some of the comprehensive developmental screening systems described involve early identification and intervention, screening as part of a total service system, multifactorial preschool development screening, and manpower consideration. (MC)

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SCREENING

and **Assessment**

of Young Children at Developmental Risk

THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION



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SCREENING AND ASSESSMENT OF YOUNG CHILDREN
AT DEVELOPMENTAL RISK

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THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

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The Boston screening conference represented the combined efforts of many agencies of the Department of Health, Education, and Welfare and numerous individuals who were concerned with the needs of children at risk of being developmentally delayed. Mrs. Jeannette Rockefeller, a co-chairperson of the conference, led the PCMR work group which, for more than two years, pursued the topic of the specific needs of children. She was joined before and during the conference by Dr. Julius Richmond who shared the conference chair with her. Technical and financial assistance were provided by the National Institute of Child Health and Human Development, Office of Child Development, Health Services and Mental Health Administration, and the Social and Rehabilitation Service. Without them the conference would not have materialized.

The staff of PCMR, under the original direction of the now retired Executive Director, Dr. Joseph Douglass, and later under the direction of the current Acting Executive Director, Mr. Fred Krause, with the assistance of Mr. Ray Nathan on public information and Messrs. Stanley Phillips and Tadashi Mayeda, as government and consulting project officers, all, in some way, contributed to this monograph.

Despite the assistance available to the writer, all opinions expressed herein are either the writer's or those he has selected and should not be construed as those of the conference participants or the sponsoring agencies. Wherever possible, the sources of opinions are cited in customary fashion, however, the writer recognizes that many of his ideas and opinions are the result of being immersed in an intellectually rich milieu and that some sources may inadvertently go unacknowledged.

The writer gratefully acknowledges the secretarial assistance of Ms. Opal Every, the arts and graphics of Mr. William Borthick, and the support and interest of the many unnamed persons who shared their time so that this monograph might help children and families less fortunate than they.

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SCREENING AND ASSESSMENT OF YOUNG CHILDREN
AT DEVELOPMENTAL RISK

Introduction and Sources

This monograph presents the current thinking about and assembles the current operational or proposed methods and materials for the early screening and assessment of young children who either already have various developmental disorders or are at considerable risk of later having them. It organizes and annotates the available relevant literature reporting sundry related but hitherto isolated studies, which in some cases represent quite elaborate and even some elegant efforts. It is virtually an impossible task to categorize neatly and consistently all that currently exists. Nevertheless, in order to establish at least a point of departure for subsequent more comprehensive and sophisticated endeavors, and also to prevent any unnecessary duplication of efforts, a compendium of what has been done is exigent.

To gain some perspective on the state of the art of early screening and assessment of children at developmental risk, a rather general inquiry was sent to a number of the brightest stars in the constellation of early childhood service, training, and research, particularly those involved in the assessment of growth and development in infants and young children. Of the many who were called upon, a few chose to ignore the request, some responded that they did not have anything substantive to contribute at the time and many others sent generous packages of reprints and related information, much of which was either abstracted or quoted from in the working conference draft.

Due to this writer's behavioral science orientation, there is an inevitable, yet acknowledged, selection bias which happily was at least partially counteracted by a sort of chain-letter effect cause by one researcher's notifying another or citing a colleague's work germane to the monograph's topic.

Moreover, a diligent pursuit of promising titles found in the references included with the materials received¹, plus the references retrieved in three computerized literature searches¹ and in a careful perusal of current Psychological and Biological Abstracts hopefully provided a balanced and representative (but admittedly by no means exhaustive) coverage. When the same references began to recur through progressive pursuit of additional supporting materials, it was deemed that the point of diminishing returns had been reached and the time was at hand for collating and synthesizing a rather ungainly body of embryonic knowledge and procedures.

¹A MEDLINE preliminary search and a MEDLARS subsequent more detailed search of over one million citations on file at the National Library of Medicine yielded 91 very helpful references; also, a U.S. Office of Education search of recent educational research yielded 257 abstracts regarding screening and assessment of young children.

An additional series of inputs emerged from many of the knowledgeable participants in a national conference² on early screening and assessment who discussed and critiqued the monograph during the conference and contributed many helpful suggestions for its improvement afterwards.

²This co-sponsored (see Acknowledgements) conference on early screening and assessment was held at the Boston Children's Hospital UAF (with the cooperation of Dr. Allen Crocker and his able staff) during October of 1972 and was co-chaired by Mrs. Jeannette Rockefeller and Dr. Julius Richmond. It was attended by more than one hundred carefully selected international participants who were either on the cutting edge of knowledge regarding early screening and assessment or representing agencies with an inherent interest in the topic. The Conference Proceedings is a separate publication available from the President's Committee on Mental Retardation, 7th and D Streets, S.W., Washington, D.C. 20201.

Purpose

The purpose of this state-of-the-art monograph was originally to establish a common and substantive basis of discussion for participants in the aforementioned national conference which addressed the feasibility, design, and implementation of a massive screening and assessment system to detect infants and children at risk of being or becoming developmentally disabled while they are very young and presumably most amenable to treatment and habilitation. It is clear that significant advances have been made beyond both the Procrustean notion of making all individuals fit a predetermined mold, regardless of individual differences, and the Spartan notion of gross screening by throwing infants into cold water and keeping only those who could save themselves. This monograph is concerned with the reverse side of the coin, that is, with the early identification of those individuals who are likely to sink at a time when they can be either taught to swim in our complex world or properly protected from the fatal and total immersing and at least enable them to crawl, walk, or run on land.

Such a massive screening program promises to reveal those factors which contribute to developmental risks in varying degrees and thereby to allow for such factors to be weighted in terms of their relative contribution to handicapping conditions. This in turn will facilitate the prevention of more serious disabilities which reportedly can be attenuated by early detection and appropriate intervention.

Also, the results from such massive screening and assessment procedures systematically applied to a representative sample of the population will help to document the prevalence of various incipient and full-fledged developmental disabilities. Such information is needed to calculate the cost/benefit estimates for large scale prevention and intervention programs, that is after sufficient time has passed to allow pilot programs to be designed, to be debugged, to take full effect, and to demonstrate the holding power of the respective prevention/intervention techniques. The analysis of data from pilot efforts at massive screening and assessment is most instructive in terms of potential money and manpower costs of fully implementing, or at least expanding in scope, the national programs serving developmentally disabled children. These programs include:

1. the 1967 Amendments to Title XIX of the Social Security Act, which are currently permissive but will soon mandate early and periodic screening, diagnosis, and treatment of all eligible Medicaid individuals under age 21 -

With respect to the early and periodic screening and diagnosis of eligible individuals under 21 years of age and treatment of conditions found, as specified in 45 CFR 249.10(b)(4)(ii), the State agency will:

1. establish administrative mechanisms to identify available screening and diagnostic facilities, to assure that eligible individuals under 21 years of age may receive the services of such facilities, and to make available such services as may be included under the State plan;
2. identify those eligible individuals in need of medical or remedial care and services furnished through title V grantees, and

assure that they are informed of the services and referred to such grantees for care and services, as appropriate;

3. enter into agreements to assure maximum utilization of existing screening, diagnostic and treatment services provided by other appropriate public and voluntary agencies;

4. make available to all eligible individuals under 21 early and periodic screening and diagnosis to ascertain physical and mental defects, and treatment of conditions discovered within the limits of this State plan on amount, duration and type of care and services; and will make available, in addition to glasses, hearing aids, and other kinds of treatment for visual and hearing defects, and at least such dental care as is necessary for relief of pain and infection and for restoration of teeth and maintenance of dental health, whether or not such additional treatment is included under this plan, subject to any utilization controls imposed by the State agency.

Such screening, diagnosis and additional treatment will be made available to all eligible individuals under 21 years of age by the effective date of 45 CFR 249.10(a)(3): February 7, 1972.

Such screening, diagnosis and additional treatment will be made available to all eligible children under 6 years of age by the effective date of 45 CFR 249.10(a)(3): February 7, 1972, and progressively to all other eligible individuals under 21 years of age by July 1, 1973...(SRS, 1971).

2. The OEO- and OCD-sponsored Parent-Child Centers, Head Start, Health Start, and Home Start programs;

3. The 1970 Developmental Disabilities Act (PL 91-517);

4. Some version of an approved welfare reform which will undoubtedly include provisions for numerous day care centers; and

5. Community mental health and mental retardation centers.

Definition

This monograph does not restrict itself to early identification methods and materials pertaining to developmentally disabled children only as they are defined by the Developmental Disabilities Act, namely:

As any person who has mental retardation, cerebral palsy, epilepsy, or other neurologically-based conditions related to mental retardation, which are of an enduring nature and have their onset before age 18 (PL 91-517).

The preceding definition, although a step in the right direction from the narrower organically-caused mental retardation, is thought to be a relatively narrow definition of developmental disorders in childhood; it still implies, or at least those who interpret it typically infer, some organic condition of at least a subclinical nature as the etiological explanation of the malfunction or maldevelopment. The operational definition of developmental disabilities for this monograph includes those conditions mentioned in the preceding definition plus any other conditions which are likely to prevent a child from achieving optimum growth and development in any of the social, emotional, intellectual, linguistic, or physical realms considered singly or in combination. This broader definition therefore includes those children who predictably will function at a less than normal developmental level due to various inborn and/or environmental deficiencies of such things as adequate nutrition, intellectual stimulation, language models, or emotional and social experiences. Such an operational definition is far more inclusive, encompassing all organic and functional forms of developmental disabilities or other related deviations from normal development. The term young, for purposes of this monograph, refers to conception through five years of age with an emphasis on infants and toddlers. The words screening and assessment will become more clearly defined in subsequent sections.

Format

This monograph makes very extensive use of generous quotations from the literature rather than attempting to paraphrase and thereby do additional violence to the authors' original intent, which inevitably suffers some distortion by being quoted out of its total context. Moreover, this document describing the state of the art makes no claim to originality, except perhaps the effort to "get it all together" for the conference participants to review and discuss. An attempt has been made to reduce the redundancy to a minimum except where a point warrants repetition from more than one perspective. Many of the more generic articles and even some of the highly esoteric articles have a common rationale and the repeated emphasis of the importance of early screening becomes very compelling to this writer; however, in attempting to assemble coherent and representative statements from a vast variety of sources, much of the repetition has been deleted, which, it is hoped, does not dilute the urgency and importance of the topic.

The format for the remaining sections breaks the screening procedure into four major categories, namely those dealing with physical factors, intellectual-cognitive factors, language factors, and social-emotional factors. After these somewhat delimited areas are dealt with, several

existing or proposed more comprehensive screening and assessment systems are described. The corpus of the monograph closes with several state-of-the-art observations. The references cited follow. A reasonably complete bibliography for the past five years, which includes a wide variety of articles not listed in the references but germane to early screening and assessment of children at developmental risk, is included at the end.

CHAPTER II

GENERAL SCREENING CONSIDERATIONS

A Screening Analogy

One of the primary concerns is the yield factor in a massive screening system. An analogy might be to some sort of size-sorting equipment comprised of several sieves or screens with progressively finer mesh (Figure 1). If, for example, oranges are being sorted according to size, a gross screening can be done by one screen (a) which prevents only the grossly oversize oranges from passing through. These extraordinarily large and relatively rare oranges can then be subjected to careful analysis (diagnosis) in terms of the causes and prevention of their oversizeness, assuming that they are undesirable for marketing, packaging, and other reasons. If there are some oranges which are too small to easily market, package, handle, etc., they too can be screened out by a second screen (b) through which only the too-small ones can pass. This leaves the "normal" oranges in the middle zone; this can be defined as narrowly or broadly as the size of the mesh in the two screens. Conversely, the yield of "abnormal" can be systematically controlled by the range defined as normal. If some normal-sized oranges fail to pass through screen (a) because they never get centered over one of the holes, or for other screening system failures, they would be false positives, i.e., erroneously screened out as abnormal; if some too-large oranges are inappropriately forced through screen (a), they would be false negatives, i.e., erroneously allowed to pass as normal in spite of abnormality. It is important to maximize the efficiency of a massive screening system by establishing relatively quick and simple procedures to be carried out with large numbers of oranges in order to sort out the grossly abnormal from the normal at Stage I with provisions for successive and more refined stages of screening, assessment, and differential diagnosis of both the grossly abnormal and the borderline cases.

If the price of acceptable oranges is a function of their size, additional cascaded screens can be used for the normal range to sort the variously-priced ones into extra-large, large, medium, and small. Of course there may be numerous other standard characteristics against which any given orange must be assessed, such as juiciness, sweetness, resistance to bruising, color, thickness of skin, peeling ease, general aesthetic appearance, etc. Some of these characteristics are more difficult to mechanically screen and assess than others, thus requiring the informed, relatively subjective assessment of trained interpreters to differentiate and classify them.

Prior Focus on Physical Factors

Such a simplistic analogy obviously limps compared to the enormous complexity of a society's classifying human beings into various qualitative and quantitative categories in accordance with ability and disability characteristics. Although this monograph adds several foci to developmental disabilities, each of which seems to complicate early screening by several orders of magnitude, the extant literature tended to focus on physical factors and the medical model. The role of the physician and medical model are certainly acknowledged and this section reveals their importance.

Recent research in both the biomedical and behavioral sciences emphasizes that the process of intellectual and physical development

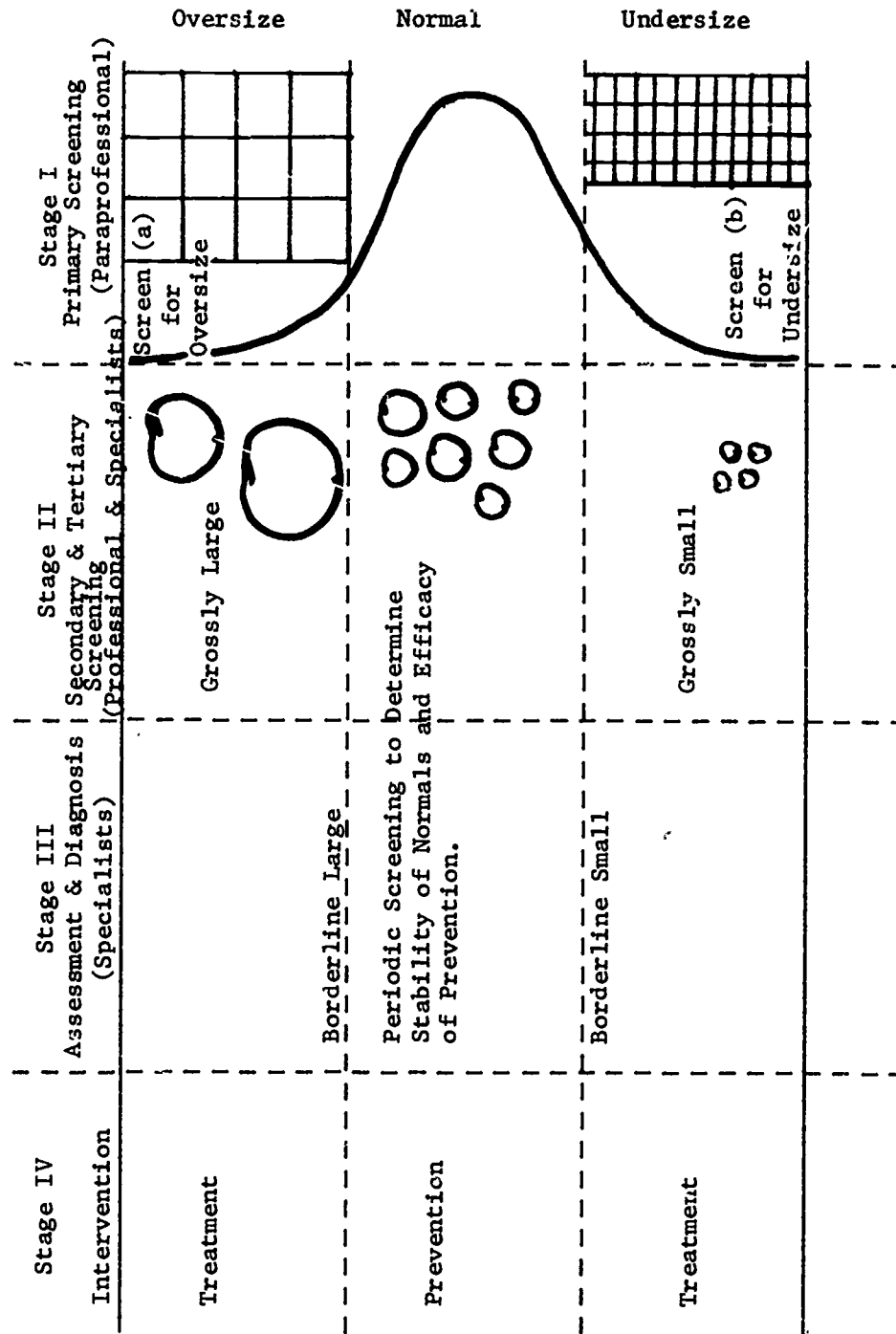


Figure 1: Hypothetical Sorting Model from Primary Screening through Intervention.

begins very early in the life of an infant and proceeds with great rapidity during the first five years. During those years the child is highly susceptible to developmental deficits resulting from detrimental hereditary or environmental factors. Yet, paradoxically, during this same period, society's capacity for identifying and treating developmental disorders is at its weakest.

Parental initiative and the awareness of the family pediatrician play a large part in present day, preschool evaluations of children. However, many children--particularly children from deprived families--have little or no access to medical, educational, and social services during these critical years. Even the best intentioned parents sometimes ignore early signs of deficiency with the pious hope that the child is merely a slow developer and that school experiences will compensate for any early limitations. In addition, the pediatrician no longer serves as the family doctor caring for and advising on all aspects of family and child health. As a result, he sometimes overlooks the possibility that an indepth evaluation by professionals in a field other than medicine can have a beneficial effect on the growth and development of the child.

In 1968, according to Bureau of the Census estimates, there were 18.5 million preschoolers in the nation. Approximately 3 million children were enrolled in kindergarten classes and other types of preschool programs.

It has been estimated that approximately 5.5 million children presently are in need of preschool programs. Of these children 2 to 3 million suffer from severe malnutrition. In New York City alone, of the well over 100,000 children who need day care services, only 8,500 presently participate in organized programs.

Thus, it is clear that many preschool youngsters--particularly in high-risk low-income neighborhoods--have little access to health and social services where early developmental disorders could be identified and treated. In addition, many existing service facilities are not organized to provide for efficient and comprehensive identification of early childhood problems. As a result, too many children with disabling conditions are not identified early enough to maximize the chances of successful intervention (Gettings and Mayeda, 1970, pp. 2-3).

Although it is true, as pointed out above, that the family physician can no longer pretend to be all things to all people, the crucial responsibility of the physician in early identification of children at developmental risk is described by Boelsche (1969):

Early Identification: Early identification of most conditions in medicine is essential for successful management, and mental retardation is no exception. At present it is the teacher who suspects mild retardation when there is learning difficulty, and identification is made sometime during the first three years of school. Perhaps if formal education began early in infancy it would be the duty of the educator to identify and establish whether or not a child is retarded. However, the physician is the professional person who has early contact with the

child and therefore has the obligation to identify these children. In addition, he has the skills to make this diagnosis. In the majority of cases he will not have the answers and the responsibility to the total treatment program, but again he must assume the responsibility to guide the family to the right professionals, to participate in the overall management, and to remain as the medical advisor. He should also support broad programs designed to alleviate conditions which cause deprivation in early childhood since this is the primary cause of retardation.

Environmental deprivation may cause cerebral dysfunction which is indistinguishable from the organic types. Even the motor involvement (cerebral palsy) will occur if, in early infancy, the child is not allowed to move around and his motor functions are thereby curtailed and not stimulated. Development is not a simple unfolding of more complicated behavior from infancy to maturity, but a process of learning and interaction (pp. 43-44).

Besides giving a number of helpful and practical suggestions and making several meaningful observations about various developmental deviations, Boelsche casts a supporting vote for routine developmental screening as a precursor to differential diagnosis.

For more formal testing of the development in infancy, there are several rather new tests available. The Denver Developmental Screening Test is an example of an excellent, well standardized measuring device. It is easily administered by a physician, nurse, educator, office assistant, or volunteer.

The differential diagnosis of these conditions may be summarized as follows: The history of a progressive central nervous system condition reveals a period of normal growth and development followed by a plateau and then a downward course. In infants and young children the downhill course is fairly rapid and therefore easy to recognize. Space occupying lesions are more variable, but also show the progressive signs (p. 47).

In recognition of the aforementioned concerns and in an effort to bring together several representative investigators interested in resolving some of the related problems, a Bi-Regional Institute on Earlier Recognition of Handicapping Conditions in Childhood was held in the Spring of 1970 at the University of California Berkeley Campus, co-sponsored by the School of Public Health and the Maternal and Child Health Services, U.S. Department of Health, Education, and Welfare. Guests invited included State Directors of Maternal and Child Health Services and Crippled Children's Services of the fourteen western states, representatives of the MCH Regional Offices in Denver and San Francisco, and representatives from local health departments and many clinical programs sponsored by MCH.

The Institute generated several papers which were presented, discussed, and subsequently issued in a book of proceedings edited by Oglesby and Sterling (1970). This Institute addressed a wide range of issues including screening for very rare physical conditions, computer-assisted diagnostic procedures, biochemical screening programs and problems, preventive techniques

for handicapping conditions such as mental retardation, high risk registers, early identification of behavior and learning disorders, related problems found in the culture of poverty, delivery of health services to children in rural and urban areas, and the evaluation of screening procedures.

During the past two decades, the practice of pediatrics has undergone a dramatic change. Today there is little argument regarding the right of all people to first-class medical care. This philosophy has been translated into many new federal health programs and together with the population explosion has resulted in more people seeking medical care. Many of these programs are aimed directly at a part of the population that has a high incidence of health problems and that has had few health resources available to it. The present proliferation of private health insurance plans and the probable government health plans will increase demands for health services from the already overburdened health system.

Another evolutionary change in health care is revealed by the shifts of focus from diagnosis and treatment of disease to earlier recognition and prevention of illness, or maintenance of health. Early recognition of disease is important because early intervention and treatment are often more effective than intervention after the disease has produced symptoms. Though this premise pertaining to early treatment is well substantiated in conditions such as amblyopia, congenital cretinism, and phenylketonuria, it is less well established for other disease states.

Screening for asymptomatic disease has come to the forefront as part of the general system of delivering health care to large populations in the most economical manner. Screening tests and procedures are intended to serve as tools that can be applied rapidly and economically to large population groups to identify the asymptomatic individual who has a high probability of harboring disease. Screening tests are not intended to make diagnoses nor are they intended as substitutes for complete health appraisals; instead they are intended as a method of surveying a large population of asymptomatic individuals in order to identify those individuals who have high probability of harboring the particular disease under study. Thus, the screening test makes it possible to concentrate the use of more elaborate and expensive diagnostic procedures upon those individuals who are most likely to have the disease (Frankenburg in Oglesby and Sterling, 1970, p. 42).

This same organically-oriented chapter, which is focused upon the evaluation of screening procedures, concludes with a statement which seems applicable to all screening endeavors:

Mass screening programs effect large masses of people and, therefore, should not be taken lightly. Screening is no panacea for good health. Rather it is a means toward an end. Before making decisions about which disease to screen for and which screening procedures to employ, one should review the available data pertaining to disease prevalence, to prognosis with and without treatment, and to the accuracy of the screening procedures. Full information about the outcome

of full-blown disease often is available; data pertaining to the outcome of pre-disease states with and without treatment are sparse. It is, therefore, of utmost importance that individuals who embark upon screening programs maintain complete records, not only of screening results, but also of results of early treatment efforts. It is only through collection of this type of data that one can establish the place of screening in a health maintenance program (p. 51).

Emergence of Environmental and Cultural Factors

As indicated earlier in the section on Definition, this monograph is not concerned exclusively with developmental disorders of organic etiology but is also concerned with the frequently more elusive environmental causes of developmental disorders and their subsequent manifestations in such conditions as behavioral and learning disabilities.

In more than 22 years of work with learning and behaviorally disabled children, I have found that the one factor which has appeared to be of central importance, but which seemed very elusive, was the question of early detection and early remediation. As knowledge of special education and remedial training progressed, the age at which remediation was begun has continually been lowered. Readiness for academic work was started within the Head Start Program and was extended to those experimental programs by Bereiter, Engelmann, and Moore in which 2-year-olds and 3-year-olds were taught to read, write, and do mathematics. There was a feeling, however, that the first two years of life were more important in the formation of learning and cognitive patterns than had ever been thought possible. It is now generally accepted that learning patterns are set by two years of age and cognitive patterns by age four. How can we afford to waste these precious years? What are the learning tasks that the infant must master during the first year of life if he is not to become a learning disabled child? The determinants of his development are: (1) his innate characteristics; (2) the characteristics of the environment with which he must interact; and (3) the interaction with his mother or mother surrogate and all the environmental, emotional, and physical stimuli that this implies (Dubnoff, in Oglesby and Sterling, 1970, p. 131).

With regard to the untoward developmental affects of the culture of poverty, Richmond has stated:

A critical evaluation of our infant health data leads us to the conclusion that we can provide infant care comparable in quality to other countries. The data suggest that further improvement in our national ranking will depend on creating a favorable prenatal and infant care environment for the low income non-white population.

Although the figures become vaguer and less easily definable, it should be obvious that with the higher level of perinatal mortality goes a higher degree of morbidity and one can safely assume that the long-term effects of perinatal morbidity, though not precisely documented, must be taking a considerable toll in human potential on the survivors (1970, p. 142).

Another long-time luminary in the field of research into handicapping conditions in childhood corroborates the above.

It appears that the non-white infant is subject to an excessive continuum of risk reflected at its extremes by perinatal, neonatal, and infant deaths, and in the survivors by reducing functional potential (Birch, in Oglesby and Sterling, 1970, p. 142).

The practically overwhelming magnitude of the societal/environmental determinants of developmental disabilities, which has been acknowledged for years and attacked by various semi-palliative attacks (wars) on poverty, is grimly detailed by Aldrich and Wedgewood:

1. Approximately 30,000,000 to 50,000,000 Americans are poor; and, of these, 40% are children. Half of the 200,000,000 people in the United States are under 25 years old and the trend of falling median age is continuing. The median age for whites has moved since 1955 from 31 years to 25 years and for non-whites from 29 years to 22 years.
2. The major crisis facing this increasing population of people under 25 years of age is urbanization. Two-thirds of the young people under 20 years old live in or near metropolitan areas. Metropolitan areas cover only 1% of the land area but contain 64% of the total population. Almost 90% of our land is still classified as rural. In 1920, the United States' population was evenly distributed between urban and rural areas; but it is estimated that, within 30 years, 90% of our population will live in three major urban centers on less than 2% of the land mass.
3. 60% of urban white children live in suburbs. 90% of non-white children live in the urban ghettos of the central cities.
4. Of the poor in this country, 70% are white; 45% live in rural areas; and 25% are old. It is easy to extrapolate that the non-white poor live in the urban ghettos of the central cities.
5. Large families by definition contain four or more children and constitute 11% of all families. Yet, this group contains 25,000,000 children, 39% of the child population. 7,000,000 children live in families with six or more children. Large families of non-whites are twice as numerous as large white families, 19% compared with 10%. The proportion of non-white families with six or more children is three times as great, 7% compared with 2%. Considering family size and income, 15,000,000 children in the United States of America live in abject poverty. This figure includes 9,000,000 poor white children, who comprise only 15% of the total white child population, and 6,000,000 non-white children who comprise 60% of the total non-white child population.
6. Groups other than the large family and the non-white family that are poor are farm families and families headed by women.
7. The number of babies of teenagers and unmarried mothers is increasing. A grim example: 60% of the girls enrolled as freshman in one urban ghetto high school drop out before graduation because of pregnancy (1969, pp. 142-3).

Perhaps the best brief and yet comprehensive article on the subject of early recognition of handicapping disorders in childhood was developed by Rogers (1971), who writes from the more socialized perspective characteristic

in England. A summary of the article is as follows:

Theoretical and practical aspects of the early recognition of the handicapping disorders in young children are reviewed.

In Part I, the rationale of early identification and its context within child health as a whole are considered and a distinction is made between the concept of the child 'at risk' and that of risk registers.

In Part II, a practical scheme for early identification is outlined and represented diagrammatically. Problems concerned with coordination of services and availability of trained personnel are discussed briefly (p. 99). See Figure 2/1.

Some rather subtle distinctions are raised by Rogers.

Screening tests in Early Detection: Early detection procedures are commonly referred to as 'screening tests' for handicaps (Egan, et al., 1969, Sheridan 1969b), implying simple and reliable techniques applied routinely to large numbers of children. Unless it is remembered how much more complex and sophisticated than this the concept of medical screening has become (Nuffield Hospitals Trust 1968), misunderstandings will occur between child health and social medicine, and the essentially clinical nature of developmental assessment may be overlooked.

Early detection and medical screening share important general principles:

- (a) The procedures must be effective.
- (b) It must make better use of resources than available alternatives.
- (c) Those providing the service take the initiative in contacting and examining the individuals concerned.
- (d) Affected persons so identified will derive benefit from subsequent treatment and care.

(a) Characteristics of Test Procedure.

Screening--simple, quick: capable of 'pass or fail' interpretation; applied once to each subject (to minimise non-co-operation); evaluated in terms of sensitivity (minimising false negatives); specificity (minimising false positives), and repeatability.

Early detection--a clinical procedure to which 'pass or fail' interpretation should not be applied; repeated examinations essential; not amenable to detailed quantitative evaluation.

(b) Personnel Administering Test.

Screening--suitable training in procedure, but no previous clinical (or even medical) experience necessary or even desirable.

Early detection--developmental assessments should, in the present state of dissemination of knowledge in this field, only be performed by a doctor with suitable training and experience (Sheridan, 1962, 1967; Koupernik, 1968, 1969; Illingworth, 1970).

Attempts to apply such concepts of screening in detail to early detection of developmental delay--such as developmental assessment by health visitors (O'Donovan and Moncrieff 1967) and the Denver Developmental Screening Test (Frankenburg and Dodds 1967, Frankenburg 1969) must be regarded as controversial (Sheridan 1967; Koupernik 1968, 1969; Holt 1969).

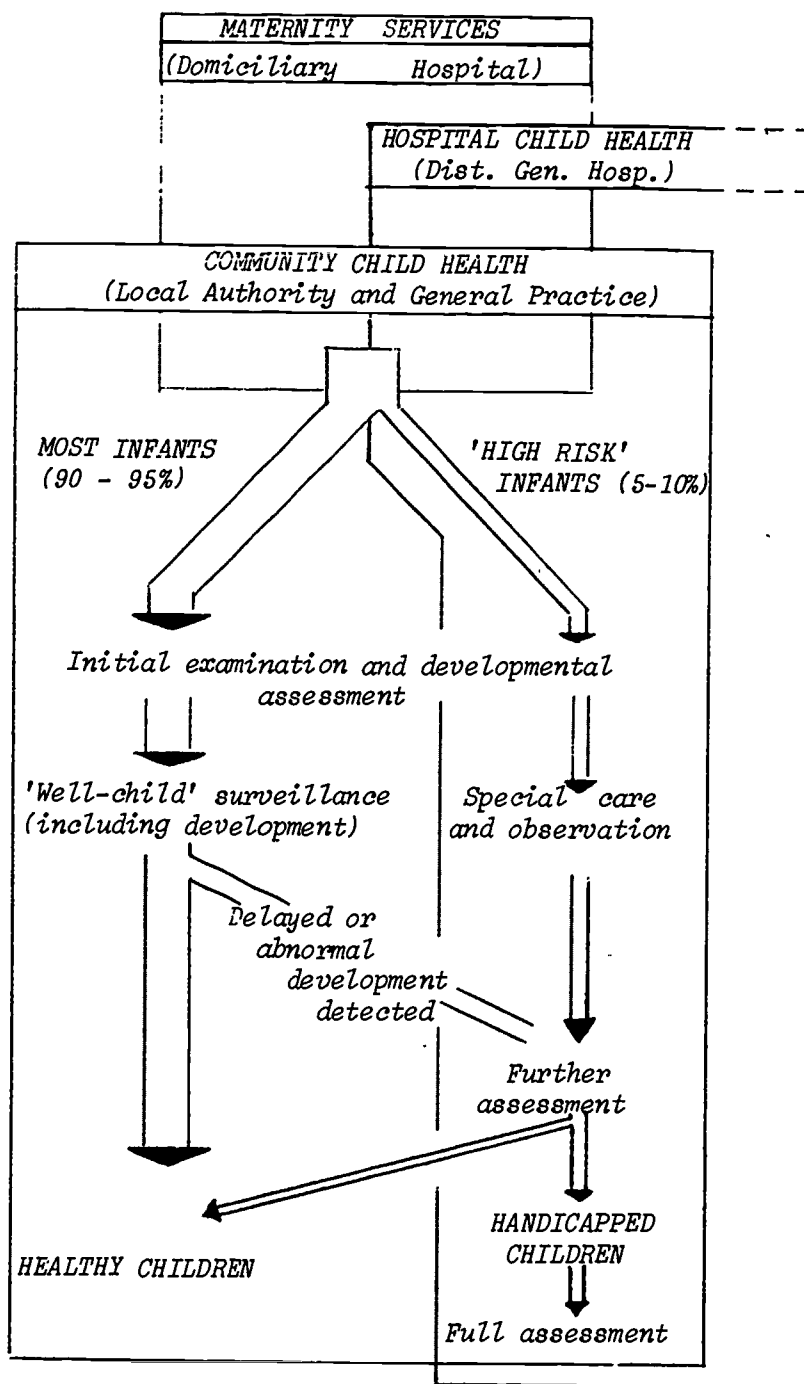


Figure 2/1: Early recognition of handicapping conditions. 'Areas of responsibility' of the various services are represented. Overlap of these areas indicates combined responsibility, and implies co-ordination of services, and flow of information (Rogers, 1971, p. 95).

Specific test procedures for detecting sensory disorders have more commonly been assigned to health visitors and other workers. Those who have devised these tests, however, have themselves emphasized the clinical nature of such procedures. (Fisch 1957; Sheridan 1958, 1969a; see also Holt 1966). The subtleties of test interpretation are little appreciated (Fisch 1967, Martin 1969, Murphy 1969), and there are grounds for concern that so much reliance has been placed on, for example, the screening of hearing by health visitors. If ancillary staff are employed in this way, standards of training and of medical supervision during testing must be more exacting than usually they are at present (pp. 91-92).

Conclusions: A number of conclusions may be drawn from the foregoing discussion to carry over into more practical considerations.

1. Early identification can be regarded as a sound, if as yet unproven, basis for the management of childhood handicap.
 2. It is extremely important that the search for a delay in development among normal children is seen as a part of a larger 'well-child' orientation to community child health.
 3. Satisfactory techniques for developmental assessment now exist. Training in developmental medicine, both at undergraduate and postgraduate level, is as yet inadequate to meet the demand.
 4. Because it is now common to refer to developmental 'screening,' it does not mean that all concepts associated with screening apply to developmental procedures. The word 'surveillance' is preferable for this reason.
 5. The risk register concept is unsound, and should not be abandoned. The concept of the child 'at risk' should be distinguished and retained for clinical use. The emphasis must be on surveillance of all children, but a few 'high risk' babies require special supervision.
- It would be desirable, but probably impracticable, to abandon all 'risk' terminology completely in the context of handicap, so that future changes of emphasis could be made without causing still further confusion (Rogers, 1971, p. 94).

At Risk Registers and Populations

Although Rogers (above) tends to dismiss the efficacy of 'at risk' registers, Alberman and Goldstein (1970) offer a statistical evaluation of 'at risk' registers and make the following comments based upon an analysis of some attempts in the United Kingdom, where the indigent allegedly are fewer and better served:

...Sheridan in particular considered that it was essential to keep children 'at risk' under surveillance until their development was seen to be progressing entirely normally. They recommended that local authorities keep 'At Risk' registers of vulnerable children, and this recommendation was reiterated by the Sheldon Committee Report (Ministry of Health, 1967) and by a working group of the World Health Organisation (1967).

Nevertheless in 1967 Oppe and Walker, who reviewed the functioning of such registers in the U.K. and Scotland respectively, found that the detection rate based on selective screening was disappointing (Oppe 1967; Walker 1967). They attributed this largely to the difficulty of

defining precisely the factors which put an infant 'at risk.' This tended to make the registers longer and longer, in some authorities comprising as many as 60% of all live births, thus negating the advantages of selective screening. Other authors confirmed the disappointing results of the 'at risk' policy and criticized the concept itself as being inherently unsound (Richards and Roberts, 1967; Rogers, 1967; Hamilton, Richards, Barron, Mackie, and Finlayson, 1968). Forfar (1968) also felt that selective screening was not a satisfactory substitute for universal screening but considered that the 'at risk' register should be retained as an additional safeguard.

The critics of the concept of selective screening based their arguments largely on the fact that no local authority has managed to achieve the goal forecast by Lindon (1961) namely, that the screening of a small group, 10 to 20% of all births, would identify the majority of those with 'invisible' handicaps. However, to our knowledge there has been no serious attempt to assess the actual benefit of differentially devoting resources for the screening of children at different risks, as opposed to screening only the children at high risk. The former is a policy which common sense alone would dictate.

It is possible to construct a mathematical model of the functioning of a system of selective screening for handicap, based on certain assumptions, and in particular one which relates the amount of resources available for a child to the probability of detecting an 'invisible' handicap. Such a model can be used to calculate the optimum size of the group and the division of the resources between this group and the remaining children in a population, in order to detect the greatest number of handicaps for a fixed amount of resources.

The percentage increase in yield is greatest in a population in which uniformly distributed resources produce only a very low detection rate, and the increase becomes smaller as this detection rate rises.

It is now universally accepted that the earliest possible diagnosis and treatment are essential in order to prevent, or at least to minimize, the handicapping effects of a disability and to make the most of the assets a child possesses. It is also generally agreed that it should be the responsibility of the local health authority to seek out young children with handicaps, or potential handicaps, and it is important that this task is performed as efficiently as possible.

Although it is impossible to lay down uniform rules, we can give some examples of our recommendations. From the present data it appears that an optimally sized high-risk group, using birth data alone as predictors, is about 13% of live births. These comprise fifth or later-born children, those who were delivered abnormally, or those whose condition caused concern after birth. Amongst these would be about 26% of all children with 'unseen' handicaps. In an authority who had been detecting only about 10% of such handicaps early--say in the first year--the detection rate could be increased by 50% simply by devoting all resources available for this exercise to this high-risk group. Where 30% of the handicaps had been detected early, this could be increased by 10% by allocating the resources in a ratio of four to one in favour of the high-risk group (Alberman & Goldstein, 1970, pp. 129, 131-2).

Judging from the foregoing somewhat controversial commentaries on the use of 'at risk' registers one might conclude that the attendant expense in terms of monetary and human resources is not worth the relatively small yield of children identified as potentially handicapped at a time when intervention would seem to be most efficacious. However, with the publication of results from various large longitudinal studies such as Great Britain's National Child Development Study (Pringle, Butler, and Davie, 1966) and the United States' Collaborative Perinatal Study (NINDS, 1968) it is becoming increasingly more feasible to identify and appropriately weight factors which singly or in combination can be used to flag a given child and increase the yield of any early screening and assessment system to the point that it would seem economical for all of the aforementioned societal reasons, not to mention the untold benefits to the individual children who are so identified and treated at a time when they are most responsive to remedial and preventive efforts. The National Child Development Study was able to obtain and analyze longitudinal data on the health, education, and development of 92% of the children of the original population in the study still resident in Great Britain at the age of seven years. It was possible in 14,862 cases to relate the data recorded at birth to that obtained on the same children at seven years of age.

Another similar study, with a considerably smaller number of subjects, which produced a number of similar correlates between early developmental status and later functioning, was published in the form of a book entitled The Children of Kauai (Werner, Bierman, & French, 1971).

The Kauai Study was unique in that it covered all pregnancies and births which occurred in an entire community--over a wide socio-economic and ethnic spectrum--for more than a decade. We were able to gain a perspective on the magnitude of reproductive and environmental casualties, on the short- and long-term effects of perinatal stress and a deprived environment, and on the predictive value of pediatric-psychologic examinations in early childhood. We were able to document the milieu and growth pattern of a substantial number of children from homes at the lower end of the socio-economic scale, and to illustrate early differences in ability and achievement among children from ethnic groups on whom little cross-cultural research has been done so far (p. 130).

Several other highlights from the summary and conclusions of this Hawaiian longitudinal study warrant attention and are quoted at length because of their relevance to early screening considerations in terms of populations at high risk of a wide array of long-term developmental disabilities.

In sum, for each 1,000 live births on Kauai there were an estimated 1,311 pregnancies that had advanced to four weeks gestation, 286 having ended in fetal deaths before 20 weeks gestation and 25 more between 20 weeks and term. The 1,000 live births yielded an estimated 844 surviving children at age two who were free of any observed physical defect requiring special care and who had IQs of at least 85. By age 10, only 660 of these children were functioning adequately in school and had no recognized physical, intellectual, or behavior problem. Thus, during the span of the months of pregnancy and the first decade of life, the reproductive and environmental casualties in this

community amounted to about one-half of those conceived and about one-third of the liveborn. (Figure 3/7)

The proportion of infants with birth weight of 2,500 grams or less, both after less than 37 weeks gestation and after 37 weeks or more, was highest for mothers (a) with a history of giving birth to small infants, (b) who gained less than 10 pounds during pregnancy, (c) were of short stature, and (d) were unmarried. A history of previous fetal deaths increased the chance of giving birth to small, preterm infants, and a low prepregnancy weight was associated with small babies born at term (dysmatures). The percentages were highest for mothers in the lowest socioeconomic group for most variables.

Except for the very few babies (less than 1 percent) weighing less than 1,500 grams at birth, the much larger group weighing 1,500-2,500 grams had approximately the same proportion of intellectual, emotional, and physical problems as did their peers who had been born heavier; only for perceptual problems did they have a significant excess.

The diagnoses for children with significant handicaps--physical, mental, or both--by age two were largely confirmed at age 10.

The poorest rate of prediction among the physical health problems involved children with eye defects. Only half of those children identified as having strabismus at age two had had any eye problem diagnosed by age 10. An equal number of additional eye problems had been diagnosed by that time, some severe enough to affect school progress. Some might have been prevented by earlier diagnosis with special sensory screening procedures.

The best single predictor of IQ and achievement at age 10 was the Cattell IQ score at age two. A combination of Cattell IQ, pediatricians' rating, SQ, perinatal stress score, and parental SES yielded a moderately high positive correlation (r .58) with 10-year IQ, with most of the added predictive power contributed by parental SES. For children with IQs below 80 at age two, a combination of Cattell IQ and pediatricians' ratings of intelligence yielded a high positive correlation (r .80) with the IQ score at 10 years.

When Knobloch and Pasamanick first introduced the concept of a "continuum of reproductive casualties" (1959; 1960), it was recognized that perinatal and infant mortality is only one aspect of reproductive wastage. A decade later, Quilligan (1968) wrote:

The submerged proportion of the iceberg which can sink families or even societies, is those individuals who do not die at birth, but who through damage during pregnancy, labor, and delivery, or the neonatal period, are never able to achieve their full potential as productive citizens. We have absolutely no idea of the magnitude of the problem. We have several ways of looking at the intrauterine fetus, starting with early pregnancy, to predict the fetal outcome of life and death. But there have been almost no studies of infants who live to see how they performed in the sixth grade in school.

The results of the Kauai study help to fill some of the gaps in our knowledge. We now have more realistic estimates of the proportion of fetal deaths at various stages of gestation; of the nature and

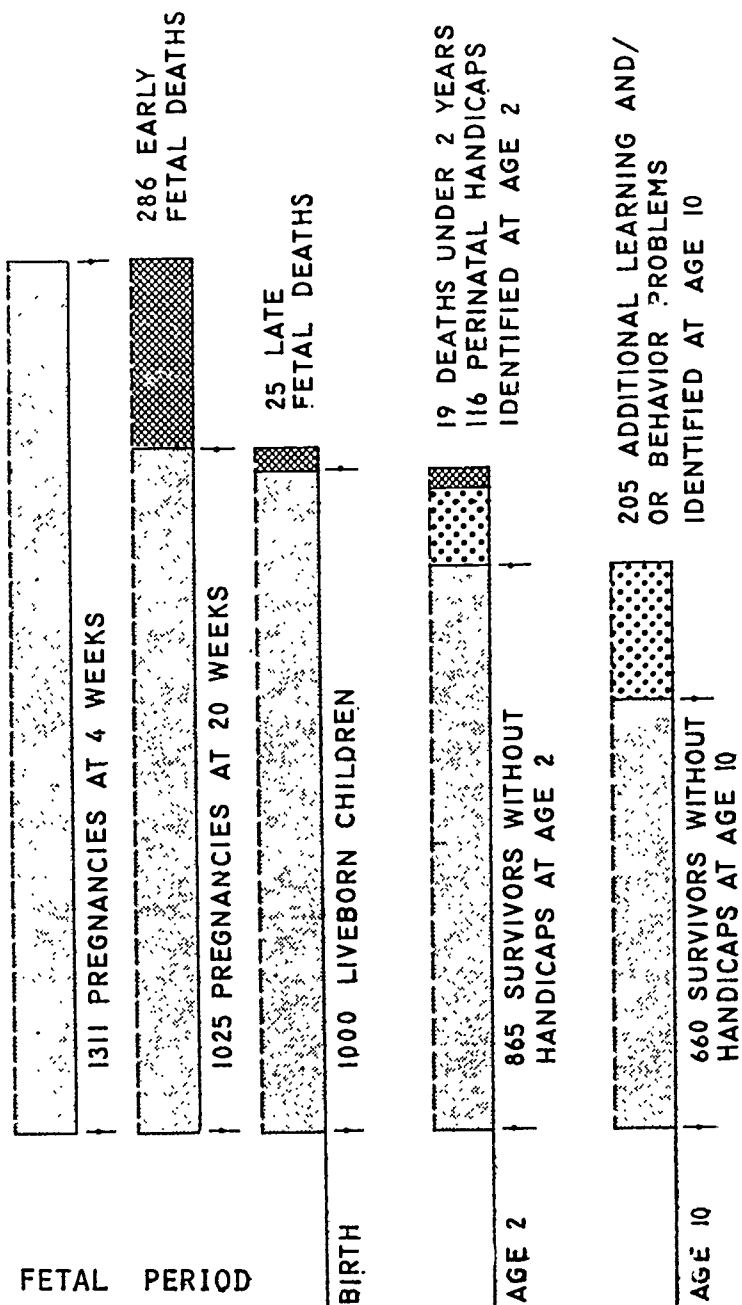


Figure 3/7: Reproductive and environmental casualties in the Kauai study (Werner, Bierman, & French, 1971).

extent of handicapping conditions resulting from damage incurred by the fetus during intrauterine life and during birth; the development and progress in school of the handicapped children in relation to that of their peers without such handicaps; the influence of the environment on the development in the crucial early years of life; and the impact on the community of the children affected by both perinatal stress and a poor environment during the first decade of life.

Our study was conducted in a community with medical, public health, educational, and mental health services that compare favorably with most communities of similar size on the United States mainland. In spite of this, the magnitude of the "casualties"--reproductive and environmental--among the young in the first decade of life was impressive.

It appears that deleterious biological effects resulting in reproductive casualties exert their peak influence in the very early weeks of pregnancy, when 90 percent of the fetal losses occur. As pregnancy advances and during labor, delivery, and early life, the external environment exerts an increasing influence. The effects of a stimulating or deprived environment appear to be most powerful in the early years of childhood when the greatest degree of rapid growth and development takes place.

Although those who are biologically more vulnerable appear also to be more vulnerable to the stress of a poor environment, it must be remembered that they represent only a very small proportion of all the children who, at the end of the first decade of their lives, fail to function adequately.

Our data suggest that ten times more children in this community had problems attributable to the effects of a poor early environment than to the effects of serious perinatal stress.

Our analysis of the relationship between the developmental status of the two-year-old children and the quality of their early family environment leaves little doubt that--aside from poor birth histories--parental language styles, attitudes toward achievement, and involvement and concern with the young child have a significant impact on his development before he reaches his second birthday.

We found the family interview a helpful tool in the assessment of those qualities of the home which have a significant effect on the child's cognitive and affective development. The educational-stimulation rating differentiated better between good and poor outcomes at age 10 than did the cruder measures of the home environment generally in use, i.e., socioeconomic status, parents' education, and parents' occupation. It also predicted the children's IQ at 10 years better than did measures of parental intelligence.

Such an assessment of the environment might become a useful instrument for early recognition of families who, because of poverty, lack of education, or lack of interest in learning, might not be able to provide the educational stimulation, emotional support, health care, and material advantages necessary to insure the normal development of their children. It could also be useful for selecting children who lack the proper language models, reinforcement, experience, and facilities in the home, and also for evaluating the extent of environmental change that could be brought about by programs of prevention and intervention. This

study has made it abundantly clear that the environmental casualties among our children need our help as urgently and as early as the reproductive casualties (pp. 131-133, 135-138, 140-141).

Some Societal, Ethnic, Ethical, and Legal Considerations

Although this monograph is primarily concerned with the screening and assessment of developmental disabilities as manifest in individual children, it would be unconscionably myopic to entirely overlook some of the larger societal issues inherent in any national massive screening system. A definitive discussion of such issues is not within the purview of this monograph but an acknowledgement of some of the more salient considerations seems both appropriate and exigent.

The legal, ethical, and ethnic ramifications of labeling humans are to be carefully considered and respected, especially in light of the recommendations forthcoming from the 1971 PCMR Conference in Monte Corona, California, which severely criticized current labeling practices and their subsequent dehumanizing effects (PCMR, 1971). For example, the determination of cut-off points separating normal development from abnormal development is extremely controversial and the Boston Conference focused much discussion and debate on this crucial issue (PCMR, 1973). In a working paper prepared for the National Advisory Committee on Classification of Exceptional Children³ (a group of widely divergent interdisciplinary experts commissioned in 1972 and co-sponsored by several federal agencies under the direction of Nicholas Hobbs to advise the Administration on all pertinent matters), Mercer (1972) addresses this normality issue in her Discussion of Alternative Value Frames for Classification of Exceptional Children.

The classification of exceptional children has become a critical social problem because those ethnic and cultural groups disadvantaged by present classification systems are protesting the taken-for-granted value frame within which psychologists, educators, and test makers have been operating. The classification of exceptional children did not become an issue because psychologists, educators, and medical practitioners were dissatisfied with the present system. This fact has great importance to the deliberations of this committee. It signifies that the central issues are conceptual and ethical rather than technical and empirical. It means that basic assumptions are being challenged. The committee must be willing to examine basic assumptions and to address the fundamental value questions being raised by those who take issue with present policies and procedures. If, instead, the committee treats its task as merely setting guidelines for establishing the

³This Committee is comprised of widely divergent interdisciplinary experts on exceptional children; it was commissioned in 1972 and is co-sponsored by several pertinent federal agencies and is under the direction of Nicholas Hobbs to advise the National Administration on all pertinent matters. A voluminous and comprehensive report about the Classification of Exceptional Children is now being prepared by some 33 task groups and is slated for publication in the Fall of 1973. Screening is but one of the 33 topics being addressed.

reliability and validity of measurement techniques in the traditional sense, its work will have little relevance to the current controversy because it will have misunderstood the nature of that controversy. The value issues must first be clarified and the implications of adopting a particular value frame explored.

The medical model is transcultural. It assumes that sociocultural factors are irrelevant to diagnosis and that similar patterns of symptoms will appear in persons of all cultures. If sociocultural factors are considered at all, they tend to be studied in an etiological (casual) context as factors producing the organic pathology. Implied in a medical-pathological classification system is the assumption that the symptoms are biologically determined and that action to prevent, ameliorate, or cure a pathology will be focused on treating the biological organism. It is assumed that diagnosis and treatment can proceed without reference to the individual's sociocultural background.

The transcultural assumptions of the medical-pathological model, when dealing with biological characteristics, are not an issue in the discussion. A child with a chromosomal anomaly, such as Down's Syndrome, can be identified and labeled in any cultural setting. His social milieu is not relevant to classification. For this reason, the discussion in this paper addresses only those cases in which there are no biological signs of deviance and classification rests entirely on behavior. In my opinion, it is the classification of the "normal-bodied" child which is the central problem facing the committee and the central issue in the current controversy.

The Statistical Model: The "Normal" Curve

Unlike the medical-pathological model, which classifies persons by the presence or absence of biological signs, the statistical model ranges individuals along a continuum based on their relative location in the distribution of others who have been measured on the characteristic being studied. Persons more than two standard deviations above or below the mean are usually classified as "abnormals" while those less than two standard deviations above or below the mean are in the "normal" range. The statistical model appears in nearly pure form in the American Association for Mental Deficiency definition of the various levels of mental retardation.

The statistical model may be used to establish norms for biological characteristics such as body temperature, height, or weight but, unlike the medical pathological model, it is not limited to the classification of biological characteristics. It can just as readily be used to establish norms for behavior. It is this use of the statistical model which is our primary concern in the present discussion.

(1) The traditional statistical model assumes that there is one normal curve and this single distribution can be used to classify all children. This one "standard norm" is based on the behavior of persons in the Anglo-American mainstream, and, consequently, produces relatively accurate predictions concerning those who will "succeed" in that mainstream. It institutionalizes the culture of the Anglo mainstream as the single, monocultural frame of reference for "normal".

It is precisely this unspoken assumption, institutionalized in present systems for classifying behavior, that is the central issue. Those who protest "biases in tests", "misinterpretation of scores"

and "discrimination" sense that there is something wrong. They are not sufficiently familiar with the statistical logic and value premises on which present practices are based to identify the source of their distress (pp. 3, 5, and 6).

The preceding quotation also points out the distinction between the medical model and the statistical model, which have several subsets, all of which serve to complicate the generation of a comprehensive, national screening system. The dangers of overgeneralizing a model which may be relatively satisfactory in one realm to other inappropriate realms become clear in subsequent chapters of this monograph; the chapter on Socio/Emotional Factors is especially germane. Moreover, such discussions are neither purely academic nor provincial in scope but have very real and international implications.

American society is moving rapidly toward becoming a meritocracy in which tests are playing an ever more central role in determining who will enter college, who will enter graduate school, who will be trained in the professions, and who will be hired for a wide variety of jobs. Tests and classifications based on tests will determine to a large extent who will hold the elite statuses in American society and who will sit in the seats of power. Consequently, testmaking and testtaking is no peripheral matter. It is of central significance in the determination of social policy.

In my opinion, the deliberations of the committee on the classification of exceptional children could, potentially, be of great significance in helping reorient American public education and American measurement and classification systems toward a broader, multicultural perspective which is more in keeping with the rich, cultural variety of American society than the present monocultural model. Such a multicultural perspective would also be more congruent with the leadership role America is playing in a multicultural world (Mercer, 1972, p. 10).

There is practically universal support for the notion that every human being is entitled to an equal opportunity for realizing his fullest developmental and human potential (see Bill of Rights for the Handicapped, PCMR, 1970). Most concerned and informed citizens agree that our society is obligated to do everything possible, within the limitations of the current state-of-the-art and science (and National economy), to insure that preventable and/or remediable developmental disabilities are identical and eliminated insofar as possible. However, a peculiar paradox rears its ironic head when, for example, an at-risk group is researched to determine its needs. The very research itself may violate the rights of the group as a whole or certain individuals within it. This phenomenon has various ethical dimensions and, in the case of developmental disabilities prevalent among identifiable racial minorities (e.g., Tay Sachs Disease, Sickle Cell Anemia, numerous cultural pseudo-defects in language and behavior, etc.), it may have ethnic overtones as well. In addition to the current rash of litigation about equal rights to treatment there may be suits regarding The Rights of the Subject in Social Research, which is the title of a provocative article.

The increasing use of social research in American society and its increasing relevance to public policy and social decisions have engendered widespread concerns about the ethical implications of such

research activities. Briefly, these concerns are of two kinds: (a) concerns relating to the processes of social research, which are exemplified best by the issue of invasion of privacy and its various ramifications; and (b) concerns relating to the products of social research, which focus largely on the fear that social research may provide tools for controlling and manipulating human behavior and, more specifically, that these tools may be used by some segments of the society at the expense of others.

Along with many social scientists, I share the conviction that both the process and the products of social research--both the attempt to ask systematic and analytic questions about human behavior and social institutions, and the answers provided by these attempts--are potentially liberating forces in our society. Social research, in my admittedly biased view, can and does contribute to enhancing the freedom of choice of the individual and to expanding the range of choices available to him. Yet, the ethical concerns about social research that are being voiced increasingly--both within and outside of the social science community--reflect the fear that the very process of social research itself or the knowledge it produces may bring about limitations of individual freedom. Thus, the concern about invasion of privacy dwells on the prospect that the individual's freedom of choice about the extent and nature of his participation in social research--and thus about what may be a significant segments of his personal life--may be restricted. The concern about control of human behavior dwells on the prospect that knowledge produced by social research may be used to reduce the individual's freedom to act in terms of his own values and interests.

The ethical problems surrounding social research, with their direct implications for human freedom, can be conceptualized in terms of the power relationship between the subjects of social research, on the one hand, and the social scientist, as well as the sponsor and user of social research, on the other hand. Ethical problems arise because of the fact that--and to the extent that--the individuals, groups, and communities that provide the data for social research are deficient in power relative to the other participants in the research process. I shall touch occasionally on the power relationships among these other participants themselves--such as that between the researcher and the research sponsor--which raise significant issues in their own right (often with implications for the research subject). The primary focus of the present analysis, however, shall be on the relative power position of the research subject.

At the level of research policy and the organization of research, there is a need for wider distribution among all segments of the population of the skills and resources needed to utilize the data of social research. Organizations representing the interests of the disadvantaged segments of the population must acquire the capabilities for using research findings in the development of their own programs and in their inputs to the debates around local and national policies. A major component of the requisite skills and resources is the capacity to counteract incomplete or faulty interpretations and applications of research data that might be detrimental to the interests of their group.

In the final analysis, the democratization of the community of research producers and research users must be seen as part of the process

of redistributing power within our society at large. Social (and other) scientists, however, can contribute to this larger process by correcting the imbalances within their own spheres (Kelman, 1972, pp. 989 and 1015).

Kelman (1972) raises many other interesting concerns, one of which is right on target in terms of the righteous protests by many researched groups who justly feel exploited.

I like to speak in this connection of the democratization of the research community. The capacities and opportunities to carry out social research must be made available to all segments of the population. By the same token, all segments should participate equally in the role of subject; the pattern must be one of reciprocal exposure rather than of a sharp division between those who do the research and those who are researched upon.

There are some inherent limitations in the extent to which the disadvantaged segments of the population can be represented genuinely in the research process. Members of these groups who receive training as social scientists are, by definition, no longer "typical" of the groups they represent. Because of their high level of education and the financial and cultural conditions associated with it, their interests and perspectives are likely to diverge in at least some important ways from those of the most disadvantaged segments of the society. Nevertheless, the base of social research would be broadened considerably if more of its participants were recruited from the segments of the society that are now underrepresented. It would bring into the field individuals who--though not quite typical of the disadvantaged groups--would have a greater identification with their problems and a greater awareness of their perspectives.

Democratization, as I see it, would enhance rather than endanger the integrity of social research. It aims for representativeness in the sense that the perspectives of the disadvantaged groups would be brought to bear more fully and fairly on the research process. Broadening the base of participation in social research would allow the interests and frames of reference of the disadvantaged groups a larger role in the formulation of the questions to which the research addresses itself and in the interpretation of the research findings. By bringing a variety of perspectives to bear on research problems, democratization would not only reduce the likelihood that the products of the research would give advantages to some groups at the expense of others, but it would also increase the overall validity of these products (pp. 1014 and 1015).

The recent (1971) establishment of the Joseph and Rose Kennedy Institute for the Study of Human Reproduction and Bioethics at Georgetown University was prompted by the many interfaces between the ethical and scientific aspects of human development. Its proceedings clearly articulate and amply testify to the seriousness of decision-making in this realm and its implications for screening and subsequently diagnosing and treating conditions which have very poor prognoses. Some of the complex contemporary bioethical issues to be considered include: 1) are parents of seriously defective children legally and/or morally bound to keep their child alive when his life

is threatened by disease? 2) do prospective parents have a right to reproduce when there is a high probability that their child will be genetically defective? 3) who gets the use of artificial kidney or other life support machines when there are not enough to go around? and 4) what are the legal and ethical issues involved in the creation of test-tube babies?

In an intriguing and disquieting article, Freeman (1972) sketched the scope of these bioethical deliberations.

While many mongols 25 years ago died a natural death from duodenal atresia, today we have surgery that is relatively simple and riskless to correct the defect; once it is performed, the baby is usually free of pain and further complications. The child, as many parents of mongols will attest, can often grow into a happy family member and a useful--if limited--citizen. Nevertheless, it is not uncommon for mongols with duodenal atresia to be allowed to die in a hospital nursery, and the legal authorities rarely hear about it; such decisions remain a well-kept secret between the parents and doctor.

Euthanasia in these cases is difficult to justify legally or, as the Kennedy panelists agreed, ethically. But there are other, more crippling infant deformities that pose more troublesome medical, legal and moral dilemmas for parents, doctors and society, as new technology makes it possible to save defective newborns from potentially fatal complications. What if a child born with a defect that was usually fatal a decade ago can now be kept alive, but only at a cost of lifelong physical and emotional suffering to the child? Should the physician perform what will probably be the first of many operations?

For the most part, a conspiracy of silence and great hesitation still pervade most discussions among physicians of when--if ever--to withhold treatment from deformed infants. Now a current debate over one of the most common structural birth defects, called meningomyelocele, has shattered that silence.

In a statement that is exceedingly bold for a medical journal, Dr. Lorber declares: 'The pendulum has now swung too far: there are now many with dreadful handicaps who a short time ago would have died.... If all the most severe cases are treated, the pressure of work will be such that adequate time cannot be devoted to the less severely affected who would benefit most.'

What, then, are the options faced by a physician when a baby is born with a severe form of meningomyelocele? As doctors have defined them, they are: (1) to kill the newborn; (2) to actively encourage the infant to die by neither treating it nor feeding it; (3) to provide only supportive, custodial care, such as feeding, but refuse to treat any of the inevitable complications either through surgery or with drugs; or (4) to actively encourage the child to live by using all means at the physician's disposal.

To some physicians there is little choice: The doctor must always intervene to save the child. The pediatric surgeon on the original team of Sheffield physicians, Dr. R.B. Zachary, argues in the British medical journal *Lancet*: 'To leave a child without food is to kill it as deliberately and directly as if one was cutting its throat. Even the prescribing of antibiotics for infection...must now be considered as ordinary care.' While granting that most of the survivors who have

had a severe meningomyelocele will remain severely handicapped, Dr. Zachary maintains that the infants should always be encouraged to live and be given early, vigorous treatment to reduce their handicaps to a minimum.

Another physician expressed serious concern about the future of a society which desperately tries to rid itself of all discomforts. 'What are the implications over the long haul for a child with a mild imperfection in a society which doesn't tolerate any imperfections?' Dr. Robert E. Cooke, pediatrician-in-chief at Johns Hopkins Hospital, asks. And he goes on: 'If you decide not to feed the abnormal child, where do you stop? How 'abnormal' should an individual be before you knock him off?'

For many doctors and parents, the tough ethical problems would be solved if the infant's handicaps could only be determined before birth. To them, the abortion issue is far less troubling than the question of withholding treatment.

Ironically, one of the most eloquent opponents of laws allowing active euthanasia in infants is the physician who admits to having actively killed six deformed infants over the course of his long career. 'The danger of active euthanasia is not to the aged or to the defective child,' this man argues, 'but to the person who does it....'

Ultimately, the decision must remain in the hands of the physician whose patient's life is at stake. What a review board will do is to insure that the decision is not based just on that one physician's prejudices. He will have the counsel of people with a wide variety of views to be sure he perceives the ethical dilemmas involved and to assist him in arriving at the best decision for the individual case.

At Hopkins a review board to advise its medical staff on 'ethics' is already in operation. The board consists of a pediatrician, a surgeon, a psychiatrist, a clergyman and a lawyer. Even before it started functioning, the board had acquired an underground title: 'The God Committee' (pp. 85, 86, 87, 88).

With regard to screening and follow-up assessment and treatment, the preceding bioethical considerations are thorny enough in the event that organically defective children are detected pre- or post-natally. But what about the relatively more horrendous issues surrounding prevention of the birth of fetuses having ethnically-linked bad genes and the consequent cries of genocide? Is the amendment to Title XIX of the Social Security Act, namely, the provision of early and periodic screening and diagnosis of eligible (under medicaid guidelines) individuals under 21 years of age and treatment of conditions found, as specified in 45CFR249.10(b)(4)(ii), a covert but nonetheless illegal type of discrimination? Or reverse-discrimination, as some interpret it? And to exacerbate the societal, ethical, and legal concerns even further, can a massive early screening system be developed which can reliably and validly detect those individuals who predictably will be sociopathic or psychopathic and should therefore not be permitted to remain in their natural home? And if a satisfactory massive screening and assessment system can be developed, what are the legal and/or moral obligations on the humans working in the system to intervene in such socio/emotionally destructive situations, assuming that the society will

provide adequate fiscal and human resources to treat or prevent the predicted condition? Is ignorance bliss? Or is there a conscience-mediated Committee of God within each helping professional and paraprofessional that will unfalteringly lead us to the best collective good and highest quality of life for all?

It was primarily for the above reason that representatives from PCMR, BEH, MCH, NICHD, NIMH, OCD, and SRS deliberated for nearly two years to determine their readiness for sponsoring a conference to address the many loaded issues involved. The remaining chapters are essentially devoid of any formal mention of such value questions as cited above but they should permeate the reader's deliberations about the more scientifically substantive procedures and materials described.

CHAPTER III

PHYSICAL FACTORS

Streamlining Routine Physical Exams and Lab Procedures

To gain some perspective on and appreciation for the multiple factors involved in physical screening, the Automated Multiphasic Health Testing and Services (AMHTS) program is exemplary. A Pediatric Multiphasic Program for children four years and older, which is patterned after this, but includes other behavioral parameters, is described in the last chapter of this monograph as an example of a promising Comprehensive Early Screening System, provided the data collection techniques and interpretation programs can be extended downward to birth. Although physical screening is often thought to be the most definitive because of the precision of measuring units and procedures for some parameters, the following lengthy expressions are quite instructive in terms of the state-of-the-art and science. It is submitted that infants and very young children are even more difficult to screen and assess definitively due to both their wide inter- and intra-individual variations as they rapidly grow and develop and their inability to communicate their more subtle sensations.

The workshop expressed concern that if a compromise was made on quality so that 'quick and dirty' gross screening methods were accepted, this would result in too many errors, and too many false positives and false negatives; as history has clearly shown, this approach would not be acceptable within the framework of medical care.

The difficulties and associated costs of achieving a high level of quality for both digital and nondigital AMHTS data were discussed. Also considered were small peripheral AMHTS laboratories versus large central facilities. There was unanimity of opinion that to achieve the lower cost and higher quality for digital data usually requires large, high-volume, automated expensive equipment and highly trained technical personnel.

For example, for the AutoAnalyzer, AutoChemist, and ECG computer analyses, the capital investment and technical expertise required will undoubtedly move these operations into larger central facilities, whereas procedures such as history taking could be done in peripheral stations. In these peripheral stations, samples of blood and urine could be collected, electrocardiograms could be taken, and signals or test results could be sent into the central computer facilities.

The workshop concurred that quality control is best done at the time of data input, when the specimen test result is read, while the patient is being tested, and while all source information is yet available. On-line processing for error detection and correction, while the patient, the specimen, and the source documents are present, is the most desirable procedure because there was general agreement that correcting errors later is many times more expensive.

In considering the quality of nondigital data (for example, history taking, interpretation of chest X-rays, and so forth), it was felt that these kinds of data are much more difficult to control. They can be monitored to some extent by assessment of their reproducibility and validity by several methods, such as periodically performing test-retests on patient histories; periodically conducting tests on observer

variability by having the same X-rays and ECGs read twice by the same physician or by comparing the same ECGs and X-rays as read by the different physicians involved in the particular interpretations; or as some have done, by comparing an AMHTS-derived history with that obtained by the more traditional interviewer method.

It was also suggested that one should look at the percentages of abnormals. For example, one might look at the frequency distributions of the various ECG abnormalities reported and, by examining peaks and valleys, apply tests of exception. It is thus possible to monitor the extent of any variations from the usual which would suggest the need to identify such deviations as due to instrumental or population variations.

It is desirable for best quality to work towards programs which monitor a combination of history questions, identification data, and laboratory test results. An example cited was the utilization of the combination of information that the patient was a woman, that she was using contraceptive pills, and that this would affect the result of a PBI determination done in the laboratory. Without all this information, of course, the test result might not be interpreted as a spuriously high one, but rather as a suspicious finding. It was also agreed that reliability can be improved by redundancy, that is, by using several questions to test the reliability of the patient's responses.

Finally, the group felt that there should be a policy of encouraging the use of allied health personnel to perform AMHTS services, not only in the testing phases but also for physical examinations of patients; to include evaluation of the possibility of using such allied health personnel for performing breast, pelvic, and rectal examinations; and even to consider the use of such personnel for proctoscopy. Allied health personnel could well accomplish the routine gathering of much physical examination information so that the physician need only check and evaluate the resulting data (Collen & Cooper, in Collen, *et al.*, 1970, pp. 95-96).

Another series of germane considerations about the AMHTS is cited as follows:

Our studies during the past ten years at the National Institute of Health of ranges and profiles of blood chemistry in normal subjects revealed that the individual's mean normal range of blood constituents is much narrower than the average population range. This suggests the possibility of detecting significant and persistent abnormal trends of physiology or chemistry within an individual before his levels reach a definite abnormal range.

If methods are sufficiently sensitive, precise, and standardized to detect such change, it is conceivable that abnormal trends of an individual's blood constituent levels, urinary constituent levels, or other parameters can be recognized before they reach the upper end of the accepted normal population range. But such early detection of abnormal trends requires knowledge of the person's base line profile and stability, previously established by multiple testing. The optimum number, spacing, and selection of tests for determining a person's chemical profile are objectives of continuing study and research. I call attention to this aspect because I believe this is one of the capabilities that AMHTS must develop and emphasize in the future. If

periodic health evaluation is to succeed, we need much more reliable methods than are now available.

Also, we found that the total range of the fluctuation in the results of tests on normal subjects is composed of two major components: (1) the fluctuation or deviation due to the laboratory manipulations of analysis, and (2) the variation which is due to the physiological fluctuations and biological differences between people.

A phenomenon that has impressed me throughout my medical experience is that we who have been trained as physicians have a strong tendency to accept laboratory results as either absolutely right or wrong. If a given test result does not agree with our other data (physical and clinical) and does not fit our concept of what we should have found in the patient, it is usually considered a laboratory error and a repetition is requested, or the information is disregarded. If it suits our concept of what we should find, we accept it as an absolute and correct result.

We must educate ourselves and our clinical colleagues to recognize a test result for what it is, an approach to a true value with a definable probability of validity. Laboratory results under rigid quality control should be reported in some fashion to convey to the physician the range of analytical deviation, the notion should be conveyed that this is an approximation, that when one receives a report of a blood sugar level of 120, it really is 120 plus or minus 10 (if measured by customary laboratory methods). If the method is better controlled on a particular day and the control methodology indicates that the deviation was plus or minus 2, this result should be reported as 120 ± 2 . The danger is that many clinicians will misunderstand and they may phone to ask the laboratory scientist to make up his mind whether the blood sugar is 130, 120, or 110.

There is no way to avoid this. We must persist in explaining the real nature of laboratory results; and physicians must learn that results are not absolute and we in the laboratory must continue to strive to reduce analytical deviation and improve reliability and accuracy.

It is important to emphasize that under the best controlled conditions we could maintain, for every laboratory test that we measured a least 50 percent of the fluctuation or variation in results was due to laboratory manipulation. In most tests it is even larger than 50 percent. Thus, for a borderline test result, we cannot be certain, because of the laboratory component of the fluctuation, whether the result is an abnormality or a high normal value. We must develop an appropriate method to indicate this to the physician and must improve our methods so we can reduce the large laboratory component of fluctuations.

It may be useful to compare analytical fluctuations of results to electronic 'noise,' that unwanted part of a signal due to the nature and actions of electronic circuits. Whenever we do a well-controlled laboratory test, we have a certain amount of noise. The further concept of the signal-to-noise ratio, borrowed from electronics, may be useful, that is, the ratio of test fluctuations due to biologic phenomena to the analytical 'noise.' We must try to decrease the noise so that the signal-to-noise ratio in well-controlled laboratories approaches 2.0 or more, that is, a ratio of physiological variations to analytical fluctuations of 2:1 or better.

This concept of a 'noise' component in measurement poses a pertinent question. If, as we found in a well-controlled laboratory with

automated procedures, the signal-to-noise ratio was only 1.0, what must it be in history taking, electrocardiography, X-ray examinations, and physical examinations where much subjective observation and interpretation is involved? I do not question the pathology we see in the X-ray film or the pathology we see in a blood sugar level that is 200, 300 or more. But I am calling attention to the problems we must face in health appraisal and surveillance even for well-controlled methods in AMHTS (Williams, in Collen, et al., 1970, pp. 84-85).

In the introductory statement to the AMHTS Operational Manual the following concerns were mentioned:

I believe it is fitting that quality in the operation of an AMHTS facility should be the first step in the stairway we are building as guidelines for a successful AMHTS program. The past 20 years of experience with multiphasic screening programs has demonstrated that such programs will stand or fall primarily on the issue of quality of testing.

Multiphasic screening programs were first initiated in the late 1940's. By the late 1950's multiphasic screening had fallen into some disrepute, primarily because most programs failed to have the support of the physicians and also because of the poor quality of testing. The use of manually performed tests of poor accuracy, poor sensitivity and poor specificity provided an unacceptably high frequency of false positives and negatives, leading to loss of confidence in the entire concept.

In the 1960's we were able to resuscitate the concept with the implementation of automated equipment to improve the quality of testing. And now once again, multiphasic screening or AMHTS is on the upswing of popularity. We must profit from the lessons of history and this time insure high standards of quality testing or we can predict that in a few years we shall again witness loss of confidence and support for the concept of AMHTS.

The quality of a test or procedure, wherever possible, was assessed to be at one of the following two levels or categories. First, unacceptable or not recommended, and second, acceptable. We then attempted to grade the latter as minimally acceptable, acceptable, and most acceptable.

I think we have properly emphasized that guidelines for quality must consider the functional objectives of the AMHTS program and tailor it for the specific characteristics of the population to be served. For some tests, differences in procedures and normal limits apply for adults versus children, male versus female, and for other socioeconomic characteristics.

We outlined the criteria for test selection so as to insure good quality of testing. We also gave attention to the effect on quality of the structural and functional design of the facility and the importance of considering the patient's safety, acceptability, comfort, and processing time. We emphasized the great need for positive identification of the patient to avoid a common source of data error.

We tried to indicate that quality control monitoring of personnel is of primary concern, and that it is more difficult than monitoring instruments... (Collen, et al., 1970, pp. 1-2).

Automated medical examinations are now becoming fairly well debugged and widespread throughout the U.S. Therapy programs are being linked to them in many instances. One example reported in the popular literature describes a Health Maintenance Center.

...First, the candidate must fill out a 378-item questionnaire on his own and his family's medical histories. That chore over, things are made as easy as possible for him. His questionnaire is fed into a computer. If the electronic brain finds inadequate or conflicting answers, it demands: "More data!" The computer prescribes the test schedule for each individual patient, based on age and sex.

After that, the process works like a luxurious assembly line. A technician takes blood and sends it to the adjacent laboratory for both blood-cell and chemistry readings. The results, along with those of urinalysis, are fed into the computer, which is programmed to rerun any tests that show questionable results. The electrocardiogram, usually elaborate, is also checked by the computer and can be double-checked if any abnormality appears.

At the end of an even hour for a man or 1½ hours for a woman (because of additional breast and genital examinations), a physician at the end of the line has a print-out of the full report. The center physician will send the report to the examinee's personal doctor or company medical department or provide him with a list of private physicians. If an examinee has a problem with smoking, nutrition (meaning, in most cases, overweight), high blood pressure or physical fitness, he can be referred immediately to one of four 'intervention clinics' maintained on the floor below by the American Health Foundation. There he may be placed on special diets or exercise regimens, or helped to stop smoking through hypnosis or psychological support. "When the center detects a health risk factor," says Wynder, "we like to intervene immediately. We don't want to lose patients--we want to get them while they're hot." Eventually, Wynder hopes, there will be a dozen or more such examination centers across the U.S. (Time, July 1972, p. 63).

Genetics and Amniocentesis

In a most enlightening and provocative article entitled "Mass Screening for Genetic Disease," Guthrie (1972), a pioneer in the development and use of bacterial inhibition tests for PKU (now more properly called phenylalaninemia), makes an eloquent case for not only continuing present neonatal screening procedures but expanding and further streamlining them. In the following quotes he writes from a knowledgeable and vast experience about several of the cardinal issues in mass screening, including yield, regionalization, automation, simultaneous multiple screening, cost/benefits, and the practical application of recent advances in the state of the art and science.

Automation has already brought our screening capability to the point where the same specimen can be used to detect a number of hereditary aminoacidurias in addition to PKU. Yet application falls far behind: only six laboratories in the U.S. now do such automated multiple testing. Regionalizing the effort could close this gap--and involve practically no increase in cost over that of screening for PKU alone.

It is therefore necessary to say flatly that--and I choose my words carefully--discontinuance of PKU screening would represent not merely medical but also fiscal irresponsibility of the grossest sort. The detection and treatment of one case of PKU represents an outlay (assuming it is the outcome of 10,000 screening tests, each costing 50¢ to \$4.00 in the U.S.) of up to \$50,000; but failure to detect that case means a child that must almost certainly be institutionalized for the rest of its life, representing an outlay of at least \$250,000 (this assumes an average life span of 50 years and an annual expenditure for custodial care conservatively estimatable at \$5,000). The \$250,000 figure includes no allowance for the future earnings of the treated case, or of the tax income from such earnings. It does not allow for the suffering experienced by the parents of a permanently retarded child--which is not, in any case, quantifiable in terms that are likely to make sense to a budgeter. We are not talking here about human values but purely economic ones: whether it is better to spend \$50,000 now or five times that sum later.

There is, for that matter, good reason to expect that the \$50,000 figure can itself be somewhat reduced. One approach to this is through the use of automated test equipment, of which I shall have more to say in a moment. However, to get full value from this apparatus, testing must be done on a large scale: a minimum of 25,000 births a year. This constitutes a powerful argument for regionalization of screening programs; given the validity of tests based on dried blood spots, which can be mailed in to the testing center, there is no good reason why any hospital should find it necessary to carry on its own, small-scale, screening program....

...The economics of mass screening will continue to rest, as they do now, on the demonstrated fact that prevention is cheaper than non-prevention.

The automated equipment grew out of the finding that the inhibition assay procedure can be adapted to the detection of several other hereditary aminoacidemias simply by varying the inhibitor dissolved in the culture medium. These conditions include valinemia, tyrosinemia, histidinemia, homocystinuria (in which we test for methioninemia), and maple syrup urine disease (leucinemia). With automation, all these tests plus the phenylalanine test can be carried out at no more cost than the latter alone, unautomated.

Recently, a practical method of using the newborn dried blood spot (or specimen) in mass screening for sickle cell hemoglobin and other hemoglobin variants has been developed by Dr. Michael Garrick in our laboratory. This method uses discs punched and placed by the punch-index machine in the dimples in the plastic dimple-tray. These discs are then eluted in the dimples, after which the eluates are used for electrophoretic separation of hemoglobin bands in cellulose acetate strips. A follow-up procedure, using agar electrophoresis, can differentiate the S A heterozygote from the S S homozygote. Using this procedure, filter paper specimens for the PKU test can be screened by a laboratory already performing multiple tests on the specimens at a material cost of \$0.03 per specimen. The capital investment for equipment is less than \$1,000 to acquire the capability for screening up to 100,000 specimens per year.

This screening procedure is the first one to be developed by our laboratory that permits detection of the 'carrier' heterozygote by mass

screening. It is also the first procedure developed anywhere, to our knowledge, that permits detection of S hemoglobin in the newborn infant by mass screening, in spite of the presence in such specimens of more than 90% fetal hemoglobin. Because of the recent increased interest in prevention and treatment of sickle cell disease within the United States, it is hoped that this test will receive a large-scale trial in the near future.

An obvious approach to this is to expand the 'six-for-the-price-of-one' achievement that automation has already brought to screening into a '20-or-30-for-the-price-of-one' arrangement. Already our laboratory is working on several approaches to this goal; all of them involve not simultaneously testing several specimens from the same individual for different anomalies, as is done with the punch-index machine, but testing a single specimen simultaneously for several anomalies.

In all these instances, of course, a positive response could mean any of the several conditions the test was designed to respond to, with differential diagnosis requiring further tests. These, however, would involve only a few score or at the most a few hundred specimens, as against the tens of thousands eliminated by the initial multiple screen.

Given the further development and perfection of multiple screening tests, mass screening can become not merely a way of rapidly detecting PKU and other treatable genetic diseases but also a source of invaluable information on biochemical differences in large populations. Given the fact that screening for PKU alone has proved itself not merely medically but also economically sound--which seems to me unarguable--we can (one hopes!) safely assume that specimens will continue to be collected by the hundred thousand and screened by one or another technique. And if that is the situation, it is surely only common sense to seek screening procedures that, for the same outlay, will yield steadily increasing 'fringe benefits' of data on both pathologic and benign innate metabolic differences (pp. 93, 96-97, 99, & 100) (see Table 1).

Although the preceding discussion is focused upon neonatal massive screening, another kind of screening automatically occurs when parents give birth to a child with any one of a variety of congenital defects, since both the parents and the physician are then alerted to the increased probability of subsequent defective offspring. A PCMR Committee Work Group on Research and Prevention issued a report of its deliberations.

The Work Group has reached this conclusion after careful assessment of those several conditions in the prenatal, perinatal and newborn periods which may predictably result in organic MR and which appear to be susceptible to biomedical and behavioral intervention. This includes maternal nutrition and malnutrition, prematurity, abnormal labor and difficult delivery, genetic defects and disorders, the newborn at risk for whatever reason, and numerous other specific situations. The Work Group has identified within this listing those which are most promising in the prevention of organic MR, for which preventive technology presently exists, and which would within the year show demonstrable results (1972, p. 1).

The bulk of the report is comprised of a series of fact sheets which are organized with a synopsis of the condition, the population at risk,

Table 1: NEWBORN SCREENING TESTS¹ for INHERITED ABNORMALITIES

<i>Disease</i>	<i>Test Substance</i>	<i>Test</i>	<i>Automated</i>	<i>Treatable</i>
Phenylketonuria	Phenylalanine	BIA ²	✓	✓
Maple Syrup Urine Disease	Leucine	BIA	✓	✓
Tyrosinemia (transient and permanent)	Tyrosine	BIA	✓	✓
Homocystinuria	Methionine	BIA	✓	✓
Histidinemia	Histidine	BIA	✓	✓
Valinemia	Valine	MBIA ³	✓	✓
Galactosemia Transferase or Kinase Deficiency	Galactose	MBIA or Coliphage	✓	✓
Transferase Deficiency only	Galactose Uridyltransferase	Beutler	Partly	✓
Argininosuccinic Aciduria	Argininosuccinic Acid Lyase	EA ⁴	✓	✓
Orotic Aciduria	Orotidine-1'-phosphate Decarboxylase	EA	✓	✓
Hereditary Angioneurotic Edema	C1 Esterase Inhibitor	FST ⁵	Partly	No
Emphysema (adult) Liver Disease (infant)	α-Trypsin Inhibitor	FST	Partly	No
Sickle Cell Anemia	Hemoglobin	Electrophoresis	Partly	Palliative only

¹ Using dried blood spot filter paper specimens

² Bacterial Inhibition Assay

³ Metabolite Bacterial Inhibition Assay

⁴ Enzyme-Auxotroph Bacterial Assay

⁵ Fluorescent Spot Test

current technology, cost/benefit estimates, current needs, and recommendations for preventive intervention. The various conditions so described as contributing to organic mental retardation and amenable to preventative procedures include Narcotic Addiction in Pregnancy, Maternal Rubella, Maternal Diabetes, Prematurity, Lack of Prenatal Care, Maternal Iron Deficiency, Maternal Malnutrition and Protein Deficiency, and Adolescent or Elderly Mothers.

An article by O'Brien entitled "How We Detect Mental Retardation Before Birth" has indicated that there are 27 or more neurological diseases involving severe mental retardation, which can now be identified and diagnosed during the fourth and fifth month of pregnancy. This is early enough for the safe termination of the pregnancy, if so desired, and it is crucial to alleviate the often unwarranted anxiety in a pregnant woman who has some increased likelihood of bearing a genetically anomalous child.

In this world of ever-increasing awareness of the quality of life and the crush of the population explosion, it is now not only possible but essential to assure married couples who have already borne a child with a genetic neuro-metabolic disorder that their expected child will not be similarly afflicted (O'Brien, 1971, p. 103).

It is pointed out that each of the diseases is individually very rare but when they are all taken together they represent a noteworthy proportion of the organic causes of mental retardation and other developmentally debilitating conditions. An example is made of the Tay-Sachs disease, with many of the symptoms described and the manner in which it is inherited explained. Insofar as screening for this disease is concerned:

All brothers, sisters and first cousins of patients with Tay-Sachs disease who are in their reproductive years should be tested for heterozygosity. Approximately 4,050 brothers and sisters of Tay-Sachs patients have been born over the past 30 years in the United States; they have a 66% risk for being carriers of the gene for Tay-Sachs disease. First cousins of these patients number 54,445; they have a 25% risk for being carriers of the gene for Tay-Sachs disease. If all of these individuals marry and reproduce and have the United States average family size, they will bear 58 children with Tay-Sachs disease. Screening for carriers in this group is a worthwhile thing to do (O'Brien, 1971, p. 106).

Although it is possible to detect older carriers of the recessive and debilitating genes by a simple blood test or skin test, O'Brien goes on to stress the importance of amniocentesis, a procedure which is still in its early stages of development but is nevertheless reliable and accurate in the developing fetus.

Although this procedure has not been advocated as yet in the screening of all pregnant women 35 years of age or older, it is likely that this will be the case in the near future. Studies are now underway to determine that the amniocentesis procedure itself has a low enough risk to the health of the fetus to permit safe mass application of the procedure. At this point, there is no technical reason why the procedure could not be routinely applied. I personally believe that it should be offered to every pregnant woman over 40 years of age,

since it is clear now that the risk of amniocentesis in causing congenital malformations or spontaneous abortion is no greater than the risk for these at large (O'Brien, 1971, p. 108).

Other Biochemical and Metabolic Indicators

Although there is a subsequent chapter in this monograph dealing with emotional disorders, it does not address the related biochemical issues, which are hinted at in the following.

It is tempting to speculate that if Freud were alive today he would be looking for loci of his theories in neurochemical systems rather than on the couch. He would perhaps conceptualize his 'mechanisms of defense' not as repression, displacement, and such but rather feedback inhibition, changes in enzyme amount or activity, increases or decreases in receptor sensitivity, and alterations in substrate supply.

The idea that some toxic agent causes mental illness appeals to researchers and laymen alike. If virulent germs and toxins can cause diseases of body, it seems only logical that diseases of the mind could have similar causes. Indeed, much biological research in psychiatry can be characterized as a quest for a psychotoxic agent--a single agent whose presence is both necessary and sufficient for the outbreak of mental disease in man. A number of practicing psychiatrists of the Freudian school refer to this quest, with thinly veiled sarcasm, as the search for the schizococcus.

Toxin. Over the years descriptions of this hypothetical psychotoxin tended to follow vogues in medicine. Back when bacteria were first heralded as the cause of disease, researchers proposed that bacteria growing in a person's intestinal flora produced a toxin that disrupted the central nervous system; this was the 'autointoxication theory.'

When attention shifted to viruses, researchers sought a viral cause of mental illness. With the discovery of hereditary metabolic diseases, psychiatrists suggested that mental illness resulted from some deficiency or aberration in biochemical pathways. Then came the autoimmune concept, which implied that mental illness might be caused by an antibody that attacked the central nervous system.

The most recent emphasis has been on the hallucinogenic drugs--such as LSD--that disrupt the natural workings of the brain in ways that resemble some mental disorders....

Enzyme. Recently, in our laboratories, we have shown that an enzyme in the human brain can convert one of the normal transmitter chemicals, serotonin, into a hallucinogenlike compound. (A transmitter chemical transmits nerve impulses across the synapses between nerve cells.) The same enzyme that affects serotonin also can convert tryptamine--another chemical of the brain and one very closely related to serotonin--into the hallucinogen DMТ (dimethyltryptamine). For those with a taste for polysyllabic mouthfuls, the enzyme that can make hallucinogens in the brain goes by the name of indole(ethyl)amine N-methyltransferase (IENMT).

Having demonstrated that the brain has the potential for making its own hallucinogens, one is tempted to go on to formulate a simple theory for a chemical cause of psychosis. Studies show that latent schizophrenics become acutely psychotic when they ingest large amounts

of tryptophan, from which the body synthesizes the neurotransmitters serotonin and tryptamine. Psychosis is most likely to occur if one takes a stimulant or an antidepressant drug with the tryptophan. This combination lowers the brain's level of monoamine oxidase, an enzyme that deactivates tryptamine and other neurotransmitters.

If we were to attribute psychosis to a chemical cause, we would predict that when the brain's level of monoamine oxidase drops below a certain point, the normal transmitter is not deactivated, but is shunted into an enzymatic pathway, where IENMT converts it into a psychotoxic agent.

Out. There is much unfinished business in this chemical theory. In normal circumstances, neurons of the brain contain much more monoamine oxidase (MAO) than IENMT enzyme. This means that the monoamine oxidase would get the first chance to work on the transmitter, unless something reduces the amount of MAO that is present. But there is no evidence that persons with mental disorders have lower levels of monoamine oxidase than normal persons. To complicate the problem still further, we have found the hallucinogen-producing IENMT enzyme in brain tissue from normal persons.

Our enthusiasm for IENMT as the schizococcus dwindled, and slowly we came to the point of view that the psychotoxic-agent theory could not, by itself, account for the syndromes that are classified as mental diseases.

Despair. It has become gnawingly apparent that major mental illnesses such as schizophrenia or manic-depressive disease are complex psychobiological phenomena made up of genetic, developmental, and psychosocial parameters. They are no more likely to have a single cause than do such traits as height, weight, personality or intelligence. For this reason, claims that some laboratory has found a 'cause' or a 'cure' for these mental diseases are highly suspect and at times may even damage the serious work by the thousands of researchers who are taking the myraid, small steps that are necessary before we can understand these illnesses. The new sophistication of neurobiological and biochemical research will continue to add pieces of understanding to the puzzle of brain and behavior. Few of us, however, expect the discovery of a single cause or cure--now or ever. The periodic claims that emerge from time to time seem to result from the desperation that these diseases evoke in patients, in their families, and in physician researchers (Mandell, Segal, Kuczenski, & Knapp, 1972, pp. 68 & 72).

There is a helpful booklet, excerpted from a thorough laboratory procedures book, which is used in the biochemical screening laboratories of the Department of Pediatrics at the Johns Hopkins University School of Medicine in Baltimore and its affiliated John F. Kennedy Institute for the Habilitation of the Mentally and Physically Handicapped Child. The booklet focuses only on those tests which are simple and practical to do on large numbers of patients and excludes tests which are routinely done in most hospital central laboratories. The tests include: the ferric chloride test; qualitative dinitrophenylhydrazine test; tests for excess concentrating of urinary cystine and homocystine; nitrosonaphthol test for increased urinary concentrations of "para-hydroxyphenyl catabolites"; acid mucopolysaccharides; single dimension chromatography for serum amino acids; procedure for amino acid electrophoresis-chromatography; thin layer chromatography of sugars in urine; and assays for aryl sulfatase A activity in urine.

Although many of these tests are extremely simple, it is most important to point out that accurate interpretation requires considerable experience. Many of these tests are for rapid screening and in most instances, before a final or specific diagnosis can be made, more definitive diagnostic tests must be run (Howell, Hoitzman, & Thomas, 1969, Preface).

Thus, it is important to bear in mind that the primary difficulty does not lie in administering the tests which were selected but rather in coming up with a valid interpretation of their results. This implies that differing levels of sophistication are necessary at different levels of the screening process. It does not lie within the purview of this monograph to attempt to give a detailed account of the administration and/or interpretation of each test mentioned, but rather to note its existence as a potentially good candidate for a massive screening system. Moreover, once a high-risk or at-risk pregnancy is detected or even suspected by various levels of screening, the far more complex and sophisticated tests (e.g., O'Brien, Ibbott, & Rodgerston, 1968) for confirming the suspicions and differentially diagnosing their nature is beyond the scope of this discussion.

There are some other promising procedures for identifying newborn infants with a high probability of being or becoming mentally retarded or otherwise developmentally disabled due to organic causes.

A newly developed ultramicro automated system for the detection and prevention of birth defects, especially those leading to mental retardation, was described to delegates here at the 4th International Congress on Human Genetics.

Dr. John A. Ambrose, Chief, Pediatric and Genetic Chemistry Laboratory, Center of Disease Control, Atlanta, Ga., told delegates that the equipment may someday allow doctors to simultaneously check a dozen blood indicators for signs of mental retardation in babies. It is now being used to check for two indicators but Ambrose says the testing capacity of the device could be greatly expanded within five years.

He explained that the importance of the equipment is that it will soon be feasible for hospitals to easily and quickly check the newborn for a wide range of signs that indicate various types of retardation.

Similar in some respects to that used to diagnose metabolic disorders in adults, the equipment chemically analyzes a tiny speck of blood and records its findings on a graph.

Existing methods of detecting abnormally high blood levels of phenylalanine and tyrosine, two amino acids whose imbalance can cause severe retardation, take 24 hours and tests must be separately run.

The equipment developed by Ambrose for detecting high levels of the acids does the job simultaneously, takes an hour and requires but one blood sample (Mental Retardation News, November 1971, p. 3).

Nutrition

In planning community health programs for children it is particularly important to identify the nature and extent of common health problems, including nutritional problems. Knowledge of the frequency and severity of nutritional problems in a community will permit reasonable allocation of resources for solving the more important nutritional problems and will provide a basis for program evaluation. Without such

knowledge, significant nutritional disorders may be ignored or an unwarranted investment of funds and effort may be made in combatting an imagined or trivial problem. For this reason, it seems desirable that some screening of groups of individuals for nutritional disorders be carried out in every health care delivery system.

Even a minimal screening program will require knowledge of the community and of food intakes and physical findings of the children. Some laboratory analyses will be necessary. Such a minimal screening program is described in Section I.

Section II includes a somewhat more sophisticated (and also more expensive and time-consuming) approach to evaluation of nutritional status. In addition, several reference tables are included as well as forms that may be utilized in recording relevant data.

Many of the suggestions in Section II are useful in evaluating nutritional status of individual children while Section I is focused primarily on nutritional screening of groups of children (Fomon, 1971, p. vii).

The above report illustrates the importance of knowing a community's nutritional characteristics (e.g., racial and ethnic food preferences, availability of vitamin fortified bread and milk, iodized salt, fluoridated water) and identifies routine physical examination and laboratory indicators of nutritional risk, which are spelled out in great detail and constitute little additional burden when these are routinely done. In addition, a relatively simple food intake questionnaire and rationale for certain laboratory procedures are presented in terms of massive screening.

Information about food intake is mandatory in screening for nutritional status. If knowledge of food intake of the group to be screened is lacking, it will be desirable to accumulate data on food intake before laboratory aspects of screening are undertaken. This sequential approach would seem particularly desirable when laboratory facilities are limited.

No single method of collection of dietary intake information will be satisfactory for all purposes. Intake of food on a single day may not be typical of usual or long-term intake and cannot be expected on an individual basis to be correlated with physical or biochemical findings. Nevertheless, for the purpose of screening groups of children of similar age, sex, income level, etc., information about 1 day's intake can be of great value in alerting health workers to the possibility of a particular nutritional problems in some groups of children in the community. Appropriate further action can then be initiated. For example, if a substantial percentage of 1- to 2-year-old children in the community were found by 24-hour recall to have extremely low intakes of ascorbic acid, it would seem important to introduce biochemical screening with respect to ascorbic acid nutritional status of that age group. Obviously, nutrition counselling in the community might also be altered.

The 24-hour recall (Table 2) has the great advantage of simplicity. It can be completed in 15 or 20 minutes by personnel with relatively little technical nutrition training. A method for machine analysis of the data has been reported. Shortcuts aimed at obtaining dietary information in less than 15 minutes usually provide data of little value. It is better to spend 20 minutes obtaining relatively reliable information from one-fourth of the children than to spend 5 minutes with every child obtaining information of questionable value.

Name _____
Date & Time of Interview _____
Length of Interview _____
Date of Recall _____
Day of the week of Recall _____
1-M 2-T 3-W 4-Th 5-F 6-Sat 7-Sun

"I would like you to tell me about everything your child ate and drank from the time he got up in the morning until the time he went to bed at night and what he ate during the night. Be sure to mention everything he ate or drank at home, at school, and away from home. Include snacks and drinks of all kinds and everything else he put in his mouth and swallowed. I also need to know where he ate the food, but now let us begin."

What time did he get up yesterday? _____

Was it the usual time? _____

What was the first time he ate or had anything to drink yesterday morning? (list on the form that follows)

Where did he eat? (list on the form that follows)

Now tell me what he had to eat and how much?

(Occasionally the interviewer will need to ask:)

When did he eat again? or, is there anything else?

Did he have anything to eat or drink during the night?

Was intake unusual in any way? Yes _____ No _____

(If answer is yes) Why? _____

In what way? _____

What time did he go to bed last night? _____

Does he take vitamin and/or mineral supplements?

Yes _____ No _____

(If answer is yes) How many per day? _____

Per week? _____

What kind? (Insert brand name if known)

Multivitamins _____

Ascorbic Acid _____

Vitamins A and D _____

Iron _____

Other _____

Table 2: FOOD INTAKE - 24-HOUR RECALL

As a minimum, it is suggested that hemoglobin concentration or hematocrit be determined. The feasibility of performing other laboratory studies on a routine basis will depend in part on the level of laboratory competency available locally or the ease with which arrangements can be made for laboratory studies to be performed at a more distant site.

Certain laboratory determinations are likely to be of greatest value in one community while other determinations may be more valuable in another community. Within the same community, priorities may vary from year to year or even within a period of several months. In general, specific analyses will be selected on the basis of clues provided by knowledge of the community, information about food intake or by physical findings.

For example, in a cloudy city where unfortified milk is widely available, screening for rickets might receive highest priority. For at least several months, preferably including the late winter, alkaline phosphatase activity might be determined in sera of all children less than 3 years of age; roentgenograms of the wrist might be made of all children with elevated alkaline phosphatase activity or with the slightest clinical suggestion of rickets. When several hundred children had been screened in this manner, it would ordinarily be possible to draw a conclusion about whether or not intensive preventive measures needed to be instituted. If rickets did not appear to be a problem of major importance in the community, routine screening would probably be discontinued.

If food intake data or physical findings suggested the possibilities of ascorbic acid deficiency and protein deficiency, high priority among laboratory studies would be given (at least for several months), to determining concentrations of ascorbic acid and albumin in sera.

As indicated in the examples just given, the laboratory can be used most effectively if analyses to be performed routinely are selected on the basis of information obtained by other screening efforts.

Laboratory studies are also important in confining or excluding the existence of nutritional disorders suspected on clinical grounds. For example, a clinical diagnosis of rickets should be confirmed by determining alkaline phosphatase activity and concentration of inorganic phosphorus in serum and by a roentgenogram of the wrist. Similarly, a clinical impression of protein malnutrition (based, for example, on edema of the lower extremities) should be confirmed by determining the concentration of albumin in serum (Fomon, 1971, pp. 2-4).

Gestational Age

Lubchenco (1970), a pioneer investigator regarding the effects of prematurity, addresses the difficulties of assessing gestational age and development at birth:

The importance of knowing the gestational age of an infant has been brought into focus by the high mortality and morbidity in the 'small-for-date' infant. Efforts to improve the criteria used to judge the gestational age are being made by obstetricians, pediatricians, and basic science workers alike.

At present, four different approaches to the determination of gestational age are recognized. The first, or 'calculated gestational age,' is based on the day of onset of the mother's last menstrual period (LMP). The next is the 'obstetric clinical estimate,' derived from events during pregnancy, the physical examination of the mother, and the growth of the fetus. The pediatric 'clinical assessment of gestational age' is possible because certain physical characteristics and neurologic signs change predictably with increasing fetal age. The fourth approach, and hopefully the most precise, remains for the future, i.e., the 'laboratory estimate of gestational age' (p. 125).

A high incidence of low birth weight infants is seen in Down's syndrome. When the weights of these infants are plotted on the intrauterine growth chart, they form a loose cluster. In other words, the scatter around a median birth weight and a median gestational age is wide (Figure 4/6). The center of the cluster can be seen to deviate from normal infants, but the scatter of weights and gestational ages is so great that the cluster loses its significance when referred to an individual baby. However, with trisomy 16-18, the cluster is tighter (Figure 5/7). In fact, the data being acquired now suggest that, instead of 40 weeks, the gestational age post-term infant should arouse immediate inquiry into this congenital anomaly (p. 133).

These charts depict the course of the postnatal growth of premature infants compared to their intrauterine growth, and indicate that the notion that these children "grow out" of their retardation, including retarded size and weight, is not supported by the data. In fact, in an earlier article by Lubchenco, et al. (1963), many other sequelae to premature birth are identified as developmentally hazardous.

A high incidence (68%) of central nervous system and visual handicaps was found in a group of small premature infants, ten years after birth. Sixty-three of 94 surviving children who weighed 1,550gm (3 lb. 4 oz.) or less at birth were available for follow-up examination at approximately ten years of age. The incidence and severity of handicaps were inversely related to the weight at birth. Difficulties in the neonatal period were also inversely related to birth weight, while obstetrical complications and oxygen administration showed no such correlation. Growth retardation was severe, social and emotional problems were encountered, and school failures among children with normal intelligence were seen in 30% of the group (p. 148).

These findings (see Figure 6/3) should underscore the importance of identifying premature infants as being at risk for many different developmental disabilities and of following them closely because of the high probability of their developing handicaps whose severity is typically inversely proportional to their birth weight. In a related study dealing with the long-term outcome of children by birth weight and gestational age:

The cause of the poor outcome of pre-term infants is not known, and it is presumptive to state that spastic diplegia or minimal cerebral dysfunction are due to a lack of glucose in the first hours

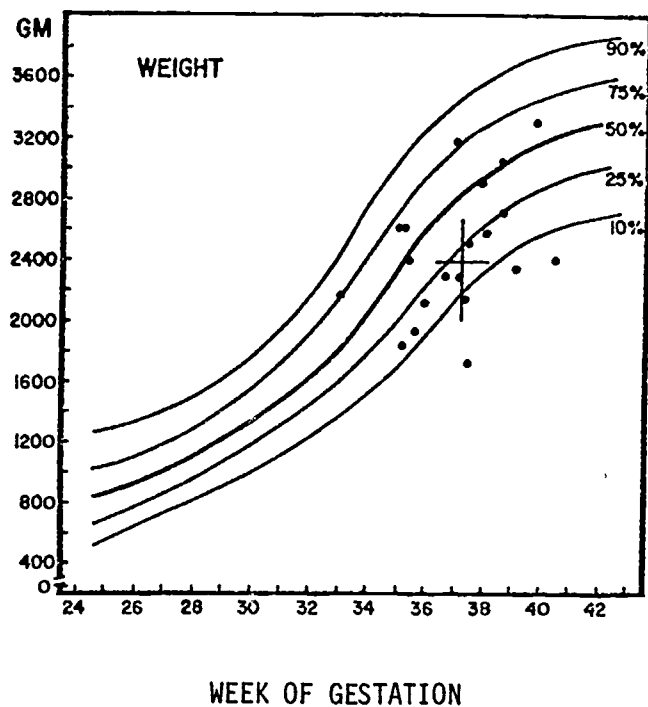
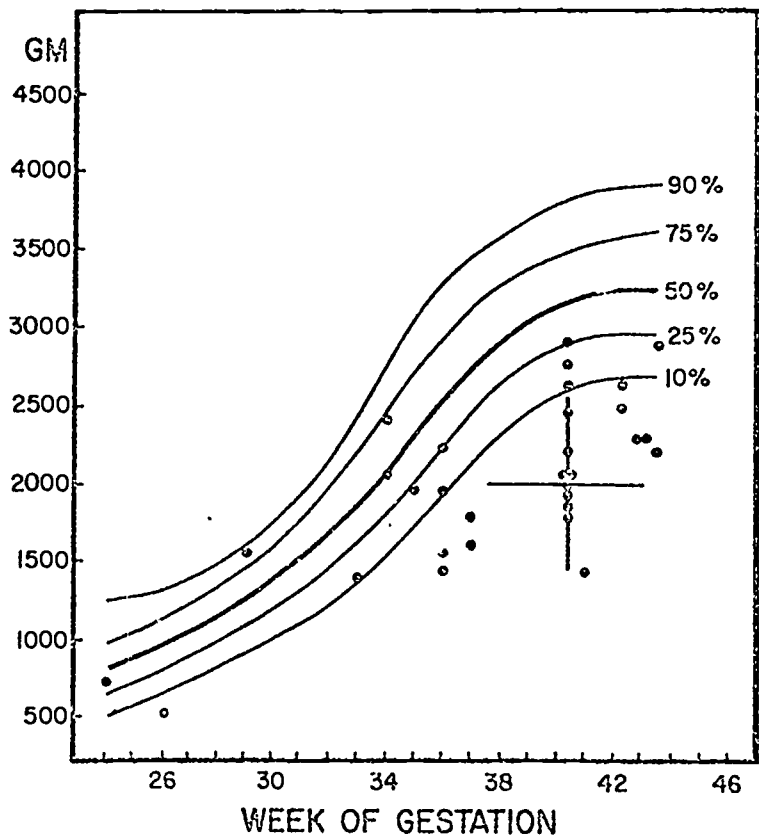


Figure 4/6: The wide scatter in birth weights and gestational ages of infants with Down's syndrome is shown. This loose cluster had a median gestational age and weight of 37 weeks and 2400 gm. (Lubchenco, 1970).



Adapted from Schutt

Figure 5/7: The median birth weight and gestational age for infants born with trisomy 16-18 centers around 40 weeks and 2000 gm. (Lubchenco, 1970).

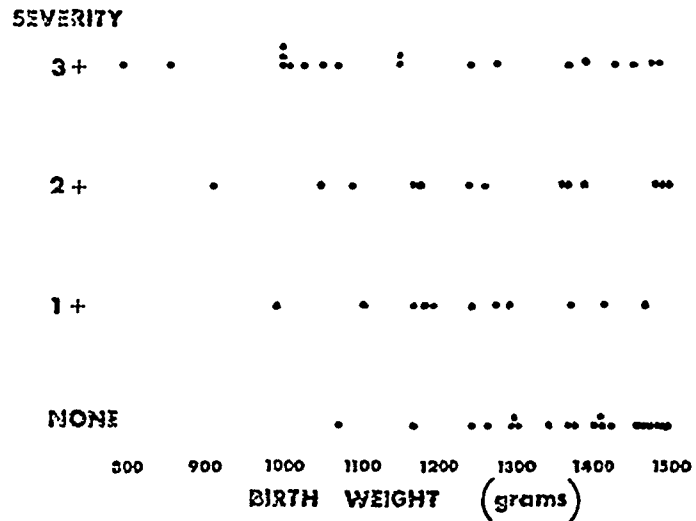


Figure 6/3: There is an inverse relationship of severity of handicaps to birth weight. There are only two normal children among those whose birth weights were less than 1,200 gm. (2 lb 10 oz), while the majority with birth weights over 1,200 gm. are normal (Lubchenco, et al., 1963).

of life. IV glucose and bicarbonate therapy may alter other metabolic parameters, such as bilirubin, which may be unbounded and toxic to the brain, or the glucose may compensate for cold stress (Figure 7/6).

In summary, the initial perinatal course of SGA infants appeared to be relatively uneventful, but their long-term prognosis turned out to be poor. Undetected neonatal hypoglycemia is one possibility for the poor outcome; another could be unrecognized intrauterine infection. Gross or definite congenital anomalies were excluded before the analyses (Lubchenco, 1971, pp. 8 & 9).

Statistical Derivation of Mortality and Morbidity Risk Indicators

In order to increase the yield of any massive screening system, it is possible to do some pre-primary screening by means of various census data. To follow the analogy in Chapter I, there are some orchards which produce far more abnormal oranges than others and, given a limited amount of resources to cull out and rectify the largest number of abnormal, the screening should concentrate on oranges from the "worst" orchards. Thus, it is suggested that initial screening systems should concentrate on the populations from the highest-risk ballparks which can be located statistically because they produce the largest percentage of stillborn or defective children per 100,000 pregnancies, etc. Further elaboration on the use of various demographic data to plan comprehensive screening system for an hypothetical representative U.S. community of 100,000 is presented in Chapter VI of this monograph. The following discussion is restricted to factors which adversely affect the physical life of the child.

For many years infant mortality levels and their reduction have been topics of major concern to persons in all nations involved with health care. These mortality levels have been studied from the point of view of sex, race, geography, degree of urbanization, age at death and underlying cause of death as reported on the death certificate. However, most studies in the U.S. have dealt with either a gross review at the national level, a detailed examination of two or three of the elements outlined above, or a relatively small geographic subset of the data. The current study at The George Washington University concerning causes of infant deaths in the United States endeavors to present, in a more comprehensive form, the relationships of all of the categories mentioned. It is hoped that this analysis will assist in health program development.

The reduction of infant mortality levels is a primary goal of the Maternal and Child Health Service and has often been cited in recent years as a national goal. Moreover, data on births, fetal loss and infant mortality are important elements of one of the major data collection efforts in this nation, from local vital records agencies to state and federal centers.

It is already known that infant mortality levels are declining and that mortality levels are different among various population groups. This study of causes of infant deaths addresses the need for a more encompassing review of infant mortality to see if it will enable health program staff to focus their program efforts more precisely. The study proposes to take a detailed look at infant deaths and infant mortality rates 1962-1967 in order:

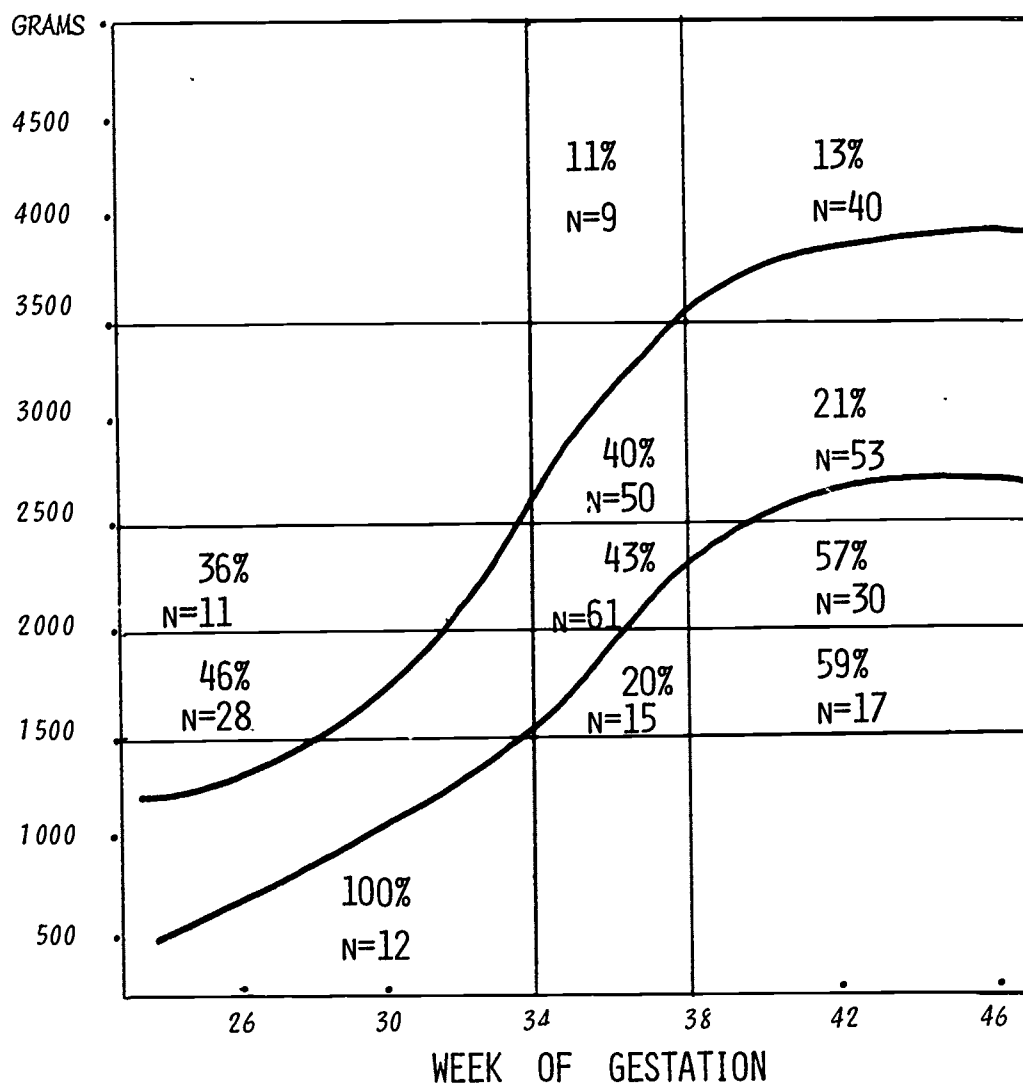


Figure 7/6: Overall incidence of handicaps by large birth weight-gestational age blocks. Congenital anomalies and minor handicaps included (Lubchenco, 1971).

- 1) to present the variables and combination of variables which describe the infant mortality problem;
- 2) to report the progress made in reducing mortality in terms of these variables; and
- 3) to point out the major categories needing improvement if infant mortality levels are to continue to decline (MCH Exchange, 1972, p. 15). (Table 3/9 and 4/13.)

With regard to some epidemiological characteristics of clinical/organic mental retardation alone in an hypothetical community of 100,000 people, these findings take on increased significance.

The statement is frequently made that 3 percent of the population of the United States, i.e. 6 million persons, is mentally retarded. This estimate assumes that: (a) the diagnosis of mental retardation is based essentially on an IQ below 70; (b) mental retardation is identified in infancy; (c) the diagnosis does not change; and (d) the mortality of retarded individuals is similar to that of the general population.

We have emphasized repeatedly that these assumptions are not supported by clinical experiences, and we have placed the estimated number of individuals in whom mental retardation is clinically diagnosed, or in whom the diagnosis would be ascertained upon examination, at 2 million rather than 6 million. The smaller figure results in a prevalence rate of 1 percent rather than 3 percent.

The following two basic considerations led us to the lower estimate. First, the commonly accepted criteria for the clinical diagnosis of mental retardation require that concurrently with a significant impairment in intelligence, as measured by psychometric tests, a similar impairment in adaptive behavior also be present, and that both of these symptoms manifest themselves during the developmental years (Heber, 1961). Many preschool children and adults, however, do not show major impairment in general adaptation even with relatively low IQ's. As a consequence, the clinical diagnosis of mental retardation, particularly when it is of mild degree, is age dependent. It is usually not established before school age and often disappears during late adolescence or young adulthood.

Second, mortality in retarded individuals is inversely related to IQ, with only the mildly retarded having life expectancies which approximate those of the general population. Though 3 percent of the newborn will be suspected and even diagnosed as mentally retarded some time during their life, probably during their school years, it is incorrect to assume that at any given time 3 percent of the population is so identified or is apt to be so diagnosed (Tarjan, Wright, Eymann, & Keeran, in press, pp. 2-3).

Figure 8/1 from this same article depicts the above relationships and demonstrates the importance of definition, much as pointed out in *The Six-Hour Retarded Child* (PCMR, 1969).

Narrowing this down even further by zeroing in on a specific state, it becomes apparent that pre-primary screening using a data system approach not only reveals the high-yield ballpark but also may substantially simplify the primary screening process.

Cause of Death	Metropolitan														
	Total Metropolitan	Urban Places							Balance of the County						
		Total Urban Places	White ¹			Other ¹			Total Balance of County	White ¹			Other ¹		
			Total White	Male	Female	Total Other	Male	Female		Total White	Male	Female	Total Other	Male	Female
Infective & Parasitic Diseases	23.9	23.9	20.1	22.0	16.1	38.7	41.8	35.6	23.8	20.7	22.0	19.4	65.7	68.4	62.9
Nervous & Sensory Diseases	37.6	38.5	31.5	34.9	28.0	64.9	70.4	59.3	35.4	31.1	33.7	28.4	90.5	98.9	82.0
Diseases of the Respiratory System	240.7	252.4	187.9	219.7	154.5	497.3	541.6	451.9	209.6	177.5	206.2	147.2	634.4	655.4	612.9
Diseases of the Digestive System	60.2	62.3	50.5	57.4	43.3	105.4	122.6	87.8	54.6	45.2	48.6	41.6	178.3	205.3	150.6
Congenital Malformations	349.4	352.3	362.9	382.4	342.3	312.6	338.6	286.0	341.8	343.0	357.5	327.7	324.0	341.5	306.1
Certain Diseases of Early Infancy	1480.5	1565.5	1344.0	1551.5	1125.3	2390.2	2654.1	2119.6	1253.0	1189.3	1382.3	986.1	2076.9	2340.9	1806.9
Ill-defined Conditions	45.7	47.1	30.4	35.3	25.2	112.9	123.8	101.8	42.0	33.6	40.1	26.8	154.8	162.5	147.0
Accidents & Violence	73.7	73.8	59.6	66.6	52.3	125.6	133.0	118.0	73.5	66.5	73.5	59.0	167.1	179.7	154.1
Residual of Diseases	45.2	45.0	42.2	46.6	37.5	56.7	65.1	47.1	45.7	43.1	47.4	38.6	80.7	91.9	69.3
Total	2357.1	2460.8	2129.1	2416.3	1826.5	3704.5	4091.9	3307.2	2079.4	1950.1	2211.4	1674.7	3772.4	4144.6	3391.9

Cause of Death	Non-metropolitan														
	Total Non-metropolitan	Urban Places							Balance of the County						
		Total Urban Places	White ¹			Other ¹			Total Balance of County	White ¹			Other ¹		
			Total White	Male	Female	Total Other	Male	Female		Total White	Male	Female	Total Other	Male	Female
Infective & Parasitic Diseases	45.5	40.5	32.9	37.8	27.6	90.6	94.9	86.2	47.5	33.6	36.6	30.5	121.8	129.5	113.8
Nervous & Sensory Diseases	40.3	36.3	31.0	36.0	25.7	71.1	76.8	65.3	42.0	33.1	36.9	29.1	89.1	99.4	78.6
Diseases of the Respiratory System	307.1	256.9	192.0	225.5	156.4	673.5	725.0	621.0	328.1	219.5	246.4	191.1	903.8	953.4	852.9
Diseases of the Digestive System	111.7	95.5	68.0	77.1	58.4	273.7	301.8	245.2	118.4	71.1	79.6	62.1	370.0	407.1	331.8
Congenital Malformations	348.1	361.9	374.2	396.4	350.7	284.7	320.5	248.3	342.3	355.1	374.7	334.5	274.7	305.4	243.3
Certain Diseases of Early Infancy	1470.9	1576.5	1454.3	1682.8	1212.3	2367.5	2655.3	2074.3	1426.9	1309.2	1521.5	1085.4	2046.5	2283.5	1803.5
Ill-defined Conditions	99.4	67.6	32.0	38.5	25.1	298.1	322.3	273.5	112.7	44.9	51.4	37.9	473.7	524.2	421.9
Accidents & Violence	121.5	106.2	87.2	94.3	79.6	230.4	241.9	218.7	127.9	103.1	116.6	89.3	259.4	273.6	244.9
Residual of Diseases	51.7	48.9	46.1	51.6	40.3	68.7	78.6	58.5	52.8	47.7	51.3	44.0	79.8	88.3	71.1
Total	2596.1	2590.3	2317.6	2640.0	1976.1	4358.4	4817.1	3891.0	2598.6	2217.6	2515.0	1903.9	4618.8	5064.4	4161.9

¹Excludes New Jersey for 1962 and 1963

Table 3/9: Infant Mortality Rates per 100,000 live Births by Degree of Urbanization, Color, Sex and Cause of Death - 1962-1967 U.S. Data (MCH Exchange, 1972, p. 37).

Cause of Death	1962-1964	1965-1967	1962-1967	Percent Distribution 1962-1967
Intracranial & Spinal Inj. w/o Immat.	4,812	3,620	8,432	2.5
Intracranial & Spinal Inj. with Immat.	3,310	3,250	6,560	1.9
Other Birth Injury w/o Immat.	5,614	4,387	10,001	2.9
Other Birth Injury with Immat.	13,168	10,110	23,278	6.8
Postnatal Asphyxia & Atel. w/o Immat.	14,333	11,268	25,601	7.5
Postnatal Asphyxia & Atel. with Immat.	39,091	30,900	69,991	20.4
Pneumonia of Newborn w/o Immat.	7,072	5,418	12,490	3.7
Pneumonia of Newborn with Immat.	2,550	2,051	4,601	1.3
Diarrhea of Newborn w/o Immat.	962	662	1,624	0.5
Diarrhea of Newborn with Immat.	234	180	414	0.1
Other Infections of Newborn w/o Immat.	1,467	1,345	2,812	0.8
Other Infections of Newborn with Immat.	1,030	1,060	2,090	0.6
Neonatal Disorders w/o Immat.	804	752	1,556	0.5
Neonatal Disorders with Immat.	1,380	1,124	2,504	0.7
Hemolytic Disease w/o Immat.	4,229	2,799	7,028	2.1
Hemolytic Disease with Immat.	1,257	1,152	2,409	0.7
Hemorrhagic Disease w/o Immat.	991	850	1,841	0.5
Hemorrhagic Disease with Immat.	639	627	1,266	0.4
Ill-defined Diseases w/o Immat.	8,037	7,176	15,213	4.4
Ill-defined Diseases with Immat.	22,294	23,395	45,689	13.3
Immaturity, No Subsidiary Condition	3,223	3,560	6,783	2.0
Immaturity, Unqualified	50,650	39,568	90,218	26.4
Total	187,147	155,254	342,401	100.0

Table 4/13: Distribution of Each Cause of Death Classification in "Certain Diseases of Early Infancy" - 1962-1967 U.S. Data (MCH Exchange, 1972, p. 48).

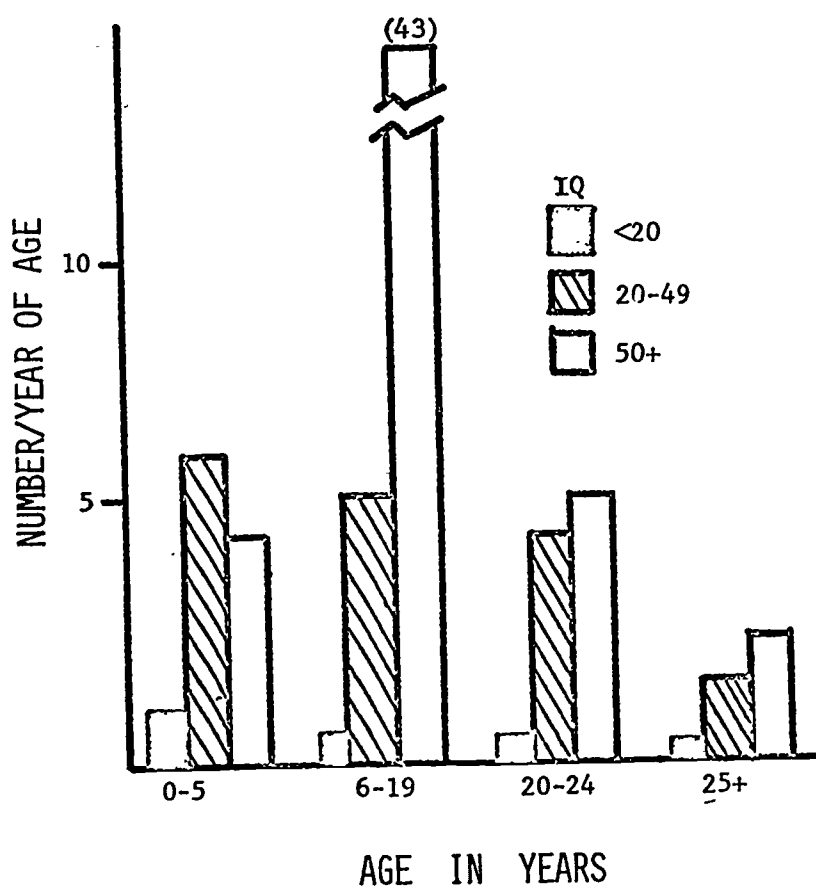


Figure 8/1: Estimates of Numbers of Retarded Persons per year of Age in a Community of 100,000 (Tarjan, et al., 1972).

This study indicates that there are selected combinations of characteristics which facilitate classification of patients as to relative risk of fetal death, neonatal death, and postneonatal death. These characteristics are clearly outlined for North Carolina in Table 5/8. Since community populations have different demographic and socioeconomic characteristics, there will be differences as to which characteristics are at play in any given community. Therefore, it is necessary that birth and death statistics be presented in such a manner as to provide each community the necessary information to classify their populations as to risk of the three morbid outcomes of interest in this paper.

A data system which can provide this information should be established. This would then allow one to promote and make effective the casefinding, outreach, and follow-up programs which initiate service for high risk women and insure that services would be maintained throughout the gamut of care prescribed. Therefore, the purpose of the data system would be to assure that all women, particularly those who are at risk, enter a system of care.

Finally, this regimen of care must be provided through a systematized concept which will insure that the individual at risk is continually under care. When any woman fails to receive or maintain service, the system should be in a position to discover the reason for the break in the pattern of care and correct it. This in turn would lead toward the identification of the avenues available for improvement of the program.

It should be apparent that the data system screens the population as to risk. This, then, eliminates the need for screening of patients at the time of entrance for care since the data system has provided the screening of the population. Screening can be established in a given community by utilizing the characteristics of individuals who have high mortality potential.

It may be necessary to modify the characteristics of risk by the experience of future years. The basis for definition could be the experiences of prior years. All of the information about the individual at risk must return to the community in a manner that is effective and efficient. Unless outreach services are directed by an adequate data system, the service system may fail since service units can only serve those women who present themselves for assistance or care.

By studying the characteristics of the birth and death population of a previous year, the characteristics of the high risk group can be established by asking each woman of childbearing age the six critical questions:

1. What is your age?
2. How many pregnancies have you had?
3. How many years of education have you completed?
4. Have you had a previous fetal death?
5. Have you had a previous child born alive who is now dead?
6. What is your marital status?

The responses to these questions will classify each woman with respect to risk of fetal, neonatal, and postneonatal death. In order to apply such a system into effective action, one should have a systemized concept of service which includes an effective outreach and follow-up program (Scurletis, Turnbull, & Corkey, 1972, pp. 19-22).

Time of Death	RACE			
	White		Nonwhite	
	High risk pair of characteristics	Rate* per 1,000 events	High risk pair of characteristics	Rate* per 1,000 events
Fetal Period	I and PFD	44.6	Age > 34 and I	82.0
	Age > 34 and Educ < 8	43.0	Age > 34 and PFD	65.9
	BO > 4 and Educ < 8	39.5	PFD and I	60.7
	I and Educ < 8	36.1	Age > 34 and Educ < 8	60.0
Neonatal Period	PLBND and Educ 9-11	52.1	PLBND and I	71.0
	PLBND and PFD	34.8	PLBND and PFD	66.4
	Age < 18 and Educ < 8	33.4	PFD and I	56.7
	PLBND and Age > 34	28.8	PLBND and Educ 9-11	48.1
Postneonatal Period	PLBND and Educ 9-11	14.7	PLBND and I	36.4
	Educ < 8 and PFD	13.2	PLBND and Age > 34	27.2
	Educ < 8 and BO > 4	10.0	PLBND and Educ 9-11	24.7
	Educ 9-11 and I	8.8	BO > 4 and I	24.0

*Rates with denominators less than 100 were excluded from consideration for this table.

I = Illegitimate Child
 PFD = Previous Fetal Death
 BO>4 = Birth Order over Fourth Child
 PLBND = Previous Live Birth Now Dead

Table 5/8: Mortality Rates for High Risk Pairs of Selected Characteristics by Time of Death and Race, North Carolina, 1970 (Scurletis, Turnbull, & Corkey, 1972).

Besides corroborating some of the socio-economic and ethnic findings in the aforementioned studies, de la Cruz and LaVeck (1970) summarize the conditions which may predispose a fetus or infant to being high-risk for developmental disabilities (see Table 6/1). After discussing the items in Table 6/1 and suggesting some modern management techniques, they proceed to address some challenging prevention and research considerations which are germane to the central theme of this monograph.

Every effort in the field of mental retardation should include prevention as one of its primary objectives. Prevention may be primary or secondary. Primary prevention consists of measures to prevent mental retardation from occurring. Secondary prevention is designed to mitigate the effects of mental subnormality once they have occurred. Examples of primary prevention include elimination and control of communicable diseases, accident prevention, adequate prenatal care, health supervision of infants and children and genetic counseling. Secondary prevention includes restriction of specific components of diet in a few metabolic disorders, administration of thyroid hormone in cretinism and neurosurgical intervention in hydrocephalus.

Physicians, social scientists, and political leaders recognize the importance of family planning in the primary prevention of mental retardation. If family planning information and services were made available to older women, mongolism and other congenital malformations would be reduced. Figure 8 shows a progressively increasing incidence of congenital hydrocephalus, anencephalus and mongolism with increasing maternal age. It has been estimated that avoidance of unwanted births will reduce prematurity by 19 per cent, neonatal deaths by 20 per cent, congenital anomalies by 22 per cent and mongolism by 31 per cent.

The quest for knowledge must continue, through research in the biomedical and behavioral sciences, if the health of our children is to be maintained and improved. Recent research has provided information about induction of enzymatic functions through administration of drugs; intrauterine diagnosis of genetic defects; diagnosis of carriers of potentially lethal diseases; development of biologic products such as rubella vaccine, and gamma G immunoglobulin to Rh factor, and the effect of nutrition on growth and development.

The physician's function--maintenance of health--has not changed but is taking different forms. With routine immunization, modern sanitation, better community and family health standards, and availability of vastly improved chemotherapeutic agents, the treatment of infectious diseases is no longer the be-all and end-all of a physician's practice. He is keeping pace with a society that no longer accepts the inevitability of disabilities and infirmities. He is concerned with preventive medicine, with birth defects, with emotional health. His care of the 'whole child' encompasses the entire continuum of growth and development including the psychological maturation that permits the individual to function in the society in which he finds himself (de la Cruz & LaVeck, 1970, pp. 8-9).

Vision

One of the more comprehensive and thorough studies of vision screening is reported in a publication entitled Vision Screening and the Preschool

- I. Preconceptional factors
 - A. Low socio-economic level
 - 1. Nutrition
 - B. Metabolic disease in the mother
 - 1. Endocrine
 - 2. Amino acid
 - 3. Carbohydrate
 - 4. Lipid
 - 5. Mucopolysaccharidoses
 - C. History of reproductive failures
- II. Prenatal
 - A. Maternal infection
 - B. Toxemia of pregnancy
 - C. Drug ingestion
 - D. Radiation
 - E. Maternal age 16 or 38
 - F. Fetal-Maternal blood group incompatibility
- III. Natal
 - A. Hemorrhage
 - B. Dystocia
 - C. Anesthesia
 - D. Trauma
 - E. Cesarean section
 - F. Prematurity, Postmaturity/Dysmaturity
 - G. Low Apgar score
 - H. Placental infarction
- IV. Postnatal factors
 - A. Trauma
 - B. Infection
 - C. Parental deprivation
 - D. Culturally disadvantaged child
 - E. Single umbilical artery
 - F. Disproportion between weight or length and gestational age

Table 6/1: HIGH-RISK INFANTS (de la Cruz and LaVeck, 1970).

Child (Savitz, Reed, and Valadian, 1964). Among many other conclusions and recommendations, the following statements, which are highly relevant to the topic of this monograph, were included:

Children from 30 months on can be screened even though about 50 percent of the younger subjects might be nontestable. It is better to start early not only because early detection permits more effective treatment, but also because it seems to take so long for referrals to seek professional attention.

The recommended tests can be used effectively with children less than 3 years old and so have the decided advantage over more conventional methods of increasing the yield of positive early findings.

The development of an effective objective vision test which could be used effectively with preschool children and infants would answer many questions. It would permit even earlier detection of low vision, perhaps in the first year of life. It would aid in defining what is normal vision--something which is not really known for young children. It would decrease the number of nontestable children because it would require minimal cooperation from the child. It would enable children who are deaf or retarded to be tested and thus better separate the problem of communicating what is seen from the fact of having seen it (pp. 64-65).

A more recent publication by Lin-Fu (1971) corroborates the preceding study's observations.

Vision screening of preschool children, particularly those under 3, presents certain problems not generally encountered among older children. But with public education, community support, careful selection, training, and supervision of screening personnel, and preparation of the children for testing procedures, vision screening programs for preschool children can be successful (p. 10).

In addition to the above remarks, Lin-Fu makes the following recommendations regarding the need for cooperative effort in public education before a large scale vision screening program can be successfully mounted.

A successful large-scale vision screening program for children requires the coordinated effort of ophthalmologists, optometrists, pediatricians, nurses, social workers, school authorities, teachers, public educators, interested public and voluntary agencies and groups such as local health departments, education departments, and PTA's. The various professions and groups will need to work together in planning screening programs that will be readily available to all children in the community. Attention must be given not only to the actual screening procedures, but also to careful selection and training of testers, preparation of the public for such a program beforehand, and adequate follow-up of children referred for diagnosis (p. 18).

One way in which a large group of paraprofessionals might become involved in the early screening of children's vision is suggested in a proposal that parents do the preliminary screening. Although some studies which were conducted using parents who were in middle- and upper-class

socioeconomic strata seemed to work out reasonably well, it is imperative that such studies be conducted in poverty populations, since they are the ones least likely to have other contact with health professionals or para-professionals. Nevertheless, the results of some of these preliminary studies are instructive and warrant further consideration and replication.

It is in the preschool years that diagnosis and treatment of amblyopia can be expected to yield reasonably good results; detection of amblyopia at school age is considered by many to be too late for treatment to be effective. Because of the difficulty of reaching children in the preschool period, the use of a 'do-it-yourself' vision screening test which can be administered at home by parents has been proposed.

Trotter, et al. (1966), conducted a study among their private patients using an illustrated pamphlet containing isolated E test types and simple directions for testing vision. Among 217 children 3 to 6 years old screened by their parents, the ophthalmologist and parents were in agreement that 183, or 84 percent, of the children had bilateral acuity of 20/30 or better. Six children, or 3 percent, were considered false referrals. Among 16 children found by the ophthalmologist to have a visual acuity of 20/40 or worse, only 8 were discovered by parents in their screening.

The Illinois Chapter of the American Academy of Pediatrics together with the Illinois Department of Public Health and the Chicago Medical Society recently developed a modified Sjogren hand card to be administered by parents to their 3- to 5-year-old children. Children are asked to point their hands in the same direction as the hand pictured on the card at a distance of 3 feet and again at 12 feet (PHS Report, 1967). Among 1,288 children screened by their parents with this card, 97, or 7.5 percent, were reported to have failed. Of these, 37, or 2.9 percent, of the overall number were found to be correct referrals on followup examination. There was no report on the number of children with defective vision who were missed by this parent-administered screening procedure (Press and Austin, 1968).

Although these preliminary studies suggest that do-it-yourself vision screening tests are feasible, one should interpret these results with due reservation since these surveys were conducted among private patients; the results may not be duplicated in a different population. Parents administering such tests should be warned of their limitations and instructed to seek professional help if visual defect is suspected, whether or not the child passes the parent-administered test. These tests have potential value in areas where vision screening programs for preschool children do not exist, and for individual children who cannot be reached by screening programs until after they enter school (Lin-Fu, 1971, pp. 16-17).

Another intriguing but as yet unsatisfactorily validated approach to assessing visual functioning in 1-to 3-year-old children is that presented by Koslowski (no date), in which the following germane observations were made:

This test has been developed by the Harvard Preschool Project as one of a battery of new assessment techniques for children of chronological age (CA) one- to three-years. A preliminary finding of the project's research is that especially talented three- to six-year-old

children are good observers. Such children notice small discrepancies in physical appearances, in the following of rules, in statements of logic, etc., sooner than do their peers. We have developed a simple test of the capacity to note discrepancies in physical appearances which may be used with children of CA one- to three-years.

Within the CA one- to three-years, we have repeatedly found it most difficult to test children fifteen- to twenty-months of age. During these few months, the normal growth of autonomous behavior very often interferes with the requirements of test situations. We, therefore, do not ordinarily recommend the use of this or similar tests which require the child of this age to perform numerous cooperative acts (p. 1).

Since only 10 children were involved in the pilot study, and since there are several other issues involved such as those cited by Kagan (1972) which are discussed in Chapter IV of the monograph, it is premature to do any more than mention the above novel and highly experimental approach.

An Eye Screening Manual has been developed by Barker and Hayes (unpublished) and is currently undergoing field testing as a guide for non-professionals to use as a part of a large developmental screening battery. It contains rationale for early screening, description of eye anatomy, and physiology, diseases of the eye, and specific instructions for taking a structured vision history and administering tests for fixation, nystagmus, acuity, muscle coordination, light reflex, general eyeball appearance, and corneal clarity. The usability, reliability and validity of the eye screening procedures have not yet been documented but they do show promise if non-professionals can be trained to satisfactorily follow them. Since the age range is from birth to six years of age, broken into three age subgroups, it is conceivable that parents might follow the instructions and screen their own infants; however, to do this they probably would have to have more than functional literacy and some special, though inexpensive, materials.

Another approach involving the visual apparatus as related to learning capacities and endocrine activity is reported by Petre-Quadens (1970). Although it was difficult to categorize this particular procedure, which could also fit well in the following intellectual/cognitive Chapter IV, it is placed in this section since it is principally concerned with visual and physical factors.

Electro-oculographic recordings were made of the eye-movements of small groups of normal and of mentally retarded subjects during periods of paradoxical sleep. Normal subjects had longer average duration of paradoxical sleep and differed sharply in that they also registered more eye-movements. Frequency of eye-movements did not vary with age in the mentally retarded subjects, whereas in the normal subjects there was noticeably more oculomotor activity between the ages of 6-12 years, the periods when intensive learning occurs. However, there was a dramatic increase in eye-movements in a group of normal pregnant women, suggesting that there may be reciprocal interactions between endocrine mechanisms and those responsible for learning capacities (pp. 738-9).

The chronic quest for physiological indices to intellectual functioning is somewhat encouraged by the correlations reported between eye movements during sleep and learning capacities.

In the mentally retarded subjects, those with an IQ near 60 have eye movements closer in frequency and occurrence to those of the normal subjects than have the retarded subjects with an IQ below 30. ...These results confirm the hypothesis that eye-movements may be the index of one or several factors responsible for learning.

It is impossible to describe the pattern of the eye-movements because of the large inter- and intra-individual variations. As far as amplitude and distribution are concerned, it is possible to point out the characteristics common to the groups to which the subjects belong. In the mentally retarded group the deflections were rather small and the eye-movements almost imperceptible. If 'saccades' appear in subjects in this group, they do so only during the last P.S. stages; however, the activity is not so great as in the normal subjects and this is more pronounced in the adult mentally retarded (p. 736).

Of course it is realized that electro-oculographic recording requires some sophisticated apparatus and trained technicians to operate it, thereby ruling it out as a primary or Stage I screening procedure. Nevertheless, such physiological indices, if proved to have a high predictive value in terms of learning capability (and in this case endocrine activity as well) might be routinely employed as secondary or tertiary screening procedures on children who are being evaluated in controlled situations for other conditions, since it is possible to make these recordings in the home as well as in the hospital setting. The developmental nature of this phenomenon is clearly illustrated by Figure 9/3 from the article which shows the large discrepancies between various age group clusters.

Data such as the above, along with electroencephalographic indices, promise to yield very early clues to central nervous system integrity, which undoubtedly has a high relationship to higher cortical and presumably cognitive functioning. Along these lines, Crowell (1972) at the University of Hawaii, has come up with some highly significant findings relating electroencephalographic data to visual, auditory, and tactile stimulus-response parameters in infants, which is suggestive of even more sophisticated early estimates of CNS functioning, and therefore would enable secondary and tertiary screening to be accomplished with increased reliability and validity.

Hearing

Perhaps an even more elusive index to developmental disabilities is auditory functioning. An article on selective hearing loss and some clues for early identification thereof has been written by Holm and Thompson (1971).

Children who are deaf or hard of hearing often are not referred for audiological evaluation as early as possible. As a consequence, medical, audiological, and educational remediation may be delayed beyond the optimum time for prevention.

Among hearing-impaired children, one of the most difficult to identify is the child with selective hearing loss. Selective hearing

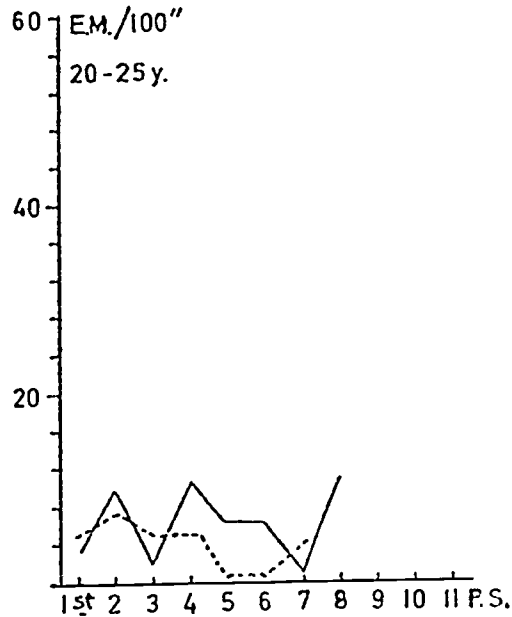
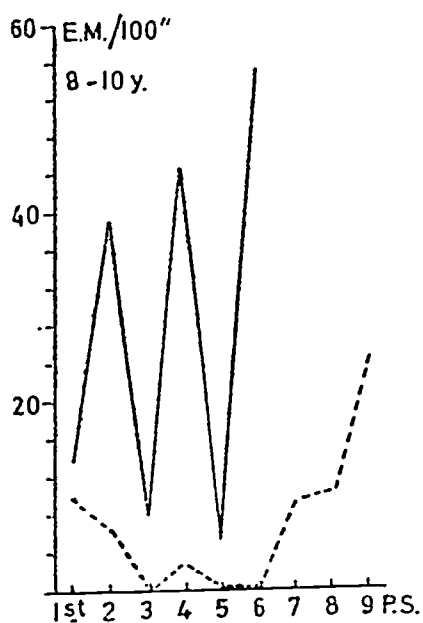
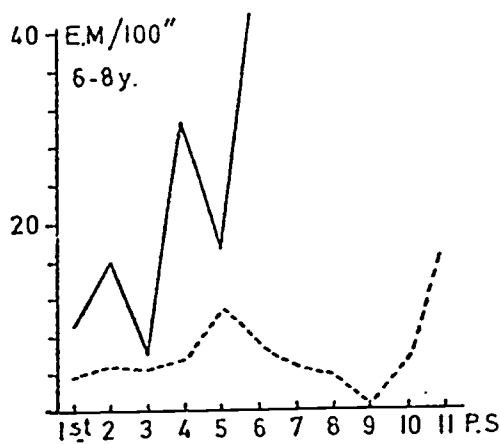
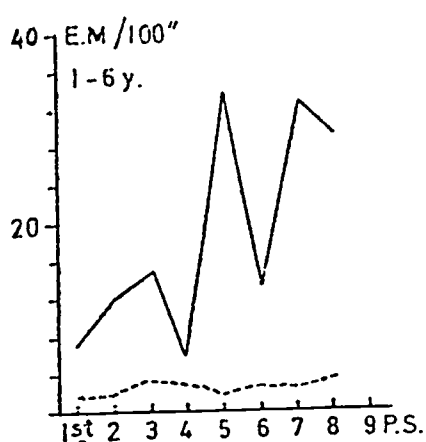


Figure 9/3: Frequency of eye movements in intervals of less than 1 second during successive paradoxical sleep stages during the night. The vertical scale indicates the frequency of intervals less than 1 second per 100 seconds of paradoxical sleep: the horizontal scale indicates the stage of paradoxical sleep (Petre-Quadens, 1970, p. 735). Normally developing children (solid line) show distinctly different pattern from children with delayed development (dotted line).

loss implies normal hearing for some frequencies and a substantial loss for others. If the loss occurs at frequencies which are important for hearing speech, the deleterious effect on speech and language development may be substantial (p. 447).

Figures 10/2 and 11/3 illustrate differences between audiograms of children with normal hearing and a high frequency hearing loss.

Summary and Conclusions: The child in this report was thought at various times to be mentally retarded, emotionally disturbed, and brain damaged before his selective hearing loss was discovered at age 5½ years. He had developed puzzling behavior secondary to the confusing verbal messages he received and his unpredictability in turn had had a disturbing effect on his environment (p. 451).

Some fairly general observations about the benefits of a high-risk register plus some specific findings and advantages from the use of such an approach are reported by Bergstrom, Hemenway, and Downs (1971) with reference to hearing loss and deafness which may be affecting as many as 100,000 children of school age in the United States.

A high risk register, regardless of the diseases it is intended to help detect, is basically a list of factors that may contribute to or be associated with a given handicap, and an individual who carries one or more of these risk factors is said to be 'at risk' for having the disorder or for developing it ultimately. Generally such a register is applied to maladies not evident on mere physical examination of the infant. The high risk concept has been sharply criticized in the last several years, but one of its critics has stated, 'Apparently loss of hearing is the only handicap in which screening of children with histories of risk factors...is likely to uncover a high proportion of handicaps (Richards & Roberts, 1967).'

Use of the high risk concept implies a 'two-tier screening procedure.' The first tier involves the selection of the at-risk population, a group in which the likelihood of the handicapping disorder is apt to be significantly greater than in the general population. For this first stage of the procedure to be feasible a minimal sensitivity level of 80 percent must be achieved. This means that the prevalence of the disorder being sought must be at least 16 times greater in the high risk group than in the general population. Therefore, in setting up a high risk register it is first imperative that we establish that such increased prevalence for congenital deafness does occur in the high risk group.

...in most instances the risk is at least 16 times greater in the high risk group than in the population at large, which carries an incidence of congenital deafness of something like one in 1000 to 2000 live births. However, the general population is 'contaminated' by its inclusion of the high risk group, and therefore in fact the true risk in the general population may be somewhat smaller than this. On theoretical bases, therefore, a high risk register for deafness has good potential usefulness, particularly when the second tier of screening, neonatal audiometry, is applied. An additional advantage is that the high risk register may be used to follow a small manageable group of patients who, because of preconception, prenatal, perinatal, and neonatal insults and inborn genetic factors, may be found to have significant hearing loss on later testing. Conservation of hearing might

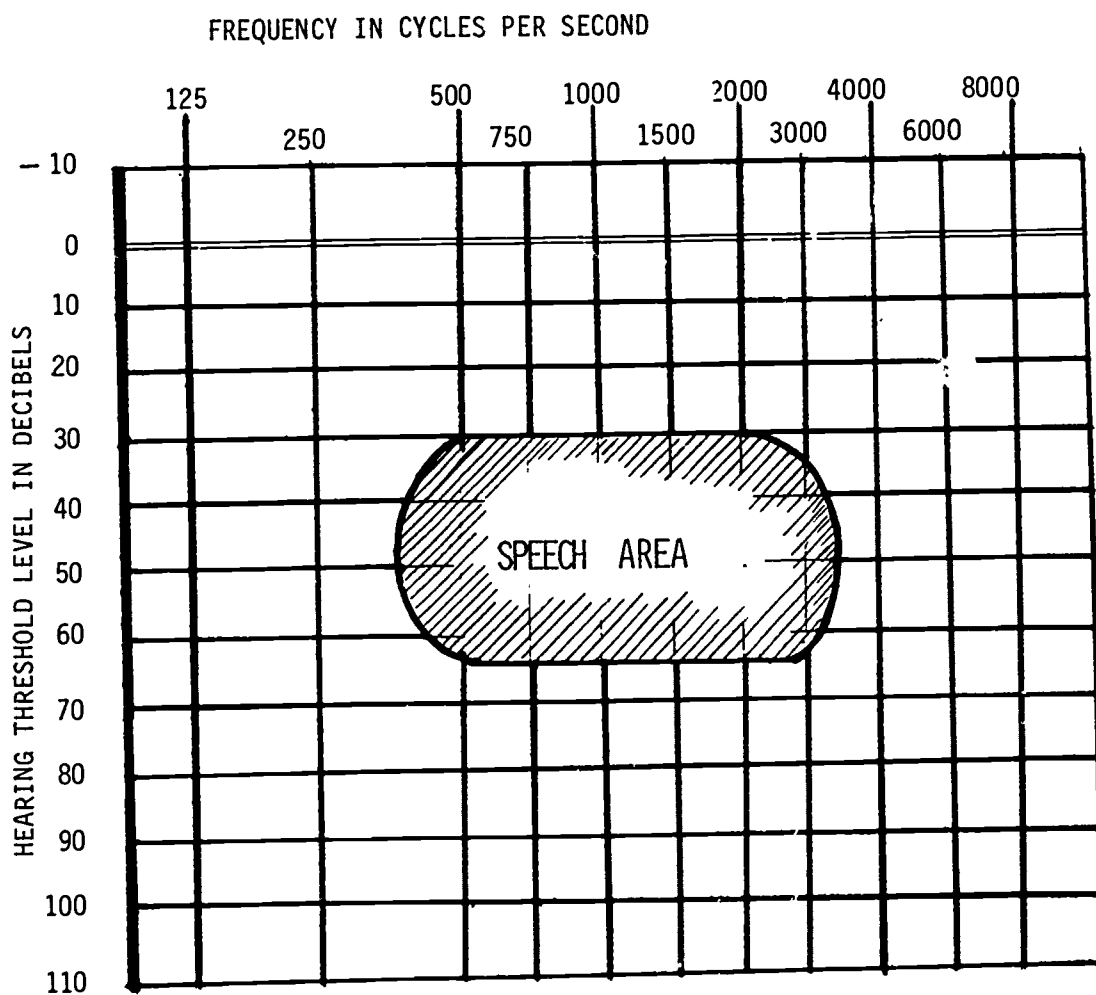


Figure 10/2: Conversational level speech plotted as a function of frequency (c.p.s.) and intensity (dB) (Holm and Thompson, 1971).

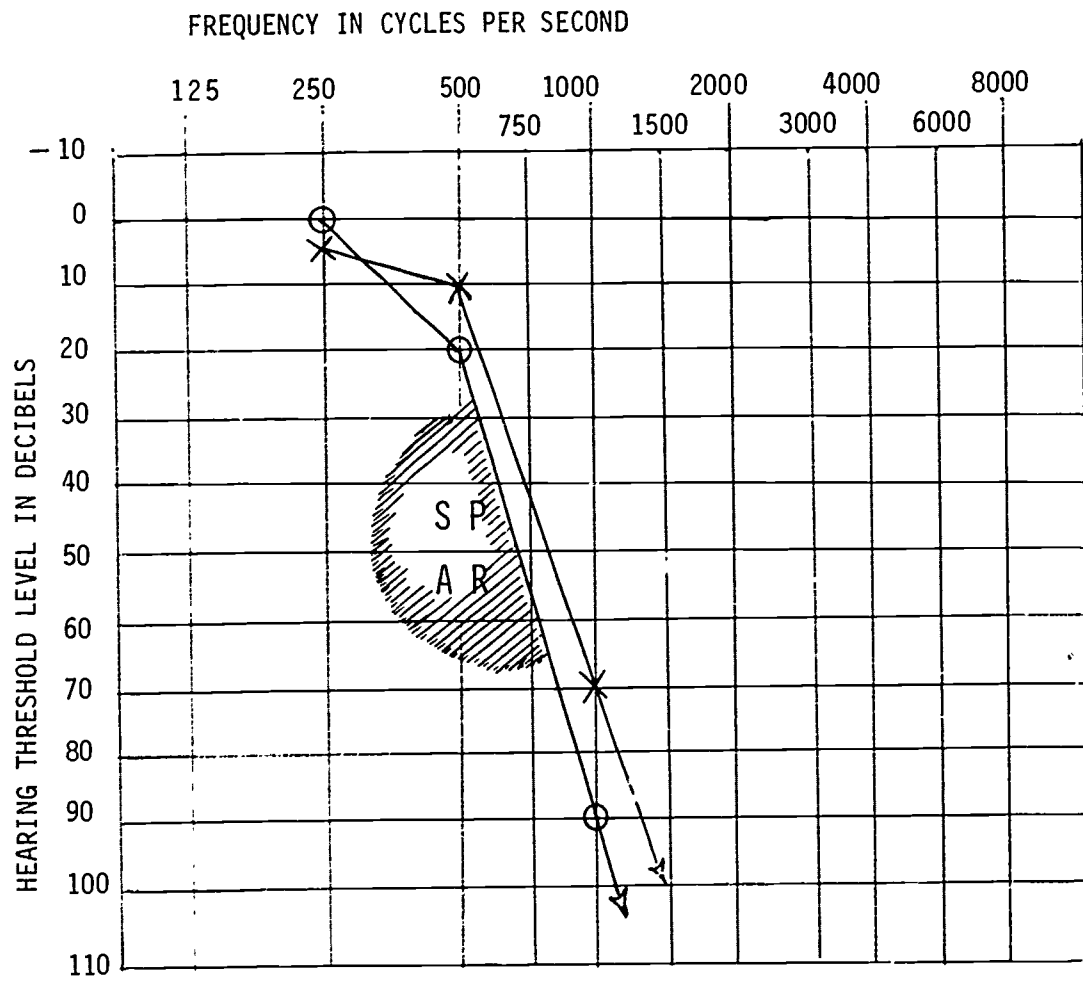


Figure 11/3: The expected effect of high frequency hearing loss on the perception of conversational level speech (Holm and Thompson, 1971).

also be applied to this group by prompt and regular otologic care, avoidance, when possible, of ototoxic drugs, and avoidance of high levels of noise and acoustic trauma (p. 372).

Along with the familiar litany of developmental red-flag phenomena, there are some which are peculiar to deafness or hearing loss; Table 7 summarizes these for a high-risk register in this realm.

Of course, one of the primary reasons for undertaking early screening is to reduce the time intervening between the onset of a condition and some institution of treatment or prevention of further deterioration. One of the most impressive achievements of the risk register and subsequent screening and assessment is stated in the following observations:

...The children in this group with severe to profound hearing losses were an average of 11 months of age when a hearing aid was fitted, as compared to 27 months of age when all children with this degree of hearing loss are assessed. This gives them an average head start of 16 months. We believe that this will give them a long-term advantage as well, but follow-up will be needed to assess this. With more extensive use of the register we anticipate lowering the age at which the child begins to hear, through amplification, the sounds of his language and environment.

...The register then can become a list of historical items and physical findings, which may be checked off on a questionnaire, using the prenatal, obstetrical, nursery, and pediatrician's records as sources, in addition to administering a standard list of questions to the mother. The assembling of these data can to a large extent be done by paramedical or specially trained assistants.... For this reason it has been difficult to convince physicians to carry out the mechanics of a high risk register (Downs, 1970). Therefore, we advocate training paramedical or nonmedical persons to survey the charts and administer the questionnaires. The physician and audiologist can then use this information to select high risk individuals for more intensive testing, follow-up, and, if desired, family studies (Bergstrom, Hemenway, & Downs, 1971, pp. 374-375).

Once again, the techniques are sufficiently simple as far as completing a questionnaire is concerned and can be satisfactorily accomplished by relatively unsophisticated personnel. Thus, the gleaning of critical questions and other indices to various physical risks and the synthesis of these into a common questionnaire and survey checklist would very likely constitute a most helpful first-stage instrument in the screening process for auditory dysfunction.

Downs and Silver (1972) have proposed an elegantly simple procedure for the physician to use for the early identification of the potentially deaf infant in the hospital nursery, his office, or clinic.

Any of the following enhances the likelihood that an infant may be deaf:

A. Affected family.

The presence of any form of hearing loss, other than presbycusis (hearing loss that begins in old age) in a family member.

- I. Antenatal
 - a) Positive family history of deafness
 - b) Familial biochemical abnormality associated with deafness.
 - c) Blood incompatibility (Rh factor).
 - d) Virus infection during early pregnancy.
 - e) Bleeding, especially during the first trimester.
 - f) Drugs, notably any of the mycin group or quinine.
- II. Complications of Labor
 - a) Premature delivery.
 - b) Fetal distress due to maternal shock, etc.
 - c) Prolonged or precipitate labor.
 - d) Difficult delivery - traction on neck or birth injury.
- III. Neonatal Difficulty
 - a) Apnea or cyanosis.
 - b) Cerebral birth injury.
 - c) Jaundice - hyperbilirubinemia (15 mg/cc and above).
 - d) Multiple anomalies - from whatever cause.
 - e) Possible iatrogenic trauma, as noise of an incubator, drugs (notably streptomycin and kanamycin), etc.
- IV. Factors in Early Childhood
 - a) Infections, such as meningitis and measles.
 - b) Chronic respiratory infection and/or allergy.
 - c) Injuries.
 - d) Hypothyroidism.
 - e) Abnormality of external ear.
- V. Possible Social Factors
 - a) Maternal mental retardation.
 - b) Socio-cultural deprivation - poor child care, etc.
 - e) Emotional problems.

Table 7: HIGH-RISK REGISTER FOR IDENTIFICATION OF POTENTIALLY DEAF OR HEARING IMPAIRED CHILDREN (Hardy, 1965).

B. Bilirubin level greater than 20 mg/100 ml serum.

Hyperbilirubinemia due to blood group incompatibility in the newborn period.

C. Congenital rubella syndrome.

Rubella at any time during pregnancy. Sometimes the hearing loss is the sole symptom.

D. Defects of the ear, nose, or throat.

A malformed, low-set, or absent pinna; a cleft lip or palate (including submucous cleft); any residual abnormalities of the first arch; any other anatomic abnormality of the otorhinolaryngeal system.

S. Small at birth.

A birth weight less than 1,500 grams.

Every infant conforming with any of the above categories should be immediately referred to a suitable facility for auditory testing and evaluation. In many instances, adequate audiologic testing in the neonatal period may uncover the existence of hearing loss and allow corrective measures to be started early.

Throughout the first two years of life, at subsequent visits, the following items should be assessed:

H. Hearing concern?

Is the mother concerned about the infant's hearing?

Most mothers of deaf children have some suspicion of this by the time the child is six months old, and often earlier.

E. Ear test normal?

Does the infant respond normally to a simple orientation test using noisemakers? (See subsequent instructions.)

A. Awaken to sound?

Does the infant stir or awake in response to noise when he is sleeping in a quiet room? If the mother has not observed such behavior, she should be asked to look for it and report at the next well-baby visit. Should she say that the infant responds to the slamming of doors or to other vibrations but not to the spoken voice or to other sounds, he may be responding only to the vibration caused by the forceable closing of the door and not to the sound.

R. Responses in the developmental and communication scales?

Are the child's prelinguistic and linguistic skills at the expected levels in the developmental and communication scales?

Negative answers to any of these questions should lead to thorough investigation for possible hearing loss.

When evaluating an assessment, one must be aware that deafness does not keep an infant from babbling or vocalizing. Until about age six months, a deaf infant makes the same sounds as a normal infant, babbles as much, vocalizes freely, and will increase his vocalizations when a parent is present. These responses are indicators of social development and are not necessarily a reflection of his ability to hear (pp. 563-565).

Young (no date) extends these concepts to their application by a broader spectrum of personnel. Table 8 gives some guidelines for primary stage hearing screening.

Age Range 2 to 6 Months

Arousal Methods

- 1) Warblette or other special sound field, pure tone generator.
- 2) Cowbell, castanet, intense clicker ("frog"), drum.
- 3) Cup and spoon.

Responses

Moro reflex,
Auropalpebral reflex,
Gross bodily movements,
Toe and finger spreading,
Changes in breathing rate
and type. A "sigh."

Comments

Criteria for referral

Failure to respond to sound.

Lack of response to sound in neonate and infant may not necessarily reflect hearing loss, but be part of a central nervous system dysfunction where other sensory and motor systems are involved.

Age Range 7 to 12 Months

Methods

Distraction methods using sounds intrinsically interesting to children, e.g., spoon in a cup, crinkling of tissue paper, squeaker toys, speech sounds such as s, sh, p, b may also be used. Infant should be seated on parent's knee and distracted by toy held in front by assistant. Sounds are presented at quiet levels (40-50 dB) behind child's back, out of vision on each side. A distance of 2 - 3 feet may be used.

Response

- 1) Location of sound source by head turning.
- 2) Movement of eyes in direction of sound.
- 3) Quieting of bodily activity.

Criteria for referral

Failure to respond or consistent turning to the wrong side.

Comments

Adaptation may be very rapid, requiring a new, unique noisemaker for each presentation. Turning to wrong side may indicate unilateral hearing loss.

Table 8: HEARING SCREENING IN INFANTS (Young, no date).

Mass auditory screening in newborn nurseries has been conducted in several parts of the country recently but problems were found in lack of observer agreement of what constituted a response, on follow-up requirements, and on the high percentage of false negative responses. There is general agreement now that the newborn period is not the best time for reliable hearing screening because of the neonate's psychophysical instability. The period from two to three months to one year is now viewed as the optimal time for assessment.

Two distinct stages in auditory maturation can be observed: the early reflexive response period under 4-6 months when intense stimuli (90 dB) elicits eye blinks, bodily startle and other behavioral changes, and the later period (beyond 6 months) when listening skills are developing. At this time rather soft (30-50 dB) sounds and voice elicit head turning in their direction, arousal and listening-like behaviors. Ideally, every infant should be screened during each period, ruling out severe to profound deafness in the first instance and ruling out probable mild to moderate hearing loss at the later stage.

There is general agreement that all infants who are at high risk for hearing impairment be screened as soon as that risk has been determined.

The development of a meaningful infant auditory screening program nationwide will require that all personnel involved in pediatric health care be trained and equipped to conduct the screening tests. This could be accomplished in well-baby clinics in hospitals, county health departments, child care centers, and in private offices of pediatricians. Both medical, nursing and health care personnel should be trained to routinely perform this screening task.

Abused and Battered Children

Another group of children which should be screened as 'at risk' are those who have a high probability of being abused or battered (Helfer and Kempe, 1968). According to a preliminary report (Walworth & Metz, unpublished), it does seem possible to identify children who are likely to suffer psychosocial or medical problems arising from often undetected physical abuse or less flagrant forms of parental mistreatment such as neglect, excessive pressure, cruel ridicule, etc. Using two new parent questionnaires as a part of the procedures for the Pediatric Multiphasic Examination, these investigators checked out parent satisfaction with the behavior of their child and the child's family background as it might relate to his emotional and physical well-being. The preliminary and confidential findings are such that replication studies with larger numbers of subjects are certainly warranted since the questionnaire findings do predict children who are very likely to suffer various kinds of parental mistreatment. Although no actual cases of child battering are reported, an identifiable group of subjects had a much higher incidence of accidental injuries, poisoning or swallowing of foreign objects, poor parental discipline, probable psychosomatic reactions, parent or teacher dissatisfaction, doctors' notations of parental neglect, and indications of the need for counseling. The parents of these children also reflected dissatisfaction with their children's behavior on the behavior questionnaire. If these findings are replicated in a larger and more carefully controlled study, such high-yield questionnaire items would certainly be important inclusions for a massive screening interview, during

which these, along with other factors related to incipient or potential developmental disabilities, could be identified.

Using a sociocultural, as opposed to a clinical, approach to physical child abuse, Gil (1971) reveals the complexity of the problem.

The culturally sanctioned use of force in child rearing thus constitutes the basic level of all physical abuse of children. Different social classes and ethnic and nationality groups tend to differ in their child-rearing practices, and also in the extent to which they approve of physical force as a socialization method. These variations among social classes and ethnic groups constitute a second dimension of the phenomenon. The third dimension is determined by environmental chance factors that may transform 'acceptable' disciplinary measures into unacceptable outcomes. The fourth dimension is a broad range of environmental stress factors that may weaken a person's psychological mechanisms of self-control and thus contribute to the uninhibited discharge of aggressive and destructive impulses toward physically powerless children. The final dimension is a broad range of deviance in physical, social, intellectual and emotional functioning of caretakers, and at times of children in their care, as well as of entire family units to which they belong. Physical abuse of children appears thus to be a multidimensional phenomenon rather than a uniform one with a single set of causal factors (p. 391).

He then places the issue of child abuse in the much larger perspective, which is what makes massive and comprehensive screening so important and at the same time enormously complex.

...The basic question seems to be not which measure to select for combating child abuse, but whether American society is indeed committed to the well-being of all its children.

It is important to keep in mind that physical abuse committed by individual caretakers constitutes a relatively small problem within the array of problems affecting the nation's children. Abuse committed by society as a whole against large segments of the next generation through poverty, discrimination, malnutrition, poor housing and neighborhoods, inadequate care for health, education and general well-being are far more dangerous problems that merit the highest priority in the development of constructive social policies (p. 394).

On the other side of the coin is an effort to identify children who are prone to violence, which in itself may be a developmental deviation and may precipitate battering or abuse in reaction to such violence. For example, the child who is violence-prone and expresses this through temper tantrums at an early age may become the subject of parental abuse and consequent additional handicaps. One novel way of detecting such children is related to speech deviations and described as follows:

The test of the speech sounds, employed in this study, is relatively simple to give, unobtrusive for child or family, and very economical in terms of use of professional time. Such virtues are a prerequisite in these days of need for large scale mental health screening.

In this study we explored only one specific relation between a particular sound abnormality and a particular behavioral pattern. We are working on several other specific correlations, as well as clusters and combinations of speech sound difficulties associated with certain personality habits.

But already some of the unique advantages of speech sound screening as a detection device can be gingerly stated: it can be administered by any person able to read and operate a tape recorder; it is very brief, taking on the average less than a few minutes to gather up the raw data; it can be given practically anywhere without tying up office space, clinic schedules, etc. The data can be obtained anytime, such as evenings or weekends when working families are more likely to be available. The data can be professionally processed at a central location in approximately one-half hour per recording (Fillippi & Rousey, 1971, p. 161).

Although the above speaks primarily to one particular behavioral pattern of proneness to violence, it does seem to be a promising technique for large scale screening, particularly if the yield in terms of other personality and health factors can be determined and reliably and validly elicited. The authors go on to point out that this relatively simple and nonthreatening procedure using speech sound findings as indicators for potential behavior should never be a substitute for comprehensive diagnosis but only as one of a series of indications that further evaluation and subsequent intervention be undertaken.

Neurological Screening

The state of the art and science for screening and assessing the integrity of the nervous system in infants and toddlers is itself in need of considerable refinement. The subtle interrelationships between neurological dysfunction and behavior disorders in early childhood is eloquently presented by Touwen and Prechtl (1970). These same distinctions are equally germane to the contents of all subsequent chapters in this monograph, which emphasizes the necessarily and inextricable interdisciplinary nature of this screening endeavor.

Despite a volume of work on these subjects, surprisingly few papers discuss in detail the neurological examination which will identify children with neurological dysfunction. Reliable assessments of behavioural problems have been made by psychologists for many years; similarly standardized techniques of neurological examination are urgently required. This is particularly true with regard to children whose signs of brain dysfunction are not gross and obvious to the clinician, but occur in rather inconspicuous form. Even recent publications on the neurological examination in infancy and childhood...pay little attention to the problems of diagnosis arising in such cases. This book may therefore fulfil a worthwhile function in providing a description of the neurological examination procedure for the detection of minor nervous dysfunction in children as developed in our department.

The nervous system must be considered as the apparatus for the performance of complex behaviour. A strict distinction between neurological phenomena as described in the previous paragraphs and

certain aspects of behaviour, such as vigilance, attention span, persistence of visual fixation or voluntary goal-directed movements, is in fact purely artificial, and based only on the traditional distinction between neurology and psychology.

The different methodological basis for each discipline has led to a divergence in approach, while at the same time, the two modes of approach have often been mixed up, giving rise to much confusion. This is the case in the so-called syndrome of 'minor brain dysfunction.' Many studies carried out in this area suffer from serious methodological shortcomings, often combined with a wide acceptance of various superstitions, especially on the part of clinicians, while factual data are extremely limited.

It must also be borne in mind that behaviour is influenced by many other factors of non-neurological origin. Together with genetic and exogenous determinants, psychogenic and somatic conditions play a decisive role as regards overt behaviour. This complex cohesion of different factors makes any analysis of the relationship between neurological dysfunction and behavioural phenomena extremely difficult. The context of this book does not allow an extensive discussion of these factors, but their significance must not be overlooked and cannot be overestimated. However, a few points may be stressed. A nervous dysfunction which manifests itself in a child's behaviour will lead to reactive behaviour from his environment. This is true even at a very young age.... For instance, the presence of signs of the hyperexcitability syndrome in the first few weeks of life may endanger the development of the child-mother interaction, involving uncertainty on the part of the mother which may persist throughout the years of the child's development and influence her relationship with the child as it grows up....

Slight nervous dysfunction may sometimes hinder a child in his school work, though quite unspecifically, and his achievement will fall below the expectations of his parents or teachers. Repercussions of this may influence the parent-child relationship or the relationship between the child and the teacher. The resulting attitudes of parents, teachers and even playmates may inflict a burden on the child. Children with slightly less than optimal functioning of the nervous system seem particularly vulnerable to such environmental influences, so that a relationship between neurological dysfunction and behavioural disturbance may develop by this devious route.

Nevertheless, the same behavioural disturbances may exist without signs of nervous dysfunction. It must now be clear that in such cases a conclusion as to the existence of a syndrome of 'minor brain damage' is quite inadmissible.

Much basic research remains to be done. In connection with our interpretation of many findings of the neurological examination, our knowledge about normal nervous functioning is still remarkably small. For instance, a further validation of the maturation of abilities such as diadochokinesia, fine finger manipulations, tests of coordination, hopping, standing on one leg, etc., is badly needed. This applies, too, to the role of cerebral dominance in such functions, the development of hand and foot preference, the significance of dominance with regard to the presence of associated movements, and its maturational course.

In summary, one is forced to conclude that it is not possible to think in terms of simple relationships between disturbances of nervous functioning and of behaviour. In each child, it is necessary to evaluate separately the dynamics of the different factors that contribute to the establishment of his ultimate behaviour. There is a stringent need for data about all these different factors which must be collected without contamination from other sources. Perhaps it will then be possible to find a specific relationship between several of them, bearing in mind that in each individual the relationship may develop along different lines (pp. vi & 90-91).

Although the above book goes into great detail for doing a sophisticated differential diagnosis of hard and soft signs of neurological dysfunction, Brazelton (1971) has systematized and somewhat simplified the heart, or nerve, of the matter. It is noteworthy that the first page of his Behavioral and Neurological Assessment Scale (see Figure 12 on next page) is largely history and organic in context, except for the optional "Descriptive Paragraph" section, whereas the second page is more concerned with the rating of observable behaviors in response to various exogenous and endogenous stimuli, some of which may be construed as being primarily cognitive, linguistic, and/or socio/emotional precursors or customary indicators thereof (see Chapters IV, V, and VI). This further emphasizes the importance and perhaps real feasibility of synthesizing a comprehensive multiple-purpose developmental screening system with a minimum of redundancy yielding maximum information. The data required for the completion of even the top of the first page and all of the second page of this Scale (Figure 12) are germane to several of the preceding and subsequent factors of this monograph. Indicative of the Neurological/Behavioral interface is the Neuro-Developmental Observation (NDO) procedure presented by Ozer and Richardson, two specialized pediatricians, who are taking a highly pragmatic approach to learning problems in school-age children. These frequently have their roots in earlier developmental disabilities. Their success in using this problem-solving model is leading them to the downward extension of it for use with younger children. The 15-minute protocol, which in part has grown out of prior efforts to standardize neurological testing, makes use of interdisciplinary health personnel, parents and teachers in the process of diagnosing and communicating what the child can do.

It is conceivable that the standardized collection of such data on all infants, with the addition of several other heavily weighted prognostic factors described throughout, would constitute a primary screening of young children at developmental risk, and could probably be accurately collected by trained paraprofessionals. The addition of these items to existing screening devices, none of which now includes them all, or the creation of supplementary scales, all of which would have to be standardized, is a next logical step. Of course, secondary and tertiary screening and assessment of those children who emerge as borderline or worse would have to be carried out by progressively more sophisticated personnel and procedures. For example, an abnormal rating on several of the items which are highly related to seizure disorders could lead to the critically earlier neurological assessment and diagnosis of these conditions.

Infant's Name _____ Sex _____ Age _____ Born _____
 Date _____ Hour _____
 Mother's Age _____ Father's Age _____ Father's S.E.S. _____
 Apparent Race _____

Examiner(s) _____ Hospital _____

Conditions of examination: _____ Date _____

Birth Weight _____ Current Weight _____ Length _____ Head Circ _____
 Time examined _____ Time last fed _____ Type of feeding _____

Information from Chart:

Type of delivery _____ Apgar _____
 Length of labor _____ Birth order _____
 Type, amount and timing of medication given Mother _____

Anesthesia? _____
 Abnormalities _____

EXAMINATION

Initial State: observe 2 minutes (Prechtl's scoring)

1 2 3 4 5 6
 deep light drowsy alert active crying

Predominant states (mark two)

1 2 3 4 5 6

		Elicited reflexes						Descriptive Paragraph (Optional)				
		X	O	L	M	H	A					
Plantar grasp				1	2	3		Attractive	0	1	2	3
Hand grasp				1	2	3		Interfering variables	0	1	2	3
Ankle clonus				1	2	3		Need for stimulation	0	1	2	3
Babinski				1	2	3		What activity does he use to quiet self?				
Standing				1	2	3		hand to mouth				
Automatic walking				1	2	3		sucking with nothing in mouth				
Placing				1	2	3		locking onto visual or auditory stimuli				
Incurvation				1	2	3		postural changes				
Crawling				1	2	3		state change for no observable reason				
Glabella				1	2	3						
Tonic deviation of head and eyes				1	2	3						
Nystagmus				1	2	3						
Tonic Neck reflex				1	2	3						
Moro				1	2	3						
Rooting (intensity)				1	2	3						
Sucking (intensity)				1	2	3						
Passive movement												
Arms	R			1	2	3						
	L			1	2	3						
Legs	R			1	2	3						
	L			1	2	3						

COMMENTS:

Figure 12: Behavioral and Neurological Assessment Scale
 Revised Edition: Feb. 1971
 (T. Berry Brazelton)

Figure 12: (cont'd)
Page 2
Scale (Note State)

Scoring Sheet

Initial State _____
Predominant State _____

	1	2	3	4	5	6	7	8	9
1. <u>Response decrement to light (2,3)</u>									
2. <u>Response decrement to rattle (2,3)</u>									
3. <u>Response decrement to bell (2,3)</u>									
4. <u>Response decrement to pinprick (1,2,3)</u>									
5. <u>Orientation inanimate visual (4 only)</u>									
6. <u>Orientation inanimate auditory (4,5)</u>									
7. <u>Orientation animate visual (4 only)</u>									
8. <u>Orientation animate auditory (4,5)</u>									
9. <u>Orientation animate visual & auditory (4 only)</u>									
10. <u>Alertness (4 only)</u>									
11. <u>General tonus (4,5)</u>									
12. <u>Motor Maturity (4,5)</u>									
13. <u>Pull-to-sit (3,5)</u>									
14. <u>Cuddliness (4,5)</u>									
15. <u>Defensive movements (4)</u>									
16. <u>Consolability (6 to 5,4,3,2)</u>									
17. <u>Peak of excitement (6)</u>									
18. <u>Rapidity of buildup (from 1,2 to 6)</u>									
19. <u>Irritability (3,4,5)</u>									
20. <u>Activity (alert states)</u>									
21. <u>Tremulousness (all states)</u>									
22. <u>Startle (3,4,5,6)</u>									
23. <u>Lability of skin color (from 1 to 6)</u>									
24. <u>Lability of states (all states)</u>									
25. <u>Self-quieting activity (6,5, to 4,3,2,1)</u>									
26. <u>Hand-mouth facility (all states)</u>									
27. <u>Smiles (all states)</u>									

Early detection and treatment of seizures in children can prevent a life of tragedy in many. Seizure disorders, in many cases, can go unnoticed by parents and physician. Faced with these facts, plus the many published accounts of the medical soundness and efficacy of early diagnosis and treatment, regardless of disorder, the logic of establishing neurological screening mechanisms in the public and private health sectors for pre-school age children becomes evident.

Much published information exists as to the need for early screening.... Therefore seizures appearing during early childhood and before five should direct the physician's attention to a diagnosis of an idiopathic or secondary epileptic disorder. Epilepsy may make its initial appearance at any time during childhood; however, there are three specific periods when it is most likely to occur: (a) during first two years of life, (b) five to seven years of age, and (c) onset of puberty. Louis Boshes (Vol. 72, #10, May 10, 1969 - Chicago Medicine) has stated:

It is of prime importance to prevent the recurrence of epileptic seizures in children by the use of known anticonvulsant drugs. With these medications presently available about 75% of children should obtain complete control; another 15 to 20% may show a moderate improvement; and some 5 to 10% will remain unimproved or stabilized or may even appear to have their spells aggravated by the medications that we now have available.

In general, the etiologic factors can be detected easier in newborns and young infants and with the passage of time the actual cause of the seizure may go unnoticed due to chronicity.

Adequate medical concepts exist in the literature which, if understood by physicians and parents, indicate that neurologic screening can detect, at the last, a suspicion of the presence of a seizure disorder in a child. In short, medical knowledge does exist, but the fact remains that screening doesn't exist...(Arangio, 1972, pp. 1, 4, 5, & 8).

Yet. And that is what this monograph is all about.

CHAPTER IV

INTELLECTUAL/COGNITIVE FACTORS

Brief Historical Introduction

Intellectual and cognitive functioning has been reserved for older children by the majority of investigators and pediatricians addressing themselves to human development. This has had the prophecy-fulfilling result that most studies of intellectual and cognitive functioning have not focused on infants and toddlers because they presumably are preoccupied by simply reacting to sensory stimuli with their motor apparatus without thinking about the relationships between the stimulus and response events. Abstract thought processes cannot be observed nor can infants and toddlers without language give any verbal hint to the intervening processes which may be conditioning their rather predictable responses to a controlled series of stimuli. Historically, homo sapiens was not regarded as very wise, much less able to reason, until approximately the age of 7 years. Several modern developmental theories postulate that the early stages of development are exclusively sensori-motor with essentially no cognitive functioning worthy of investigation occurring until sufficient language capability has been achieved. In fact, the controversy continues to rage about whether or not an individual can think without having the necessary language to label and represent those events or phenomena about which he is thinking. Of course this monograph cannot treat the numerous subtle nuances of these esoteric debates, but it does serve to point up the inextricable interrelationships among physical, intellectual/cognitive, language, and socio/emotional factors.

Despite the many preconceived notions about infant growth and development, several investigators on the cutting edge of this intellectual/cognitive area of inquiry have recently generated some evidence which is contrary to many earlier fatalistic anachronisms.

A decade ago a rash of factor analytic studies (Meier, 1965) were undertaken in an attempt to ferret out the salient dimensions of intellectual and related functions partly in the parsimonious interest of consolidating and simplifying the assessment of these functions within and across various age and ability subgroups. Another interest was that of creating more accurate assessment instruments and procedures for progressively younger children.

Is there substantiation of the hypotheses which served as the basis for this investigation? The general hypothesis, as worded in the early pages, was to the effect that psychometric tasks of sufficiently broad spectrum would reveal more than a 'general intelligence' and would show in fact some structuring to abilities. This hypothesis is of course well sustained, in all ages and in all six groups tested, including normal children of two and retardates of mental age two

It is evident now, by perusal of these and others' findings, that a general ability concept is insufficient to describe the abilities of young children. It is evident that mental ability is structured at two years if not before. The exploratory studies such as the one described here have not described the nature of young mentality so much as they open up the doors to systematic exploration. The reader should note

that several domains of intellect were not reported on here: various memory functions; various semantic skills beyond the vocabulary; discrimination between perceptual identification and 'oddity' tasks; verbal inference as well as figural, and the like. The above says nothing for the manifold psychomotor functions that may be identified as well, provided adequate testing is set up.

None of the above presupposes that the 'general intelligence test' such as is generally employed for research and clinical service is insufficient or outmoded. Not yet. The Binet scale, for example, certainly samples broadly of functions, though not systematically from age to age, and with notable omissions, such as the divergent domain of abilities. It is possible to envision a factor-oriented scale which may systematically probe for abilities clearly identified in replicated study, but it is possible that some of the identified abilities are luxuries of human nature, without present utility in the culture.

It is possible, as the earlier pages pointed out, to extend downward on an ability continuum the functions of a specific test, through the use of greater realism in materials, reduced complexity, three dimensionality, and the like. The examiners judged that good differential testing (though time consuming and expensive) was carried out down to 18 months in normal children; a few subjects from 13 to 17 months were also successfully presented the materials, though their data were not here employed (Meyers, et al., 1964, pp. 46, 48-49).

In another article of the same vintage by some of the same authors, the agonizingly tedious process of teasing out the factors which would be included in a comprehensive screening system is acknowledged.

As to next steps, it is believed that the factor content of existing scales has been nearly milked out, that further effort will have to be in the direction of hypothesizing and instrumenting for different groups and different levels, the directions guided by previous studies and adult models. Until it is possible to know what factors exist in continuity, they cannot be placed into age scales designed to reveal them longitudinally. Until more is known about emergence, no comparison of emergence can be accomplished. There is, in short, much to be done (Meyers & Dingman, 1965, p. 25).

Infant Attention to Discrepancies

More recently, Kagan (1972) reports a series of ingenious experiments, the results of which can be legitimately interpreted to substantiate that infants demonstrate considerable cognitive or hypothesis-forming abilities even before they are one year of age. The following citations reveal some of the more cogent arguments and findings from one of his articles:

In our studies the primary measures of the infant's cognitive processes are selected kinds of behavior that accompany attention to an interesting event. By 'attention' we do not mean the brief two-second orienting reaction of an infant to any sudden change in stimulus energy but rather the duration of sustained orientation that follows the initially orienting response. We believe that during the period of sustained orientation an infant more than 30 days old is trying to build

a representation of the event. The duration of sustained attention is a rough index of how easy or how difficult it is for him to understand a new experience.

The attention of newborn infants is attracted by objects that move or have sharp contours and light-dark contrast. These perceptual preferences seem to be inherent in the structure of the visual system. A two-day-old infant is more attentive to a moving or intermittently flashing light than to a steady light; he looks longer at a solid black figure on a white background than at a low-contrast gray figure. The rate of stimulus change is also important during this first era of growth. If a stimulus is introduced too rapidly, the infant may become fearful. Similarly, as Richard Kearsley of Harvard has found, if an unexpected sound, say 70 decibels of 'white' noise reaches maximum intensity within a few milliseconds, a newborn infant closes his eyes, starts, and shows an increase in heart rate, all of which are signs of a defensive response. If the same sound reaches its maximum intensity in two seconds, the infant then opens his eyes, looks around and is likely to show a decrease in heart rate, all of which are signs of interest.

The attention-recruiting power of contrast, which is maximal at birth or soon after, loses its force to a second property as early as the second month. As a result of the infant's encounters with the environment he acquires mental representations of events. We call these representations schemata. Toward the end of the second month the infant begins paying more attention to stimuli that differ moderately from those he usually encounters. The functional relation between duration of attention and the nature of the external event is summarized by the discrepancy principle: events that are moderately different from an infant's schema elicit longer spans of attention than either totally familiar events or totally novel events. Moreover, we suggest that the time of emergence of the infant's special reaction to discrepancy is controlled by no maturational processes (p. 74). (See Figures 13 and 14.)

After marshalling a great deal of supporting evidence from other laboratories and presenting a compelling synthesis of results from his own investigations, Kagan concludes the article with some implications and suggestions related to early screening.

Both theoretical and practical implications flow from these findings. It appears that before an infant is a year old he has become a thinking creature who activates cognitive structures to resolve discrepancies and solve problems. Over the past 20 years many students of child development have held a different view. For example, the eminent Swiss psychologist Jean Piaget has argued that during the first 18 months of life an infant knows the world only in terms of his sensory impressions and motor activities. Cognitive development, says Piaget, begins after the sensorimotor period ends. These results provide a mild challenge to his view. The infant may be more thoughtful than most psychologists have surmised (1972, p. 81).

The preceding provocative remarks provoke more than interest in infant thinking; they provoke some disagreement with Piagetian disciples and, judging from the first few pages of Piaget and Inhelder (1969), perhaps with

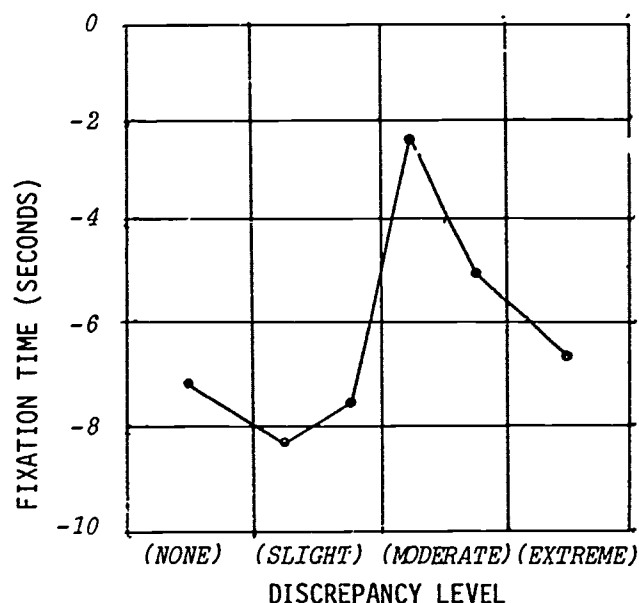


Fig. 13: VISUAL DISCREPANCY study with four-month-old infants involved measuring the amount of attention (eye fixation) given to an arrangement of geometrical objects. After baseline measurements were made in the laboratory the infants were returned home with special 'mobiles' to be hung above their crib for 30 minutes a day. Some infants had an arrangement identical with what they had viewed in the laboratory. Others had slightly, moderately or extremely discrepant arrangements. A control group had no home mobile. After three weeks changes in attention to the initial arrangement were determined. There was no change in the attention span of infants who did not view a mobile at home. Of the infants who had viewed a mobile at home, those with the moderately discrepant mobiles showed the smallest drop in attention. Infants who had identical or similar mobiles showed the greatest drop in attention. Extreme discrepancy also drew less attention (Kagan, 1972, p. 78).

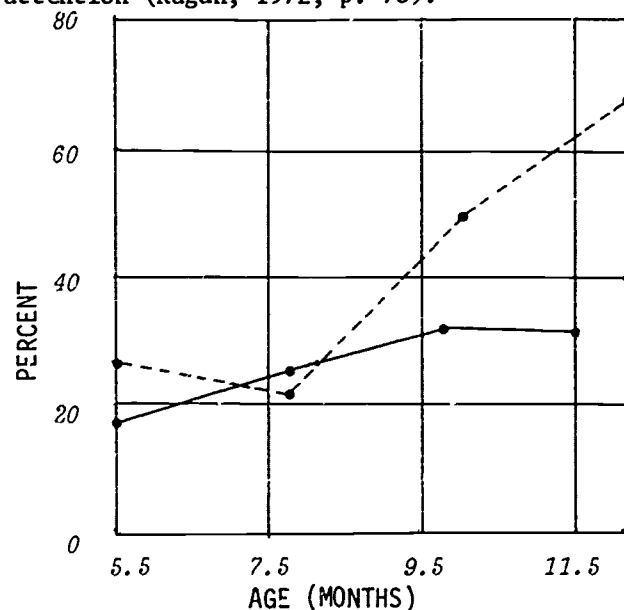


Fig. 14: INCREASE IN VOCALIZATION following a discrepant event also is linked to the age of the infant. The percentage of infants in each age group who vocalized during the stimulus (solid curve) did not vary much. A large proportion of older infants vocalized after the stimulus had ended (dotted curve). The poststimulus vocalization could be an indication that the older infants were engaged in some mental activity related to the discrepant event (Kagan, 1972, p. 81).

Piaget himself. However, rather than becoming embroiled in what may be a pot of semantic hot water, it seems important to proceed with Kagan's findings, which reflect back upon the contents of Chapter III.

A second implication takes the form of a suggestion to developmental psychologists and anatomists to search for important changes in the function and structure of the central nervous system between eight and 12 months of age. The infant becomes consistently reactive to discrepancy between two and three months, and the emergence of this competence is accompanied by a cluster of biological phenomena (including a mature form of the visual evoked potential and consistent occurrence of sleep spindles in the electroencephalogram). Nine months seems to be a frontier that announces the child's ability to generate simple hypotheses, but the existing literature does not mention a comparable set of biological changes in the central nervous system. We suggest that this new competence is dependent on correlated changes in the brain. A new cluster of biological phenomena should appear at that time. It would seem appropriate for neurophysiologists and developmental anatomists to look for changes in the structure and function of the central nervous system of infants between eight months and one year old.

The final suggestion is more practical. Up to six months of age the differences among infants in motor and cognitive development are fairly independent of the child's social class, his ethnic origin and even some aspects of his rearing conditions. By one year of age, however, differences in rearing experience seriously affect cognitive functioning. This means that pediatricians and psychologists might assess the reactions of one-year-old infants to discrepant stimuli to obtain information about their developmental status, particularly the status of infants who may have been exposed to psychic risks or who suffer from metabolic or structural defects (1972, pp. 81-82).

Ordinal Scales of Cognitive Development

One article which addresses some of the exogenous variables affecting cognitive development in infancy, although it is primarily concerned with various intervention and stimulation efforts, makes the following observation which has important screening and assessment implications.

First, there is a need to examine the appropriateness of our measuring instruments for assessing the development of disadvantaged infants. You will recall Gordon's graduate students' criticism of the use of the Bayley Scales as an assessment device and that, indeed, there were no significant differences between his experimental and control Ss in Bayley performance at two years. We need to know more about the cognitive development of the lower-class child within his own environment. We should examine the cognitive environment of the lower-class infant in detail and then design more specific intervention programs that focus on the strengths that his natural environment provides, in addition to providing stimulation relevant to the attainment of later academic success. One of the most promising new assessment devices is the Uzgiris-Hunt Scale which has been used as one of the bases for the development of some of the intervention strategies such as Weikart and Lambie's, in addition to being used as an assessment device (Starr, 1971, p. 181).

In this same article, which is primarily concerned with the many intervention efforts throughout the United States and their results, Starr reiterates the importance of not only assessing the individual infant but also the context within which he is growing and developing in order to arrive at a contextual and more valid prediction of whether or not he stands some risk of developmental disabilities.

Historically, developmental psychology has dramatically turned in the last ten years from the maturational viewpoint of development espoused by Gesell and others toward a view which has varied between strict environmentalism and moderate interactionism. In general, psychologists have been most interested in environmental effects given the genetic status of a particular individual with whom they are dealing. Within this context they must assess the effects of environment and, if possible, eliminate deleterious environmental effects while providing appropriate experience (p. 153).

The literature makes increasingly frequent reference to Uzgiris and Hunt's instrument for assessing psychological development in infants and toddlers. This instrument was originally conceived to study the effects of specific environmental experiences on the rate and course of development in a group of experimental infants. The following excerpts illustrate the complexity and partial ordinality-ambiguity of interaction between individual infants and their environments. Some of the semantic nuances become evident when one compares Kagan's notions of representation and his challenge to Piaget with Uzgiris and Hunt's interpretation of Piaget's notions of representation.

This second version of our provisional instrument for assessing infant psychological development consists of six series of behavioral schemata with directions for presenting the situations to elicit them and a listing of the most commonly observed behavioral reactions to these situations, ranked according to their emergence in the course of development of each schemata.

Although it would have been feasible to describe an infant's development in terms of Piaget's stages, we have decided that a finer grading of steps along these developmental sequences would be desirable, especially for subsequent experimental work. Since the time an infant takes to move between two steps in a series or the infant's age at attaining a particular step may be the best way to assess the effects of differential experience with such an instrument, we have not even attempted to provide a definite scoring system. Nevertheless, a ranking of a sample of infants might be obtained by assigning a point for each step along each of the series, provided that such 'scores' are used only for ranking purposes and are made to carry no further meaning. Thus, an infant who exhibits good following to a slowly moving object might be assigned a 'score' of 2 for the first situation in the permanence-of-objects series, in contrast to an infant who exhibits only partial following and is assigned a 'score' of 1. This is feasible so long as no equality of intervals is implied and the numbers are only used to indicate that the first infant is further advanced in the emergence of that particular schema than the second infant.

Performing the scaling analyses for this sample and especially for the sample to be tested in Step 2 may lead to construction of still finer scales, since impressionistic evidence suggests that infants do show combinations of intermediate reactions to these situations, *i.e.*, they do not necessarily manifest the highest reaction to Situation 1 before manifesting one of the intermediate reactions to Situation 2.

Development may be viewed as a branching process. The infant acquires numerous schemata through assimilation to- and accommodation of- the first ready-made schemata which he possesses at birth. Therefore, several series have similar starting points. Furthermore, development along the various series is probably to some extent interdependent. We do not yet know what the interrelationships are. One may guess that, up to a point, the rate of development may vary considerably along each of the series. However, at certain points the various series seem to come together, so that progress in one becomes the basis for progress in another. For instance, the infant has to develop the coordination between the schemata of vision and prehension in order to begin to grasp objects which, in turn, enables the infant to develop the variety of schemas that accommodation to numerous objects forces upon the schema of prehension. On the other hand, the grasping schema itself and the resulting interesting events which it enables the infant to obtain and to regain through secondary circular reactions both feed into his primordial feelings of intention and causality, contributing to development in Series II and IV. Or, as a second example, progress in the development of object permanence leads to search for objects which have disappeared along various trajectories and may be important for the construction of objective space. It is easy to agree with Piaget that the development of representation is a unifying theme for progress during the first two years of life.

...In Piaget's own children, this last development occurred at approximately 18 months of age, but even Piaget (1953) himself has noted that there is nothing sacrosanct about the age at which any of these schemata appear. This age would certainly be expected to vary as a function of the environmental interactions experienced by an infant (Uzgiris and Hunt, 1966, pp. 9-12 & 14).

Since a number of the behaviors which must be observed and interpreted are somewhat subtle and time-consuming to elicit, this instrument would presumably be a secondary or tertiary stage in the total screening and assessment process and applied only to those children who demonstrated developmental discrepancies on earlier more gross screens. Furthermore, the carefully sequenced and detailed approach of Uzgiris and Hunt, in spite of the controversies about semantics and ordinality of developmental unfolding, has lent itself very nicely to the assessment of growth and development during experimental studies on intervention.

The advances made by the sixteen low income experimental 12-month-old black infants in this study both on the Object Permanence Scale and the Means-Ends Scale compared to their controls offer encouragement to explicitly planned enrichment efforts, based on a Piagetian cognitive-developmental model and designed to offset cognitive deficits that sometimes result when an infant is not provided the variety, sequencing, and challenge appropriate to his level of experiences.

Further longitudinal study is certainly necessary to see whether the experimental gains obtained will continue or prove ephemeral as the

control infants catch up in their abilities to handle tasks of higher developmental maturity (Honig & Brill, 1970, p. 19).

Nevertheless, in light of the important challenge made by Kagan (above), it seems imperative that any studies investigating the salient factors in the cognitive growth and development of infants and toddlers cannot be restricted to the theoretical frame of reference espoused by any one investigator when there is sufficient evidence supporting other equally important factors in the behavioral repertoire of the subjects under study. A theoretically and practically balanced and comprehensive consideration of all intellectual/cognitive factors is exigent, regardless of whether the concern is for screening and assessing children at risk of developmental disabilities or for evaluating the results of a carefully designed and implemented intervention and/or prevention program.

Other Infant Test Instruments

In addition to the individual testing procedures for intellectual/cognitive functioning proposed by Uzgiris and Hunt, there are numerous other instruments which might well serve as the primary, secondary, or tertiary levels of screening for development in this realm (see Thomas, 1970). One of the main difficulties with infant tests of intellectual/cognitive functioning is that most of the items for the infant and toddler have traditionally been based on and consequently biased toward sensori-motor functioning (reflecting the aforementioned controversial theories) and are therefore more highly related to subsequent sensori-motor development than to intelligence and thinking. Because of this, the predictive validity of such tests has been so low that the results have routinely been regarded with well-advised skepticism in terms of their ability to predict the level of intellectual functioning during later childhood and adulthood.

Two infant tests which have been subjected to extensive standardization procedures and have been used in secondary stages of screening and assessment are the Cattell Infant Intelligence Scale and the Bayley Scales of Infant Development. One study by Erickson, Johnson, and Campbell investigated the interrelationships among scores on these infant tests when used with children who appeared to be having developmental disabilities.

The Cattell Infant Intelligence Scale (Cattell, 1940) has been used for the evaluations of these children because of the large number of items at each age level, the small intervals between age levels, and its having been designed as a downward extension of the Stanford-Binet. However, a number of difficulties with the Cattell have been recognized (Erickson, 1968), i.e., the small and restricted sample on which the norms were based and the lack of revision since its publication in 1940.

The recently published Bayley Scales of Infant Development (Bayley, 1969) appear to have a number of advantages when compared with the Cattell. The Bayley Scales are based on a considerably larger and more representative sample, have separate measures of mental and motor development, have a greater variety of items, and include items for the first 2 months of life. It therefore seemed useful to compare test scores on the Bayley and Cattell and to evaluate the clinical utility of the two scales. Since the Vineland Social Maturity Scale (Doll, 1953) has commonly been employed as a measure of developmental functioning, its relationships to both the Bayley and Cattell tests were examined in order

to determine its efficiency in estimating developmental level with young handicapped children.

Thirty preschool children referred for diagnosis of developmental problems were administered the Bayley Scale of Mental Development, the Cattell Infant Intelligence Scale, and the Vineland Social Maturity Scale. Results indicated that the scores on the 2 infant tests were so similar and highly correlated that they might be considered interchangeable in diagnostic settings. Clinically, the Bayley presented advantages of a greater variety of items and separate mental and motor scales, while the Cattell took less time to administer and could be combined with the Stanford-Binet. Although significantly correlated with the 2 infant tests, the Vineland consistently yielded higher scores (1970, p. 102).

Once again, the Bayley and Cattell tests, as well as the Vineland, rely heavily upon motor items for the very young child and are probably not assessing cognitive and intellectual functioning in the sense that Kagan, Crowell, and others are suggesting it should be assessed. In a separate validation study of the Cattell Infant Intelligence Scale for young mentally retarded children the following results were reported.

The results of this study gave evidence that the Cattell Infant Intelligence Scale (CIIS) was useful for predicting the later IQ scores of children referred to a clinic for possible developmental problems. The predictive validity of the Cattell scale with this sample of children proved to be substantially greater than that found for samples restricted to normal children. The children in this sample, however, were also a biased group in that they were deviant to the extent that physicians had referred them for more intensive examination. This study, then, offers no predictive validity information on the CIIS for normal children or even for deviant children selected by other methods (e.g., screening tests). The value of this study lies in the demonstration of the predictive validity of the CIIS in a University medical setting.

The fact that young retarded children's IQ scores were highly predictable during the first three years of life should not be interpreted to mean that their IQs are fixed in the deterministic sense. The results indicate, rather, that for this group of children environmental factors interact with organic factors such that relatively stable IQ scores are produced over time. It is essentially unknown to what extent IQ scores for this sample of children could be altered with various kinds of environmental intervention (Erickson, 1968, p. 732).

The preceding citations make a couple of important points, namely that the Cattell Infant Intelligence Scale does not have satisfactory predictive validity for normal children or even those referred through screening tests, that two-year-old children seem to be more easily examined than three-year-old children partly because of their increased emotional instability during the third year, and as Wechsler (1966) pointed out in defense of his intelligence scales when they were being challenged and ultimately dismissed in the New York school systems, that IQ stability is very probably in large part a function of environmental stability and in no way predicts how an individual might do when the environment is radically modified toward greater enrichment or deprivation.

The I.Q. has had a long life and will probably withstand the latest assaults or it. The most discouraging thing about them is not that they are without merit, but that they are directed against the wrong target. It is true that the results of intelligence tests, and of others, too, are unfair to the disadvantaged, deprived and various minority groups but it is not the I.Q. that has made them so. The culprits are poor housing, broken homes, a lack of basic opportunities, etc., etc. If the various pressure groups succeed in eliminating these problems, the I.Q.'s of the disadvantaged will take care of themselves (p. 66).

Two other tests have been frequently mentioned as being of great usefulness with developmentally disabled infants, namely, the Kuhlmann-Binet Infant Scale (Shotwell, 1964) and the Griffiths Mental Development Scale (Lally, 1968).

...The Griffiths Scale consists of subtests in five areas: locomotor skills, personal-social skills, hearing and speech skills, eye and hand coordination skills, and performance skills. An overall score, and General Intelligence Quotient (GIQ) is obtained in addition to scores for each subtest.

The results provide at least partial support for the hypothesis that trained infants would score higher than untrained infants. The experimental group taken as a whole scored significantly higher than the control group on the eye/hand and on the hearing/speech subtests.

The results also point up the importance for infants of measuring instruments which separately assess the components of intelligence. Many more differences between control and experimental subjects were found on the eye/hand and hearing and speech subtests than on other tests. Such findings provide researchers with an indication of where their training has been most and least effective (Williams, 1972, p. 160).

Prediction of Later Intellectual/Cognitive Functioning

In an article which might legitimately have been included in the later Chapter VI dealing with social/emotional factors since it brings out their importance, too, Holden (1972) reported a study dealing with the prediction of mental retardation in infancy. The concluding sentence in his discussion of the study elaborates upon the difficulties of using a single predictive factor such as the relatively primitive estimates of intellectual/cognitive functioning now available for infants.

It appears that both views concerning the prediction of mental deficiency have been supported, depending on which part of the data is examined. For example, if one looks at the number of cases with IQs below 69, then the predictability appears to be rather impressive when compared with the normal control group. However, if one considers the mental or motor development at age 8 months, one is impressed by the great variability apparent in the wide range of scores obtained at age four or at age seven. It is this vantage point which leads to the conclusion that mental retardation is not predictable in infancy. Certainly this is true in the individual case, and further refinements of assessment techniques, including other variables such as socio-economic

status and even parental attitude need to be considered as potential influences on the development of intellectual ability (p. 30).

Holden makes the point and backs it up with several studies, including his own data, that prediction of a group's mean intelligence from infant test results is far better than prediction of an individual's intelligence from his infant performance on intelligence tests. It is interesting to note that he quotes Bayley, whose developmental scales he employed in his own study, which is part of the collaborative perinatal project supported by the National Institute of Neurological Diseases and Stroke.

Early studies of mental development in normal infants have demonstrated little or no relationship between mental ability in infancy and intelligence at a later age (Bayley, 1949). Nancy Bayley went so far as to say, "it is now well established that we cannot predict later intelligence from the scores of tests made in infancy" (Bayley, 1955, in Holden, 1972, p. 28).

In contrast to the above, Holden presents some more encouraging findings; similar data must have encouraged Bayley to undertake the development and standardization of the elaborate scales bearing her name.

The problem of accurate prediction of mental development in normal infants has often been controversial. Out of a population of 2,875 infants in the Child Development Study at Brown University, 230 subjects were followed to age four and 115 to age seven. Each child was 1 month or more below average on the Bayley Scales of Mental or Motor Development at age 8 months. At both ages four and seven, mean I.Q. scores were significantly lower than a control group of 150 children (1972, p. 28).

Even the Gesell Developmental Scale (Gesell and Amatruda, 1941) works relatively well for differentiating infants in terms of their neuro-motor development, which is frequently co-existing with organic causes of mental retardation.

It is noteworthy that no discrepancies were found between the three areas tested: motor, adaptive, and social behavior. The Down's syndrome infants do not seem to develop more quickly in one area than another. It would seem unwarranted to draw definite conclusions from this: few of the items in the Gesell test schedule 'may be properly described as tests. most of the items in these schedules being purely observational,' Anastasi (1961). The distinction between areas is more convenient for descriptive rather than predictive purposes.

There has been much controversy concerning the usefulness of the Gesell developmental scale. By showing the discrepancy between Down's syndrome children and normal children our results confirmed Illingworth's view (1966) that the Gesell schedules have great value in demonstrating the presence of mental retardation in early childhood. The fact that the normal group showed the expected steady rate of development points furthermore to the usefulness of these scales for assessing development in young children (Dicks-Mireaux, 1972, p. 31).

Holden further complicates the matter by making the point that additional factors such as socio-economic status of the family and its members' emotional stability often contributes substantially to the accuracy of predicting developmental disabilities, particularly in borderline cases (see Chapter VI for suggestions along these lines).

Reminiscent of observations made at the beginning of this chapter, using a principal-components factor analysis of infant test scores, McCall, Hogarty, and Hurlburt (1972) continued to trace a path of predominant skills through infancy, suggesting that this path may represent the developmental progression of skills culminating in childhood intellectual skills. A developmental trend is identified as proceeding from "manipulating objects that yield perceptual consequences" to "social imitation of fine motor and verbal behavior" to "verbal labeling and comprehension" to "verbal fluency and grammatical fluency." The authors conclude their thorough-going analysis of the apparent futility of attempting to predict childhood intelligence from scores on extant infant tests by offering several observations which seem germane to the design of screening and assessment procedures for greater predictive validity.

Several conclusions can be drawn from this review. First, until the second year of life there is relatively poor prediction from infant tests to IQ assessed in middle or late childhood. Infant tests may have some value in detecting neuromotor abnormalities, however, and a severely low score has somewhat greater predictive significance than average or high scores. Second, the low predictive correlations are not a function of poor test reliability. Third, while there are no pronounced sex differences on infant test total scores, girls may show higher correlations with later IQ than boys, especially for some infant tests and for relationships covering early infancy and childhood. Fourth, predictions from 12 to 24 months may be increased slightly by adding parental socio-economic class into a multiple-regression formula with infant test score; prior to 12 months, parental socioeconomic status alone is the best single predictor. Fifth, infant tests administered in the first year of life have more predictive power in their item pool than the total score reflects, and early vocal-verbal behavior may have salience in predicting later IQ for girls and frolicsome social activity may have inverse predictability for boys. Sixth, despite the fact that correlations can be increased somewhat by the above procedures, for the most part the level of prediction from the total score for normal children remains modest and of minimum practical utility.

When specific skill areas were determined by subjecting Gesell items taken at 6, 12, 18, and 24 months to separate principal components analyses, the correlations of component scores across these ages as well as with childhood IQ indicated several patterns of developmental transitions. The most pronounced trend spanning the entire infancy period involved the manipulative exploration of objects that produced perceptual contingencies at 6 months, the imitation of simple fine motor and elementary verbal behavior particularly in a social context at 12 months, verbal labeling and comprehension at 18 months, and verbal fluency and grammatical maturity at 24 months. Tentatively, these data highlight the potential importance of early exploration and manipulation, especially the production of contingent perceptual and social consequences,

and the role of imitation as the possible developmental mediator between exploration behavior in the first 6 months and verbal production and fluency in the second year of life. The fact that this major trend of development did not predict late IQ until 12 (females) or 18 months (males) illustrates how early behavior in infancy might form the basis out of which later childhood skills emerge without itself directly predicting those childhood performances. Parallels to the epigenic development of Piaget were illustrated. Another interpretation of these data suggested that a common factor underlying this major developmental pattern might be a socially uninhibited "extroversion" which moderates the behavior of infants in the test situation.

The overriding implication of this discussion is that a simple conception of a constant and pervasive g factor is probably not tenable as a model for "mental" development, especially for the infancy period. The data are strong in their denial of simple continuity of general precocity at one age with general precocity at another age during the infancy period, and emphatic in demonstrating marked qualitative shifts in behavioral dispositions. Moreover, to label as "mental" performances at every age perpetuates the belief in a pervasive and developmentally constant intelligence. Consequently, the term mental as applied to infant behavior or tests should be abandoned in favor of some conceptually more neutral label, perhaps Piaget's "sensorimotor," "perceptual-motor," or even more specific classes of behaviors (e.g., exploration of perceptual contingencies, imitation, language). The network of transitions between skills at one age and another is likely more specific and complex than once thought, and not accurately subsumed under one general concept (McCall, Hogarty, and Hurlburt, 1972, pp. 745-46).

As the child gets older, and the number and complexity of tasks to be mastered become more numerous and more alike those which adult intellectual/cognitive functioning involve, it is easier to reliably and validly screen and assess those who seem to be lagging behind normal intelligence. In a computer-assisted search of the literature dealing with assessment of young children, practically all of the 115 annotated references dealing with preschool tests, screening procedures, and standardized examination methods and materials dealt with children three years to six years of age. The listings range from standardized procedures for assessing self-concept to standardized neurological examinations and numerous related inventories. This is also true of the listings found in Buros (1965) but the reader is nevertheless referred to this classic reference for further information. The Head Start collection, published in 1971 by the Educational Testing Service, provides information about instruments for those engaged in research or the direction of projects involving young (again, largely 3-6 years old) children.

Changes in Infant State and Response Rate

In an effort to get at sheer intellectual/cognitive functioning in infants, Garber relates some of his experience with a promising Russian technique and mentions some of the problems encountered in testing cognitive functioning in very young children with the suggestion that some screening application be made of this technique after it has been further refined.

Researchers are confronted by a two-fold problem when attempting to assess the development of young children. One part of the problem has

been the availability of sensitive and reliable instruments for assessing early cognitive development. This is due to the fact that young children, especially those less than five years of age, are neither patient enough nor do they have the verbal facility to cope with anything but the simplest of tasks. Such tasks are superficial and are usually not predictive of a child's intellectual performance. The second part of the problem relates to the nature of the young child as a subject. Young children tend to respond more as a function of some response biases than as a function of the meaning of the stimulus problem. For example, there are color-form preferences, position preferences, idiosyncratic response strategies, etc. The consequences of this problem is that a child's response may not be indicative of his cognitive development but merely a behavioral artifact.

An early reliable assessment of cognitive development is particularly important for the identification of deficits which may be remediable with early intervention. An example in which the early identification of delayed cognitive development might be critical is suggested by recent evidence reported by Heber (Heber, Dever and Conry, 1968). He found that certain groups of disadvantaged children, particularly those whose mothers have an IQ of 75 or below, from the age of three show a slow but steady decline from a normal IQ to the retarded level of their mothers. Early detection could, in this case, lead to early intervention, which might help to mitigate whatever depressing effects are involved in this intellectual decline.

Thus, the problem that remains is one of trying to index the cognitive development of children less than four years of age. We have been working with such a group of very young children. In order to circumvent some of the problems of research with this population and still measure the differential development of two groups of young children, we attempted the use of a technique employed extensively by Luria (e.g., 1963) and other Russian workers. This technique, called the Ivanov-Smolensky procedure, does not bind the child either to single designative or recognition responses but still allows for a demonstration of differential cognitive development. The procedure requires merely that a child respond to simple verbal commands and colored lights by squeezing a rubber bulb. It was expressly developed for assessing development in young children with limited verbal skills and minimizes some of the research problems associated with young children. Russian researchers report having considerable success with its use, although replication attempts in this country have not been entirely supportive (e.g., Jarvis, 1968).

In this case, since physical differences are minimized, the finding of lower response amplitude can be taken as an indication of an increase in response economy with increasing intellectual development, which is consistent with the Luria hypothesis.

In summary, it was felt that there is promise for the Ivanov-Smolensky procedure as a research device. If it is to be used as an early screening device, the sensitivity of the technique must be increased. This probably can be accomplished by applying it to a wider range of populations varying in intellectual development (Garber, 1971, pp. 1 & 3).

Lewis, Goldberg, and Campbell (1969) have also attempted to obtain a "purer" measure of infant cognitive development, and have also been influenced

by Soviet research, primarily that of Sokolov (1963). Their argument is that the rate of habituation of attentional responses to a repeatedly presented signal provides an index of cognitive development. Specifically, more rapid habituation is interpreted to mean that the infant is processing information more effectively, forming a representation or schema of the event more rapidly, and thus is cognitively advanced compared with an infant who habituates more slowly. The authors present a variety of evidence in support of this hypothesis, e.g., more rapid habituation among infants with Apgar scores of 10 than among infants with scores less than 10, and correlations between rate of habituation at one year of age and Stanford-Binet IQ at 44 months ($r=.46$ for girls, $.50$ for boys).

Given that response decrement to a visual signal follows a lawful developmental pattern and is related to perceptual-cognitive development, several provoking consequences follow, the most interesting of which is use of decrement scores as an index of cognitive development. This index could be used to evaluate the developmental organization of the very young or, equally important, to determine the effects of a variety of intervention programs; for example, the effects of a variety of environmental, pharmacological, or maternal behaviors. Or it might be of use in determining the perceptual-cognitive consequences of adverse conditions in infancy; for example, diet deficiency such as Kwashiorkor (protein-calorie malnutrition), iodine insufficiency, birth trauma, or socioeconomic variables.

The results of this technique in determining the effects of such individual differences variables as degree of birth trauma (as measured by the Apgar Score) suggest that early measurement of present and subsequent perceptual-cognitive development may be possible. This has not been possible or available before. Moreover, should pharmacological or other therapeutic means for initiating change become available, one could measure their effectiveness by determining the change in decrement rate as well as comparing the infant with 'normals' of his developmental level. Therefore, response decrement as a measure of cognitive development may be an extremely useful experimental tool for the investigation of a wide variety of early individual differences and the effect of an intervention technique (Lewis, Goldberg, and Campbell, 1969, p. 36).

In an effort to analyze the biological substrate which is the precursor and sine quo non of cognitive functioning, Crowell (1972) has been gathering and interpreting heartrate and electroencephalographic data on several hundred newborns during the past few years. He has clearly demonstrated the relationship between central nervous system integrity and these data, as affected by carefully controlled auditory, visual, and tactile stimuli. Although such sophisticated procedures require elaborate and expensive equipment and trained technicians, they would seem quite appropriate for tertiary stage screening and assessment of infants whose sensory sensitivities seem below par on other more gross behavioral levels. Thus, there are psychophysiological measures of intellectual/cognitive capacity, or at least its precursors, which can be obtained in infancy. After describing the psychophysiological procedures and findings regarding orienting, attending, and habituation responses as manifest by heartrate and EEG measures, Crowell goes on to discuss some of the very practical ramifications of these rudimentary data.

Now there is little question as to the importance of defining the precursors of cognitive functioning. While they are significant in and

of themselves, the broad span of cognitive functioning requires additional assessment. There have been two notions which have significantly affected the assessment of infant cognition. The first consists of steps towards clarifying the content of infant tests; and the second are Piaget's notions of ordinality with respect to intellectual development. The work of Meyers and Dingman (1960) and Stott and Ball (1965) are examples of contributions on the early structure of abilities. Their results supply us with

- (1) a factorial description of the abilities of infants and young children
- (2) they established evidence on the early appearance of hypothesized factors
- (3) they determine that test items conceived of as motoric in nature can be interpreted as intellectual or psychological and they reflect 'thinking processes' in infants as young as three months.

In Figure 7 is an outline of Meyers and Dingman (1960). They present a number of factors 1-7. The important thing to me is that beginning as early as one month, and those of you who know newborns realize that you can see these response patterns earlier than one month, there are some cognitive abilities that can be tapped.

The mode of clinical assessment I visualize is a package compiled by the clinician and focused on producing objective information as to whether an ability is or is not present. The point is not to obtain a score with it, a DQ or IQ or MA, but a description of functioning abilities. Figure 10 outlines the possibilities that we have discussed.

I think I should remind you that any assessment is incomplete unless some measure of learning is incorporated.

Habituation or the progressive decrement in response to a repetitive stimulus...appears to offer the most direct approach to estimating learning capacity. Customarily this has involved presenting S_1 with the exponential fall-off, then S_2 , the new stimulus, producing an increased level of response. The discrepancy principle of Kagan (1972) offers a broader extension of this model. Collard and Rydberg (1972) provide a simple means of exposure to toys which taps the generalization of habituation to size, color, and/or form by human infants (Crowell, 1972, pp. 6 & 7-8) (Table 9/10).

Of course such efforts as the ones described above in this section require a certain amount of instrumentation and additional studies to streamline the administration for screening and to establish more firmly their validity and reliability. The difficulties in obtaining meaningful behavior of an intellectual/cognitive kind from infants is attested to by all investigators in the field and underlies the fact that most infant screening and assessment procedures focus primarily on the more easily elicited, observed and measured sensori-motor factors. The fact that such sensori-motor development does statistically correlate rather highly with subsequent cognitive functioning, when the data for large groups of normally developing children are reviewed, contributes to a great deal of the confusion in the field, since an illicit judgment is frequently made that a statistical co-relation is the same as a cause-effect relationship. Although difficulties in eye-hand coordination or basic reflexes or achievement of gross and fine motor developmental milestones may in some instances reflect disturbance not only of lower brain functions but also of higher

SUMMARY CLASSIFICATION SHEET
(3-6 Months Evaluation)

Behavioral Assessment		
<u>A</u>	<u>B</u>	<u>C</u>
Domain 1 (Psychomotor)	Cognitive	Object Permanence
Domain 2 (Psychomotor)	Memory	Space
Domain 3 (Visual Perception)	Divergent	Time
Domain 4 (Auditory Perception)	Convergent	Causality
Domain 5 (Receptive Psycholin- guistics)	Evaluation	
Domain 6 (Expressive Psycholin- guistics)	Others	
Domain 7 (Mental-Memory & Thinking)		

Table 9/10: SUMMARY CLASSIFICATION OF TESTS AVAILABLE FOR BEHAVIORAL ASSESSMENT FROM 3-6 MONTHS. Column A from Meyers & Dingman, 1960, Column B from Stott and Ball, 1965 (adapted from Guilford, 1959) and, Column C from Piaget (Flavell, 1963).

cortical functioning, it is quite possible for an individual with severe sensori-motor problems to have totally intact higher cortical processes as demonstrated by an intellectually bright quadriplegic or even cerebral palsied child; conversely, a given child may be seriously intellectually impaired but be physically well coordinated and up to par in his gross and fine motor milestones--the all-brawn-no-brain syndrome is an exaggerated description of this.

This discussion of assessment of early cognitive development should not close without a cautionary note. The state of the infant at the time of testing, that is, the degree of wakefulness/alertness, is an important confounding factor in practically all screening and assessment efforts and has frequently been overlooked. Thus, it is possible that a low score on some screening or assessment procedure may not be a function of some deficiency, but rather a function of the infant's being in a state inappropriate for that assessment at that time. Hutt, Lenard, and Precht1 (1969) make the point:

The importance of the state of the infant at the moment of testing, and of state changes during the course of a neurological or psychophysiological investigation has been stressed in recent years by several writers.... Nevertheless, state has not consistently been accorded the importance it merits as a variable in neonatal studies....

It is thus seen that even relatively simple reflex responses are intimately bound up with state. The optimal state for eliciting one reflex is not necessarily the optimal state for eliciting another. Only nociceptive reflexes appear to function independently of state, and it is biologically adaptive that this should be the case. If, therefore, the changes of state from I to V are considered as a gradual increase in 'wakefulness,' 'activation,' or 'arousal,' it is seen that there is no corresponding orderly change in reflex responsivity. In regular sleep some reflexes are easily elicited, only to disappear in irregular sleep and then to reappear on waking. Other reflexes appear in irregular sleep, but disappear on waking; some appear only when the baby shows a high level of behavioral activity and yet others seem to be present continually.... The point is, however, that because state is not consistently treated as an experimental variable, we are always left in doubt as to whether a significant amount of the variance could have been accounted for by this factor. Moreover, the amount of time spent in any state is, in part, a function of the environmental conditions under which the experiment is conducted. In one study, the environment may be conducive to producing regular sleep, in another wakefulness... (pp. 140, 154, 156).

Kagan recently promulgated claims about a carefully studied sample of Guatemalan Indian children reared in extreme environmental deprivation who, despite uniform retardation of about four months in cognitive and affective development during the first year and a half of life, at eleven years of age performed at levels comparable to American children on tests of recall and recognition, memory, perceptual and conceptual inference and analysis. These findings (to date unpublished) lead him to assert a much greater plasticity in cognitive development than he and most other children developmentalists have acknowledged and they suggest major discontinuities in early cognitive development that interfere with any attempts to predict later ability from early testing. (Figure 15/53.)

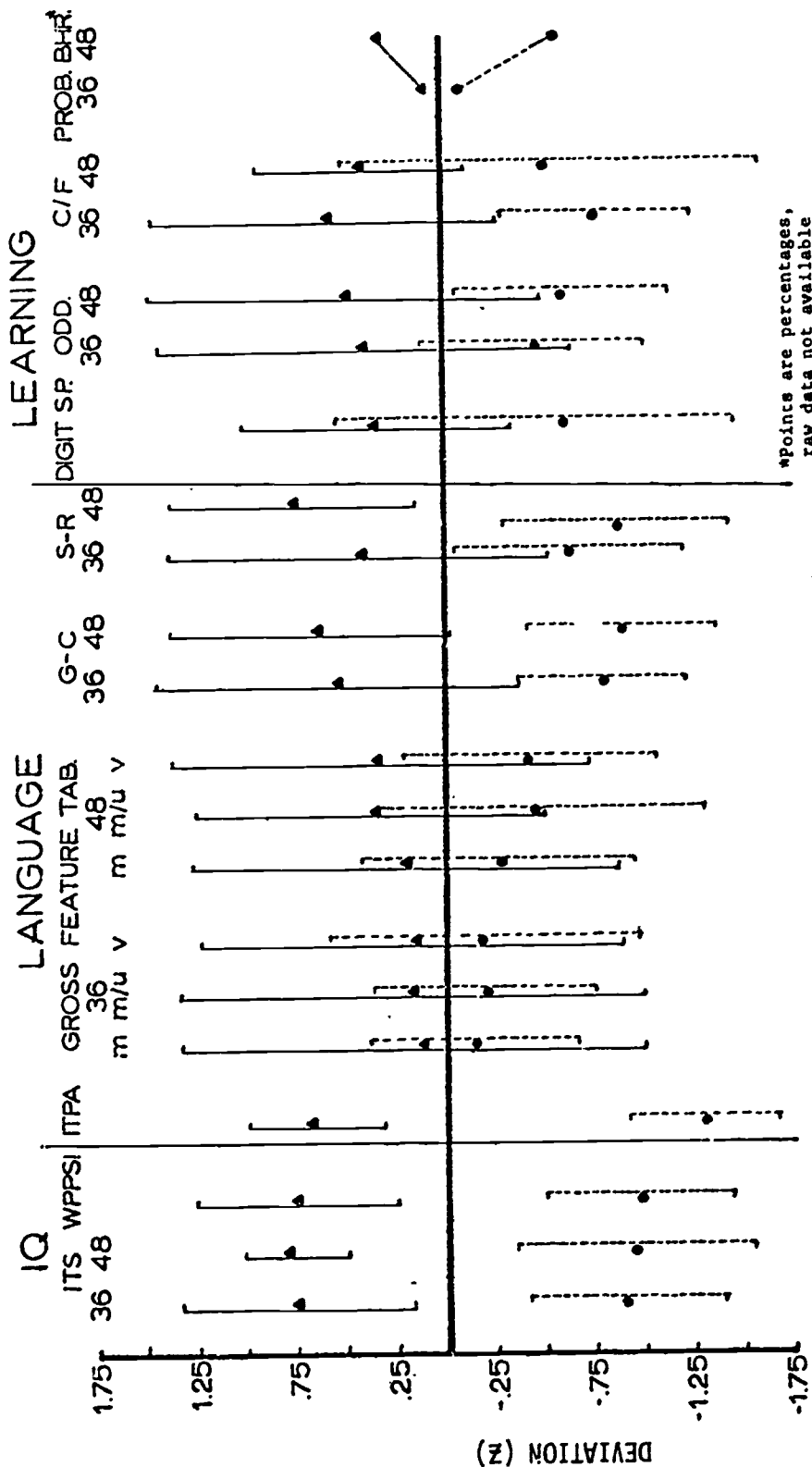


Figure 15/53: Composite of transformed developmental measures from 36 months and 48 months; solid line shows range and mean ▲ of experimental Ss and dotted line shows range and mean ● of controls (Heber, et al., 1971, p. 274). These trends became evident earlier and have allegedly continued, giving some hope for the predictive validity of some of the measures, if study is replicated with better controlled and described procedures.

CHAPTER V

LANGUAGE FACTORS

Receptive Language Development

As stated in Chapter IV, in the past until a child had begun to express his thoughts in a verbal way he was not considered to be a thinking person. In fact, for several centuries it was believed, and still is by many, that the age of reason does not arrive until seven years of age. Within recent years, however, investigators have developed increasingly accurate and ingenious equipment and procedures for evaluating receptive language in infants and young children. One of the prime investigators in the field gives some notions of the state of the art and science.

Serious receptive language deficits in infancy and early childhood can have severely damaging effects on mental development, and standard hearing tests often fail to detect these disabilities.

The techniques of audiological evaluation have been greatly refined in recent years, even with the very young who were formerly regarded as untestable. In addition to establishing thresholds of hearing with different varieties of laboratory sound and speech samples, it is also important to assess a child's ability to perceive sounds and voices that are representative of those surrounding him in the natural world.

As one recent comprehensive review points out, "In contrast to the body of knowledge which has been gathered on hearing acuity, comparatively little research has been done on the processing of auditory stimuli (*italics added*).¹" In other words, an audiogram and a hearing aid do not necessarily constitute a sufficient solution to the problems of babies and young children who show up at the clinic or at school with diffuse delays and disruptions of language growth. More information is needed on the effectiveness of their listening to the fine-grained aspects of natural sound and language stimuli, on their methods of using natural sound inputs in the integration of their sensory experiences, and on their integration of these listening experiences with other aspects of their adaptation to complex events in their physical, social, and emotional environments.

This report describes a program of research and evaluation aimed at improving methods for assessing receptive language development in infants and young children with known or suspected deficits of hearing and language. The main goal of the program is to expand the pool of information about a child's listening and language perception (Friedlander, 1971, p. 9).

In the same article Friedlander goes on to explain the value of his automated evaluation techniques for assessing selective listening in infants and young children.

Procedures already developed have tested the effect of such important listening variables as loudness, language redundancy, speaker identity, filtered frequencies, and controlled signal to noise ratios. Studies in progress, or planned for the early future, include more extended research on the effects of variables such as fundamental

frequencies, time values, speech-like noise, linguistic familiarity, and grammatical-syntactic values.

The principal results show that the two groups of normal children were more and more decisive in their rejection of the degraded sound tracks as the noise interference increased in intensity. However, the language-impaired children listened to both the normal and the increasingly incomprehensible sound tracks with almost identical degrees of attention. Furthermore, these children's total listening response time was just as high as that of the normal children, emphasizing the difference between them.

These non-deaf children with diffuse disorders of speech development showed the same high level of interest in watching and listening to a television story-teller whose words were totally incomprehensible as to the same speaker whose story narration was clear and easy to understand. It was apparent that these children suffered from some primary disorder of speech input recognition that made it impossible for them to demonstrate a preferential distinction between true speech and auditory garbage.

The first finding of primary failures of receptive language organization has been extended to other populations of children in whom speech disabilities are a major element in other symptom patterns. The data are remarkably similar. Systematic basic studies with seriously emotionally disturbed children at preschool and kindergarten levels and with pre-teen autistic boys show high levels of total listening response time and almost total failure to distinguish between real and incomprehensible video sound tracks. (Figures 16/1 and 17/@)

These early stages of basic and clinical research suggest that disorders of language perception may lie at the root of more readily observable problems of productive speech performance.

The problems of serious receptive language impairments in infants and young children are so extraordinarily intricate that no single evaluation technique can, by itself, play an exclusive role in assistive intervention. Nevertheless, more precise and effective evaluation of a child's subjective listening deficits is a primary requirement for selecting remediation programs that are best suited to a child's real needs. Studies such as those described above help identify these needs in terms of listening experiences which the child can regulate himself, using stimulus materials carefully developed by the clinical research team to identify specific receptive language processes (pp. 9 and 12).

Once again the utilization of rather sophisticated apparatus is required to assess the selective listening patterns of infants and even more elegant instrumentation is required to get at the integration of sound with slight experiences and the interpretation of these by normal and abnormal infants. Nevertheless, the screening, at perhaps the tertiary level, of infants in terms of their ability to relate what they see to what they hear would certainly provide a meaningful assessment and prediction of likely learning disabilities in subsequent years.

Diagnostic Significance of Infant Cry

Ostwald, Phibbs, and Fox (1968) present a review of published infant cry studies along with some of their own laboratory findings, which all tend to indicate that the very crying of infants has diagnostic value when subjected

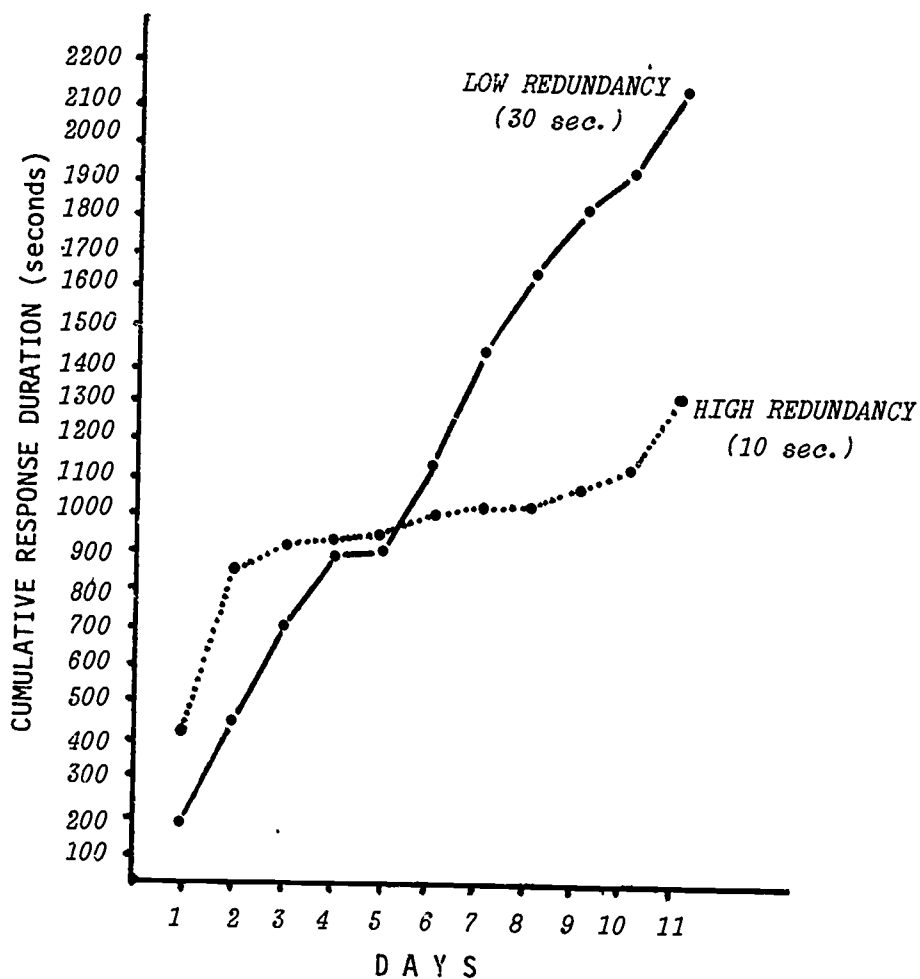


Figure 16/1: Discriminative crossover listening selection of high and low redundancy story segments, recorded automatically in the home by an 11-month infant girl with suspected hearing/language disability due to perinatal asphyxia. This response pattern substantially approximates performance by presumed normal and superior control infants.

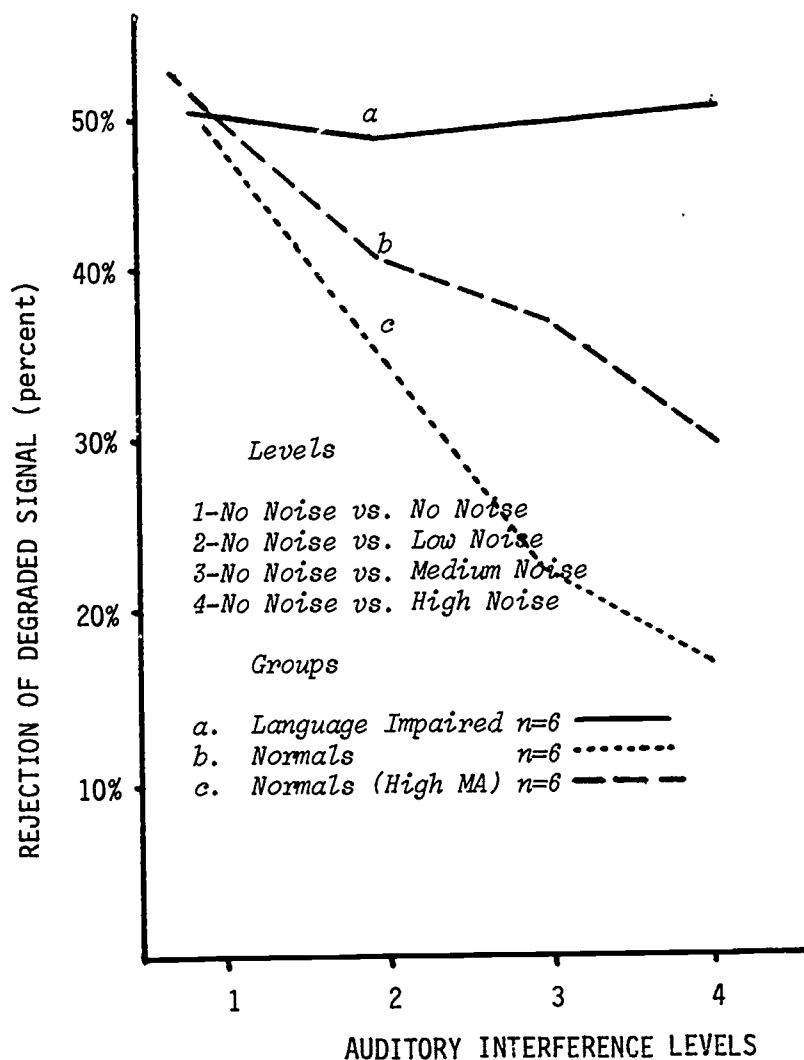


Fig. 17/©: Effects of stimulus degradation on discriminative listening to television sound tracks by three groups of preschool children: a) language impaired, mean MA 5.5; b) normal, mean MA 5.6; c) normal, mean MA 6.8. Normal children at both MA levels rejected degraded sound tracks in television game ($p < .01$). Language impaired children did not discriminate sound tracks at any interference level.

to careful analysis. Indeed, the infant cry is the individual's first expressive language and has real meaning and communication value. Of the 24 studies they report from 1838 to 1967, 22 of them have been done since 1927, and over half since 1960.

The question arises whether certain features of infant cry may be used to predict a future developmental delay or defect. Karelitz and coworkers (1964) have long suspected and tentatively confirmed a relationship between crying activity in early infancy and preschool intelligence ratings. The age at which babbling begins is predictive of later intelligence scores among girls (Cameron, Livson and Bayley, 1967). But until more is known about cry-transformations, cooing, and other prelinguistic communication patterns during the first year of life (Spitz, 1965), one must proceed with great caution in attempting to base any forecasts on the cry-behavior of infants.

Since even the normal physiology of infant vocalization is something of a mystery, all we can say about the cause of 'abnormal' cry sounds is that they presumably result from imbalances between subglottal respiratory pressure and the laryngeal tension mechanisms (Lieberman, 1967). To what degree and in what manner there may be central nervous system control over the pattern of the neonate cry requires further research. In our opinion the infant cry reflects an innate, genetically-determined, species-specific pattern of organization. This would be consistent with the finding of abnormal cry patterns associated with chromosomal disorders like Down's Syndrome and Cri-du-Chat. The likelihood that cooing and babbling are also determined by innate propensities for communicative development has been discussed by Lenneberg (1967). Psychoanalytic theory would suggest that anomalous vocalization in infancy reflects a disturbance in the development of age-appropriate ego control-mechanisms (Spitz, 1965). It therefore seems possible that more accurate definition of the pattern of structural and temporal characteristics of prelinguistic soundmaking might be useful in the early detection of pathology.

Auditory assessment of cry patterns has a traditional usefulness in clinical evaluation of the infant. Within the last decade acoustic studies have contributed more precise information about neonatal sound productions, specifically in regard to the properties of cries associated with different clinical states and disease conditions. The present study involves sonographic analysis of 356 expiratory cry utterances derived from 13 infants that on the basis of clinical data, behavioral development, and neurological status were classified as normal, impaired, or abnormal. Duration measurements showed no consistent differences between the three groups. Pitch measurements showed a marked increase of the fundamental tone only among infants rated as impaired or abnormal. It is postulated that this reflects a disorganization of innate adaptive mechanisms which assure that infants can elicit appropriate social responses from their environment. More thorough and detailed study of abnormalities in vocalization patterns within the first six months of life might be helpful in predicting results of subsequent language and intelligence tests, especially when there are early signs of neurological or developmental pathology (pp. 70, 80-81). (Figure 18/2)

Diagnostic Use of Infant Cry

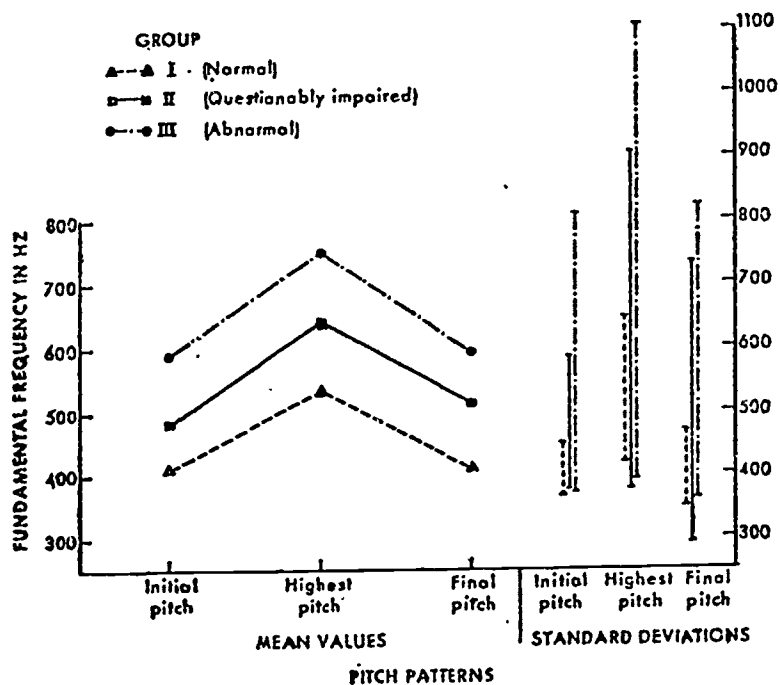


Figure 18/2: Results of fundamental tone measurements of 356 cries from three clinical groups. There is a marked difference in pitch pattern between normal (Group I) and abnormal (Group III) infants.

Expressive Language Development

A technique of assessing expressive language development for three- to four-year-old children is that of a sentence repetition task, such as the one developed by Reyes, et al.

Researchers in developmental psycholinguistics have utilized three measures for determining the level of a child's linguistic development: (1) the child's ability to repeat grammatical structures presented to him as models; (2) his understanding of these structures; and (3) his ability to produce the structures himself. Although the first measure may not be as definitive of the child's actual ability as the other two, it has been found to be a predictor of his performance on tests for comprehension and production (Menyuk, 1963, Fraser, Bellugi, and Brown, 1963; Lovell and Dixon, 1967).

While the present study is not primarily concerned with determining the extent of the relationship between imitation, comprehension, and production, it intends to provide additional evidence regarding the effectiveness of the sentence repetition test as a tool for measuring linguistic development, viz., differential linguistic development. In this study, a wide sample of sentence types has been presented for repetition at three-month intervals to two groups of children. Our primary concern is the differential rate of linguistic progress between the three- and four-year-old children participating in a preschool education program and those who are not. There are two major differences between our study and previous ones involving imitation tasks. First, all of the subjects are disadvantaged black children from the same urban community who have presumably been exposed to the same non-standard dialect of English. Secondly, the tests have been replicated over a 24-month period, allowing observations to be made on the subjects' differential performance as they continued to take the same test at different stages of their linguistic development.

In general, the Experimental Group demonstrated not only greater imitative skills than the Control Group at any age level, but also a more rapid and constant rate of improvement, as a comparison of the figures for the different age levels will show (Reyes, et al., in Heber & Garber, 1971, pp. 1, 2, & 4).

This technique plus several others developed to assess the impact of a thorough intervention program (Heber, et al., 1971) has considerable empirical validation in the sense that the experimental groups, which experienced considerable language enrichment, predictably and empirically performed better than their control counterparts on various and sundry receptive and expressive language assessments. It does seem from the data reported that although there is yet much to learn about factors of length in syntactic complexity, the results of the sentence completion test may be used as a reasonable estimate of children's language functioning and, because of its straightforward and simple administration, it might actually serve as a part of a screening battery.

In addition to the standardized technique of sentence repetition for assessing expressive language development, it is also important to determine how well an individual can produce speech in a free and open situation.

For each free speech sample, upwards of 25 times the time length of the sample is required for its proper transcription. But as has been pointed out, it is through this technique that a realistic speech sample can be approximated. Free speech samples, we feel, are a very necessary complement to other data being used in the development of a comprehensive picture of language acquisition. Without it, data would otherwise be obtained only by structured, elicitation techniques which can increase cumulatively the number of artifacts entering the data.

The data from free speech language analysis seems to be most sensitive to inter-group differences at the earlier month periods. The free-speech analysis demonstrates initial language growth of the experimental group far superior to the control. The eight quantitative measures yield some interesting developmental trends. The first eight months of growth seem to be a critical period of development for the experimental groups, or conversely, a retarded period of growth for the control group. Even though a number of morphemes is obviously highly interrelated with total utterances, the fact that the experimental children are producing a significantly larger number of unique vocabulary items, and are also using utterances that are almost 50 percent longer than the control, gives added meaning to the measure of gross numbers of morphemes. Indeed, this holds serious implications for the development of both linguistic and perceptual skills. An early start at perceptual discrimination and labelling is, it appears, crucial for subsequent development of language skills.

As our results indicate, free speech language analysis appears to be an effective method of delineating both quantitative and qualitative differences between the control and the experimental groups. Quantitative differences at the early months favor the experimental group. The qualitative differences suggested by four factors in the quantitative data, viz., 1) the number of repetitive utterances (Fig. 19/V), 2) the number of single-word utterances, 3) vocabulary range (Fig. 20/VI), and 4) the mean number of morphemes per utterance are replicated by highly structured language measures (e.g., sentence repetition and the ITPA) that also seek to establish developmental language patterns. The fact that there is a great deal of congruence between these tests and the free-speech data provides a more comprehensive picture of the process of language acquisition and development. It is true that the sensitivity of free speech measures decreases at later month periods. This may be due to the increase in the 'semantic load' factor for any utterance in the speech of both groups of children. If a scale were devised to measure the 'semantic load' of a child's speech -- a scale that would quantify the amount of communication contained in an utterance -- perhaps free speech data would reflect the differences between experimental and control groups that more structured tests indicate occur at later month periods. Thus far, free speech sampling techniques are most sensitive to early language growth performance when language behavior is far more quantitative than qualitative. It is in this early period that language tends to be used to react to situations and to make a comment all with a demonstrative or identifying remark. Later, language tends to act upon the environment in attempts to initiate or actively appreciate the situation. These attempts introduce the abstract and more complex syntactic aspect of thought and language. This thesis is

REPETITIVE UTTERANCES

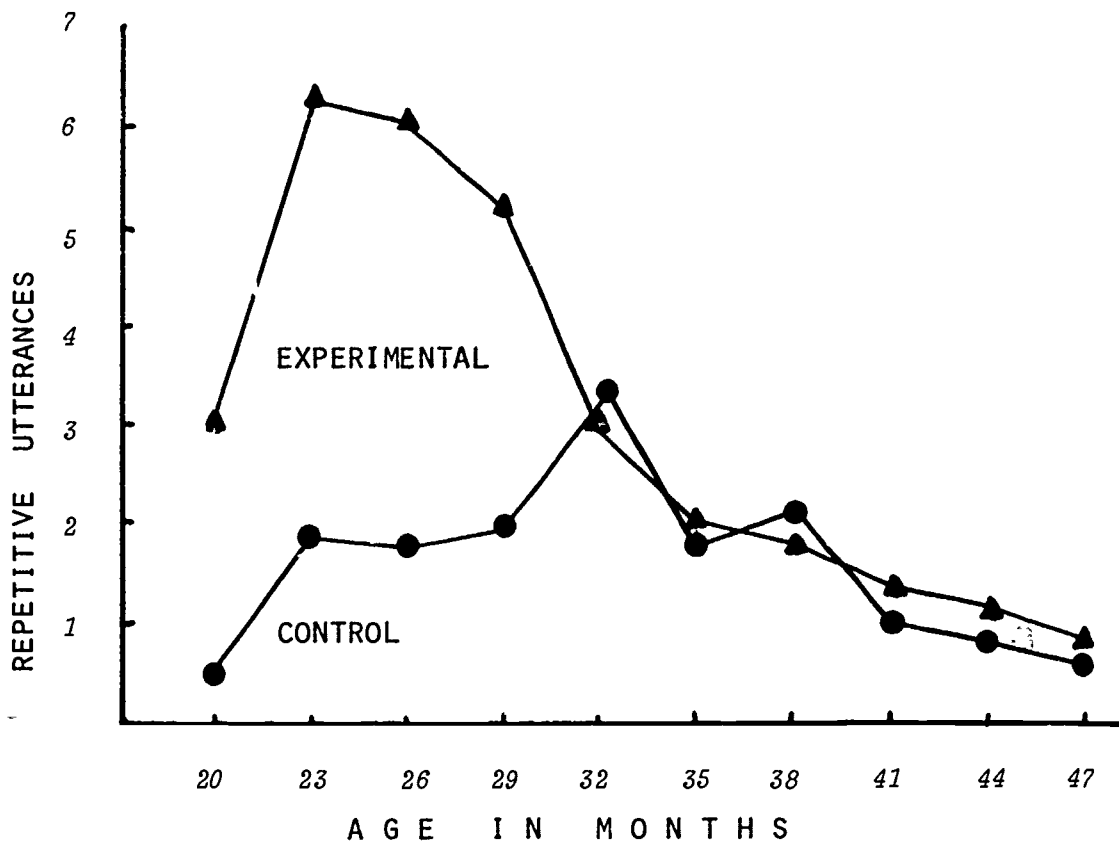


Figure 19/V: Repetitive Utterances are much greater in early months by language-enriched experimentals but diminish later as "semantic load" begins to increase and replace mere sound imitation (Bernard, Thelen, & Garber, no date).

VOCABULARY RANGE

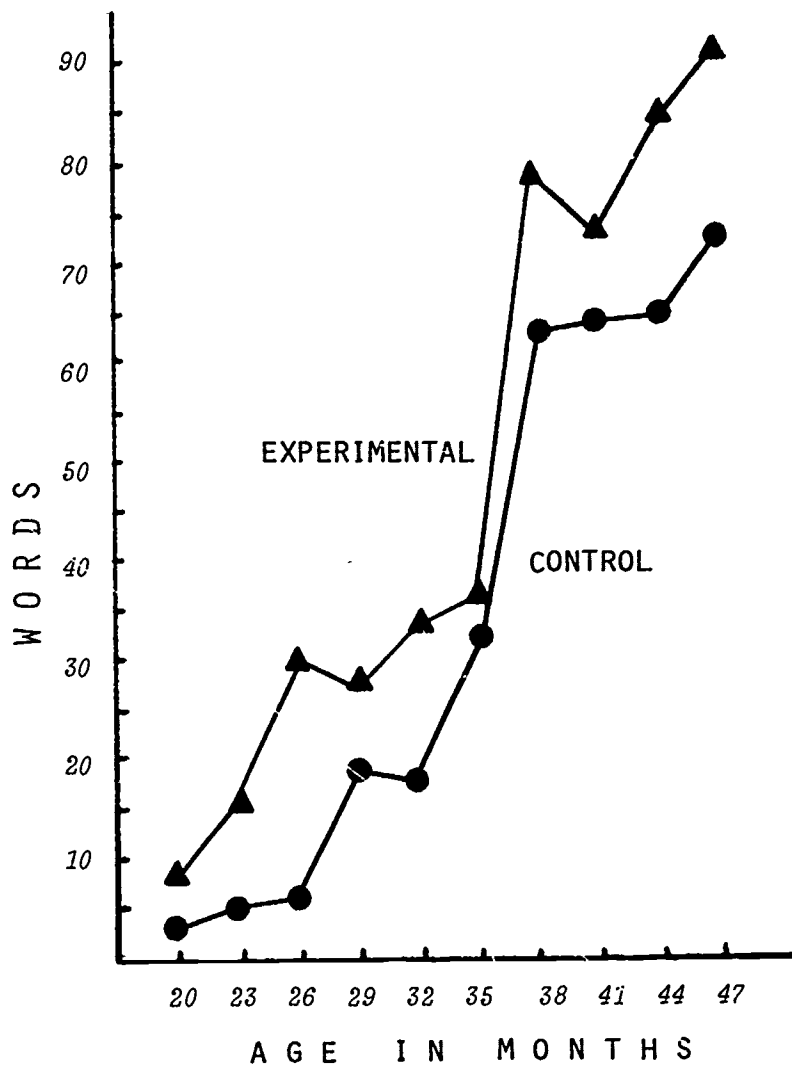


Figure 20/VI: Range of unique vocabulary items in free speech is significantly greater among language-enriched experimentals and their utterance are almost 50 percent longer than controls (Bernard, Thelen, & Garber, no date).

consistent with the treatment of thought and language by both Vygotsky and Piaget (Bernard, Thelen, and Garber, no date, pp. 2, 14, and 17).

Language Tests and Scales

Marmor (1971) has developed a manual for testing the receptive language ability of one- to three-year-old children. The portion of the test for one- to two-year-old children measures their ability to understand vocabulary words and to follow verbal instructions by responding to simple object labels and to more difficult labels for classes of objects by identifying their reference object. The instructions require the child to follow simple familiar commands and progress to the more difficult phases of carrying out more complex sequences of behavior. The test items draw upon several established picture vocabulary and language comprehension tests. The manual instructs the examiner in specific procedures in scoring information using the materials to assess receptive language ability. The final score for the two- to three-year-olds is expressed as a developmental age equivalent and the reliability of interobservers in all cases exceeded .90 but the instrument still requires additional validation on the basis of longitudinal data before it can be used confidently in a massive screening and assessment project.

Another effort along these lines is found in the early language assessment scale developed by Honig and Caldwell (1966 -- Part I) and Honig (1970 -- Part II). These scales, complete with instructions and scoring or rating sheets (see Figures 21 and 22 on next pages), tap both the receptive and expressive language of infants and toddlers. It is evident from reviewing the reports on the scales that they could be administered and scored rather easily by trained paraprofessionals and might serve as a good secondary stage of language development screening.

Language Screening -- An Interdisciplinary Process

It has been repeatedly stated and implied that screening is a multi-stage procedure and Grewel makes a cogent case for both an interdisciplinary and differential diagnosis.

It is a fact that most linguists have not the slightest idea of speech pathology, whereas as a rule neurologists are unaware of modern linguistics. Most psychologists and many speech pathologists who study the development of speech in children are unable to differentiate sufficiently between delay or insufficiency in the mastering of language and on the other hand difficulties in articulation.

Local and generalized lesions as well as local delay of the development of the brain give rise to multifarious neurological symptoms. Some of these cause psychological disorders. They are studied in the overlapping fields of neurology and psychopathology, called clinical neuropsychology which in the last decades has developed into a special field of study. It is not sufficiently realized that many developmental delays in children must be regarded as belonging to developmental neuropsychology. Speech and language disorders in children confront us with a special aspect of neurology and neuropsychology. The study of these disorders requires thorough knowledge of speech and its disorders, articulatory as well as verbal. Whereas the neurological symptoms must be ascertained, phonetic as well as linguistic analysis of the symptoms is

PART I RATING SHEET

Child's Name _____ ID# _____ Time _____ Date _____ Yr. Mo. Day _____
 (1-4)
 Sex _____ Age in Months _____ Examiner _____ Birth Date _____
 Age _____

<p><u>Crying</u></p> <p>1 Frequency-assessed _____ 2 Quality-assessed _____ 3 Frequency-reported _____ 4 Quality-reported _____</p> <p><u>Smiling</u></p> <p>5 Frequency-assessed _____ 6 Stimuli-assessed _____ 7 Frequency-reported _____ 8 Stimuli-reported _____</p> <p><u>Babbling Without Stimulation</u></p> <p>9 Frequency Here _____ 10 Type assessed _____ 11 Type reported _____</p> <p><u>Response to Scripts</u></p> <p>Script A - (Ba-Ba) 12 Style _____ 13 Smile and Latency _____</p> <p>Script B - (Da-Da) 14 Style _____ 15 Smile and Latency _____</p> <p>Script C - (Ma-Ma) 16 Style _____ 17 Smile and Latency _____</p> <p><u>Overall Frequency of Babbling with Stimulation</u></p> <p>18 _____</p>	<p><u>Laughter: Quality Rating</u></p> <p>19 Tickle _____ 20 Object _____ 21 Voc-vis _____ 22 Voc-vis-tacts _____ 23 Stim reported _____ 24 Qual reported _____</p> <p><u>Response to Bell</u></p> <p>25 Style _____ 26 Smile _____</p> <p><u>Response to Music Box</u></p> <p>27 Style _____ 28 Smile _____</p> <p><u>Response to Own Name</u></p> <p>29 _____</p> <p><u>Response to Voice Change</u></p> <p>30 _____</p> <p><u>Response to Masks Pleasant</u></p> <p>31 _____ 32 _____</p> <p><u>Smiling Unpleasant</u></p> <p>33 _____ 34 _____ 35 _____ 36 _____</p>	<p><u>Response to E's Impassive Face</u></p> <p>37 _____ 38 _____</p> <p><u>Response to Self-Image in Mirror</u></p> <p>39 _____ 40 _____</p> <p><u>Word Imitation Response</u></p> <p>41 Baby _____ 42 Bottle _____ 43 Ball _____ 44 Spoon _____ 45 Box _____</p> <p><u>Verbal or Gestural Control for Behavior</u></p> <p>46 Give me _____ 47 " _____ 48 Pat-a-cake _____ 49 " _____ 50 Peek-a-boo _____ 51 " _____ 52 Bye-bye _____ 53 " _____ 54 No-no _____</p>	<p><u>Learned Imitation For Gestures</u></p> <p>55 Bang Table _____ 56 Tongue _____ 57 Cock head _____ 58 Puff air _____</p> <p><u>Vocabulary-Body Parts</u></p> <p>59 Nose _____ 60 Mouth _____ 61 Eyes _____ 62 Hair _____ 63 Hand _____ 64 Teeth _____ 65 Feet _____ 66 Toes _____ 67 Fingers _____</p> <p><u>Remarks</u></p>
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Figure 21: Early Language Assessment Scale
 Syracuse University Children's Center,
 Honig & Caldwell, 1966.

PART II - RATING SHEET¹

<u>RESPONSE TO VERBAL REQUESTS</u>	<u>SOCIAL INTERACTIONS</u>	<u>ROOM PARTS</u>	<u>CAREGIVING AND CLOTHING</u>
68 Come here _____	88 Up _____	106 Table _____	121 Cup _____
69 Go away _____	89 Please _____	107 Window _____	122 Coat _____
70 Put it down _____	90 Thank you _____	108 Light _____	123 Hat _____
71 Sit _____	91 Hi; hello _____	109 Door _____	124 Shoe _____
72 Kiss; hug _____	92 What are you doing? _____	<u>ANIMAL SOUNDS</u>	125 Blanket _____
73 Open the... _____	93 What's that? _____	110 Meow _____	126 Bed _____
74 Close the... _____	94 I want _____	111 Bow-wow _____	<u>COMPLEXITY</u>
75 Put on your... _____	95 Mine; my _____	112 Moo-moo _____	127 2-word combina- tions present _____
76 Run _____	96 Sorry _____	<u>ANIMAL NAMES</u>	
77 Dance _____	<u>FOOD ITEMS</u>	113 Dog _____	128 Number of words in vocabulary _____
78 Eat _____	97 Juice _____	114 Cat _____	
79 Put...in _____	98 Milk _____	115 Bird _____	
80 Take...out _____	99 Cookie _____	116 Horse _____	
81 Let's go for a walk _____	100 Soda, Koolaid _____	117 Bunny _____	
82 Go potty _____	101 Candy _____	<u>PLANT NAMES</u>	
83 Try to... _____	102 Meat, Hamburger _____	118 Flower _____	
84 Pretty _____	103 Hot dog _____	119 Tree _____	
85 Hot _____	104 Apple _____	120 Leaf _____	
86 Dark _____	105 Banana _____		
87 Hard, Heavy _____			

¹The point scores achieved by the infant are directly entered next to each item number. See Table 4 for rules for allotting points for these items.

Figure 22: Early Language Assessment Scale

Syracuse University Children's Center
(Honig, A., 1970).

necessary, whereas the relation or correlation with psychological delay or deterioration must be studied. Differential diagnosis is necessary.

It is a well-known fact that the brainpathology of lesions causing speaking disorders and that of lesions with difficulties in the use of language are quite different. In adults aphasia and dysarthria are the prototypes of this difference. Moreover, language deterioration in dementia and paucity of the use of language in cases with abulia must be taken apart (no date, pp. 861 & 864).

From the foregoing very cursory and incomplete review of some language factors, it should be clear that there is much more to receptive language in infants than their ability to hear sound and there is more to their expressive language than the neurophysiological and neuroanatomical integrity of the speech mechanisms (see McNeill, 1970; Berry, 1969; & Travis, 1971, for a much more extensive and intensive treatment of the acquisition of and anomalies in language from various developmental approaches). Also, implicit throughout all of the comments about screening for developmental disabilities in receptive and expressive language, it must be remembered that various associative processes are also inferred from the findings on studies of language input and output. The actual integrity of the central nervous system in processing the linguistic input properly, i.e., in efficiently categorizing, storing, retrieving, and associating data, is still not possible to systematically and scientifically measure. It is nevertheless conceivable that certain neurophysiological and electrobiochemical indices to central nervous system integrity and overall efficiency will be forthcoming in the near future much as forecast by studies such as Crowell's (1972) reported in Chapter (Figure 23/1 from Crowell's article represents the multifaceted features of communication ability and suggests the many disciplines involved.)

Moreover, the interaction between heredity and environment in terms of language development and, in turn, its importance for optimum intellectual/cognitive functioning lead to the next section dealing with the social and emotional manifestations which are equally complex and interdependent with the other factors. This makes comprehensive and massive screening and assessment of children at risk for any of the vast range of developmental disabilities an extremely complex process.

As in other previously described sophisticated measures of fine phenomena, rather elaborate instrumentation is required simply in order to properly analyze the characteristics of infant cries. A properly designed combination screening console may very well allow much of the salient data from the several domains described in this monograph to be collected and analyzed quite efficiently. Judging from the efficacy of many early intervention programs which have the benefit of early differential diagnosis of developmental disabilities, the attendant cost in design and development of such instrumentation would be very small compared to the savings in human functional competence. Cost/benefit analyses may likely indicate that only a few regional screening centers be established for conducting the tertiary stage screening and assessment and for coordinating the primary and secondary stage screening. Some members of the network of University Affiliated Facilities would be eminently well qualified to serve in this capacity.

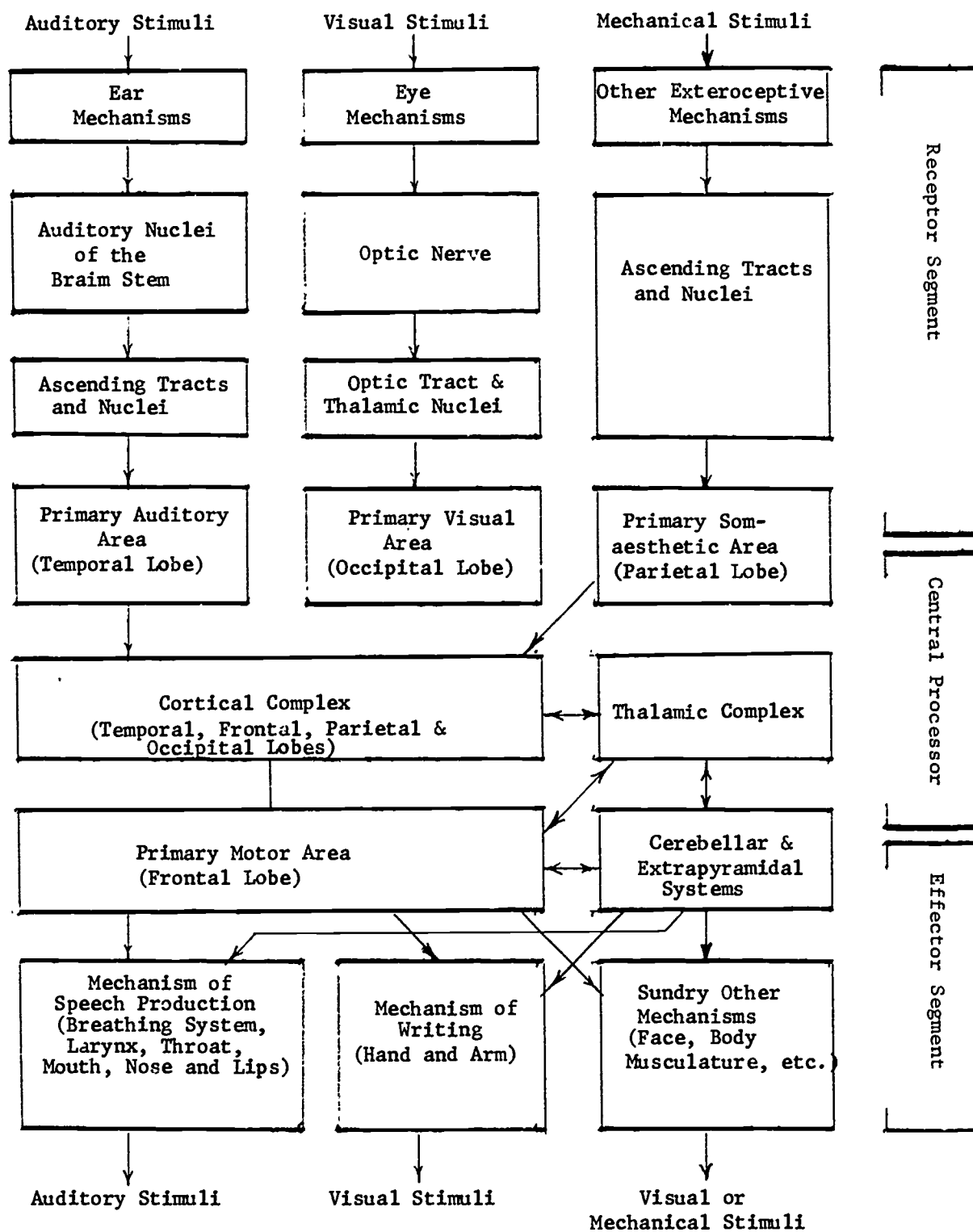


Figure 23/1: Schematic diagram of neural mechanisms for human communication. (From Human Communication and its Disorders - an Overview, 1969) (Crowell, 1972).

CHAPTER VI

SOCIAL/EMOTIONAL FACTORS

Mother-Infant Attachment Dynamics

In a rather thorough-going review of literature and synthesis of current knowledge about the social-emotional developmental factors from birth to two years, Starr concludes his review:

Although there has been a rapid increase in research concerning socio-emotional development in infancy over the past decade, we are only beginning to understand topics such as the origins of socio-emotional behavior and the development of infant-mother attachment. Other major topics have remained virtually untouched. Knowledge of development in the second year is lacking in all areas, even with respect to attachment. The peer affectional system is only starting to come under study, and we know even less about the development of mother-infant and father-infant systems. Our knowledge of the development of many major emotional responses comes from studies forty-years old and in areas such as achievement, pro-social behavior, independence, and impulse control even that knowledge is not available. Research is, however, directed properly, and, with much time and effort, our knowledge of socio-emotional development in infancy should be more complete and our suggestions for child care more accurate and precise (no date, p. 17).

In addressing simply the area of attachment behavior and the current state of knowledge, Starr makes several summary observations.

Attachment behavior and factors influencing its development are of prime importance to the study of overall socio-emotional development. Ainsworth and Wittig (1969) conclude five factors are of basic importance in fostering attachment: (a) frequent, sustained infant-mother physical contact combined with a maternal ability to soothe the infant through such contact; (b) the patterning of the mother's responses to her baby's needs and her sensitivity to his signals; (c) a predictable environment allowing for the development of a sense of autonomy and competence; (d) "freedom to explore"; and (e) "mutual delight" between mother and infant.

We also need to be continually aware of the limitations of our present knowledge of the factors influencing attachment. We are a long way from designing the "perfect" plan of child rearing. At the present time we know that infants are resilient, but not the minimal amount, type, and patterning of care necessary for adequate development. Until such a time occurs we must remain conservative in our approaches to child care. Ainsworth (in press) and Anna Freud (1965) suggest that in the light of our present knowledge we should avoid separations before three, and perhaps six years of age. Hopefully through more research such as the longitudinal studies of Ainsworth and Moss we can more thoroughly define the factors of importance in the development of attachment in particular and socio-emotional attributes in general (no date, pp. 9-10).

Germane to the social/emotional issues of early screening and assessment is an article presenting a neonatal behavioral assessment scale by Brazelton, et al.:

We would hope that this scale might fill the needs of clinicians and researchers - viz. an instrument for assessing the subtler behavioral responses of the neonate as he adjusts to his new environment and gains mastery of his physiological equipment, as he prepares to begin the important period of emotional and cognitive development of infancy. We hope that it will help us understand a caretaker's response to him as we use the assessment scale, and thereby predict the kind of interaction he is likely to set up in his environment.

If Bowlby's thesis (1) of attachment behavior is as powerful as it seems to be, observations of the neonate and the reactions he engenders in his parents in the early weeks may become the best predictors of the outcome of the mother-father-infant interaction (pp. 1 and 6).

Although this particular paper is addressed primarily to the neurological 'state' of the infant, its intent is to predict his later personality development, which is regarded, for purposes of this monograph, to be largely social-emotional in nature. The first page of the rating scale, which is entitled: A Behavioral and Neurological Assessment Scale (1971), is almost exclusively physically oriented and the behaviors to be rated on the second page are largely oriented around sensory-motor behavior; thus, the scale itself has been included in Chapter III. Nevertheless, the scoring sheet also rates such things as cuddliness, consolability, smiles, and general activity level, all of which may be variables contributing to the "sending power" (Murphy, 1967) of the infant and the consequent quality of interaction between him and his mothering one(s). This example also serves to emphasize the difficulty of separating many of the screening procedures, which overlap several developmental domains.

Without going into all of the details, it seems appropriate to mention at this juncture a germane comment made by Professor Rene Spitz during a regular meeting of our Developmental Seminar, which was critiquing this monograph. He recalled a recent conversation he had enjoyed with Professor Margaret Mead in which she expressed her deep concern for the present youth generation because it was reared largely without the benefits of the physical/emotional satisfactions of breast-feeding. One might speculate about the adverse affect the absence of this reciprocally satisfying experience is having on today's young mothers as perhaps reflected in inadequate attachment behavior and even neglect and abuse cited in Chapter III.

Structured Parental Observations of Children

An alternative to observing infants and toddlers in order to screen and assist their socio-emotional developmental status is to rely upon the principal mothering adult in the child's life as an informant for completing various questionnaires, checklists, or inventories. One such instrument is a Behavior Problem Checklist developed by Quay and Peterson (1967) which has been used with a wide variety of child samples and the results have been replicated many times in spite of somewhat less than desirable interrater correlations.

Parent symptom-rating data on 173 child patients, 357 siblings of child patients, and 445 nonclinic children are reported. Analysis of the data indicated that parent ratings clearly differentiate child patients from their siblings and from nonclinic children on three of four Behavior Problem Checklist factor scales: Conduct Disorder, Personality Disorder, and Inadequacy-Immaturity. An unexpected but consistent finding across age and sex groups was that parents rated nonclinic children as more deviant than siblings of child patients. Analysis of high point scale frequencies indicated that parents of nonpatient children reported most frequent greatest concern on the Socialized Delinquency Scale, while this was the least frequent dimension of greatest concern among parents of child patients. Interscale correlations by sex and patient-nonpatient status suggest considerable practical scale independence and also suggest that interscale correlations are greater among the ratings of nonpatients than among parental ratings of patients (Speer, 1971, p. 221).

With regard to the interrater correlations, which are highly variable, and the fairly extensive literature which implies that parental recall is rather unreliable, Speer makes a rather pragmatic observation, which justifies a wide variability in data for a screening collection system and indicates a circumstantial analysis of any series of data gathered in this fashion. It would, indeed, complicate the process of selecting children at risk, since the degree of their risk estimate would be a function of idiosyncratic perceptions on the part of those reporting about them.

The most surprising finding was the consistency with which parents of nonclinic children reported greater concerns about, and more 'symptoms' among, their children than did clinic parents about siblings. The data do not offer a ready interpretation. Among the possibilities are (a) a biased sample of nonclinic families such that there were unrepresentative degrees of parental concern or family difficulty or (b) a compensatory process among clinic families possibly related to intrafamily 'scapegoating,' whereby problematic concern about one child may lead parents to an overly optimistic report of other children in the family.

Returning to the highly variable and often low order interrater correlations referred to earlier, we are still left with the paradoxical conclusion that although different adults appear to use highly similar semantic dimensions (factor scales) in describing their perceptions of children's symptom behavior, they also have considerable difficulty consistently agreeing on the symptom patterns of specific children. One way out of this conceptual and psychometric dilemma is to assume a phenomenistic view of adults' reactions to children's behavior. That is, we can begin by frankly acknowledging (a) the role of situational variables (including adult behavior) in precipitating children's 'symptomatic' behavior; (b) the marked individual differences in adults' tolerances for, and sensitivities and reactions to, various kinds of child behavior; and (c) the marked individual differences in adults' interpretations, evaluations, and labeling of children's behaviors. Thus, if, for example, a parent rates a child as a severe conduct problem and the child's classroom teacher rates his behavior within the normal expectable range, or vice versa, we would not have to assume that either of the adults' ratings are

necessarily invalid or biased. We could tenably assume that in the context of that given situation and that adult's (or group of adults') behavioral-affective-cognitive system, that child's behavior constituted a 'problem.' The point is that it is probably theoretically and pragmatically unrealistic to demand high interrater agreement (interjudge reliability) on subjective instruments such as checklists, rating scales, and Q sorts, particularly when the child is being seen in markedly different situations and social system contexts. If this position is accepted, we can then get on to the business of collecting baseline and normative data for adults in different relationships to children and for adults who are involved with the children in different social contexts (home, school, hospitals, etc.). The evaluative research implication of this point of view, if we are forced to use subjective instruments, is that the perceptions and reactions of several adults in different relationships to, and situations with, the child must be assessed in order to achieve a comprehensive view of his social and personal adjustment (1971, pp. 227-228).

This approach might prove enlightening to such findings as those reported by Albert and Davis (1971):

The Rimland Diagnostic Check List (Form E-1) was administered to 31 parental couples of normal children, ages 3-5 years. Each parent answered the Check List independently. Interparental agreement for autism scores and for schizophrenia scores correlated .72 and .69, respectively. Also noted was a parents' A/S ratio of 3 to 2. The major question that the results raise is the clinical meaning of the obtained A/S ratio in the discrimination of autistic, normal, and schizophrenic children (p. 501).

It may be that the discrepant results on such checklists are to be expected and dealt with in a constructive fashion as representing differences in general perceptions of a child, not only by parents of both sexes, but by any other care-taking adults who have primary relations with the child in varying circumstances. They assume that it is more reasonable to ascribe behavioral discrepancies to the reality of qualitative and quantitative differences in interaction patterns due to the phenomenological reporting and perceiving adult than it is to misperceptions on the part of that adult, since it is readily acknowledged that individuals perform differently in different situations with different people (Gergen, 1972), including children.

Social Adaptation Ratings

A somewhat more complex checklist for assessing the social abilities of 1- to 6-year-old children has been developed and is in the process of being refined by Ogilvie and Shapiro (1969). The intent of the checklist is quite appropriate for a screening system.

It is important to note that no attempt has been made to score all social actions and interactions of children. As described elsewhere, great care has been taken to select variables that have been known to differentiate well-developed children from poorly-developed children. Hence, the observer should not expect to score all social

behaviors. Some actions cannot be categorized and should not be 'forced' into the checklist.

An attempt has been made to describe each category with sufficient clarity to avoid both mis-scoring and multiple scoring. In a number of sections of the manual, categories likely to cause confusion are contrasted with related categories in an attempt to delineate category boundaries as carefully as possible (pp. 2 & 3).

It probably would be very difficult to train paraprofessionals to use this checklist reliably and validly in its current form. An overall correlation coefficient of .87 was computed on paired one-half hour observations of 20 children, age 3-6, in seven preschools. This approach is desirable in the sense that it samples current behavior and does not rely upon recall by parents or other caretaking individuals. However, it does require a structured setting and well-trained observers in order to get valid and reliable data.

Another somewhat sophisticated approach toward analyzing behavior of 1- to 6-year-old children is that contained in a Manual for Quantitative Analysis of Tasks of One- to Six-Year-Old Children by White and Kaban (1971).

The task is simply whatever a child seems to be trying to do. Taking his cues from the child's behavior and from any environmental stimuli to which the child attends, the observer describes the apparent purpose behind the child's efforts. For example, a child who is ostensibly washing his hands may or may not be trying to clean himself. He may be occupied with making the soap bar slide back and forth through his hands, or with feeling the water. The observer attempts to identify the exact focus of the child's attention at the moment, and then codes the child's action as a type of task. A child in a classroom may or may not have the task the teacher has in mind. The teacher very often wants the child's task to be to gain information. If she is successful, the child may indeed be primarily concerned with gaining information. In many instances, however, a child may prefer to orient his efforts elsewhere. If disinterested in the "lesson," a child's task may be to pass time. Another common alternative is social activity, yet another is attention-seeking behavior. The clue to the use of the system is to adopt the child's orientation (p. 1).

The manual goes on to delineate scoring criteria and cites several examples of various kinds of social tasks such as to please, to cooperate, to gain approval, to procure service, to achieve social contact, to gain attention, to maintain social contact, to avoid unpleasant circumstances, to reject overtures, pure contact, to avoid attention, to annoy, to dominate, to direct or lead, to compete, to gain status, resist domination and assert self, to enjoy pets, to provide information, to converse, and production of verbalizations. As an example of the specificity of coding, the following is cited:

...Mother and young S (1-1/2 years) are home from the grocery store. They have to walk up three flights of stairs to get to their apartment. M says "here we go" and takes S's hand at the bottom of the first flight of stairs. S soon drops his mother's hand and struggles upstairs by himself. He huffs and puffs. The sequence is coded

gross motor activity with the notations added "mother initiated and encouraged," if it lasts more than 15 seconds; to cooperate, if it lasts less than 15 seconds.

To Cooperate vs. To Gain Information

If a peer begins to talk to S, and S listens for less than 15 seconds the listening is coded to cooperate. If S listens for 15 seconds or longer, it is coded to gain information.

To Cooperate vs. To Maintain Social Contact

To maintain social contact is proactive; to cooperate is reactive. Look at the source of direction for sustaining the cooperation. If someone else tries to maintain social contact, e.g., if someone else directs S, S's compliant behavior will be coded to cooperate. If S initiates the behavior in question, without being told to do so, his behavior will be coded to maintain social contact (White & Kaban, 1971, p. 12).

Some other measures of adaptive behavior have been organized and annotated by Mercer (1971). Three of these seem to offer promise in use at the primary or secondary levels of screening. The first was developed by Terdal, et al., and is entitled Behavior Management Observation Schedules.

Prepared in the form of a manual, this paper provides a format for evaluating parent-child and family-child interactions looking toward forming a basis for developing rehabilitation plans for families with a retarded child. Specifically, it relates to behavior management and describes standard observational techniques to be applied in evaluating mother-child interactions that may form a basis for teaching 'alternative repertoires' for handling retarded children. Laboratory observations are suggested in addition to interview-based information. Two types of coding sheets are presented which take the form of a matrix coding system. Each employ a time-sampling technique, and tap the child's behavior as well as the parent's response to the child (p. 1).

Social Maturity and Achievement

Two other instruments, which are complementary and obviously extend into several of the preceding categories, are the Vineland Social Maturity Scales (Doll, 1965) and the Preschool Attainment Record (Doll, 1966).

The Vineland Scales, to quote its author, 'provide a definite outline of detailed performances in respect to which children show a progressive capacity for looking after themselves and for participating in those activities which lead toward ultimate independence as adults.' The items are arranged in order of increasing average difficulty, age-graded 0-25 years. Their content is arranged into areas of self-help, self-direction, locomotion, occupation, communication, and social relations. The items are presented in a combined item and scoring form. Assessment is carried out by interview (of a parent) and observation (if the person is present or available).

PAR was designed to supplement the Vineland Social Maturity Scale with a 'more intensive and extensive inventory of specific attainments.' The PAR comes in a combined item and scoring form. Assessment is carried out by interview (of a parent) and observation (if the child is

present or available). The PAR combines an assessment of the physical, social, and intellectual aspects of a child's usual behavior. Eight categories of age-graded items 0-7 years are presented: Ambulation, Manipulation, Rapport, Communication, Responsibility, Information, Ideation and Creativity (Mercer, 1971, p. 3).

The flexibility of being able to rely both upon informant and the subject is helpful but would have to be controlled in any standard screening and assessment situation where comparable data are being collected. Many of the items would be quite appropriate for inclusion in any primary screening questionnaire.

Emmerick's (1969) Parent Role Questionnaire also has the potential of being useful in this regard. However, the instrument has not yet been used, let alone validated, with parents other than those of the middle class.

Prediction of Childhood Psychosis

It seems ironical that a conference concerned with high-risk factors predictive of childhood schizophrenia was being held at almost the same time as the Boston Early Screening and Assessment Conference for which an earlier, less elaborate version of this monograph was written. The irony lies in the fact that the schedulers for both conferences attempted to avoid as many potential conflicts for likely participants as possible and yet these two certainly competed for some of the behaviorally-oriented members of the community of scholars. It is of no great consolation to learn from several who attended the conference on schizophrenia that the collective conclusion from their considerations of the more recent studies and from their deliberations about the implications was that there really are no valid and reliable predictors of schizophrenia for very young children. Regardless of the rather seductive overly-simplistic theories, ranging from sheer organic etiopathogenesis (see section in Chapter III regarding the quest for a schizococcus) to purely environmental causes (such as the schizophrenogenic mothering syndrome), childhood schizophrenia is evidently not yet satisfactorily predictable from early infancy.

Nevertheless, progress is being made at separating young children into at least the more gross categories of psychotic vs. non-psychotic, which is a major task of a screening system. The differential diagnosis of psychotic conditions seems to hinge upon definitions, which in turn influence diagnostic systems (see Table 10/3) and scales as reported by DeMyer, et al.

Five diagnostic systems designed to differentiate infantile autism and early childhood schizophrenia were compared by deriving scores on 44 children referred consecutively to the same clinical center. While the autistic scales devised by Rimland, Polan and Spencer, Lotter, and the British Working Party correlated significantly, the degree of correspondence (35%) indicated that several children obtained high autistic scores in one system but low scores in another. The BWP's term 'schizophrenia' has more correspondence with the term 'autism' used by others than with Rimland's 'schizophrenia.' In the DeMyer-Churchill categorical system (early schizophrenia, primary autism, secondary autism, and nonpsychotic subnormal), 'primary autism' most resembles Rimland's concept of infantile autism as measured by his E-1 version. All other systems differentiate

RIM-Autism	POS	LOT	BWP-Schizophrenia	RIM-Schizophrenia
SOCIAL INTERACTION AND AFFECT				
<ul style="list-style-type: none"> •Stiff, hard to hold first 2 yrs. 2-6 yrs •Banged head •Didn't reach out; fearful, disinterested in strangers •Treats people impersonally •Afraid to get child's attention •Aloof, disinterested, self-sufficient •Disturbed by changes •"Looks or walks through" people •Not concerned with criticism •No hallucinations or delusions •Not self-concerned •Indifferent, happy when left alone •Unpliable when held 	<ul style="list-style-type: none"> •Detached, preoccupied, disinterested •Unresponsive to affection •More interested in objects than people •Contact with others painful •Conformity an effort, tactless, inappropriate •No anticipatory posture •Angered by interference •React to pin rather than to person pricking him 	<ul style="list-style-type: none"> •Visual avoidance •Solitary •Ignores children •Aloof and disinterested •Walks through people 	<ul style="list-style-type: none"> •Failure to form normal relationships with people, withdrawal from reality •Anget, terror, excitement or withdrawn with environmental change •Ritualistic 	<ul style="list-style-type: none"> •Clinging first 2 yrs; 2-6 yrs •Didn't bang head against person •Reached out to be held 4-5 mos •Confused, frightened, perplexed, dependent •Sensitive to criticism •Hears or sees things not there •Concerned about himself •Wants to be liked •"Melts into arms" of person
SPEECH				
<ul style="list-style-type: none"> •Words used 8-15 mos •Sudden switch to sentences before 24 mos •Seldom used yes before 6 yrs •Never used "I" •Affirms by repeating question •Used question or phrase for no •Subs a word for another •Echolalia, hollow tone often •Pronouns reversed •Whispers instead of talks •Became silent after talking •Doesn't understand speech 	<ul style="list-style-type: none"> •Mute past age of usual speech development; considered deaf •Slow to use pronouns; pronoun reversal, uses preps and pronouns as nouns •Echolalia •Speech not communicative •Speech unrelated to actions •Unresponsive to speech; uncomprehensive •Affirms by repeating quest •Does not answer quest 	<ul style="list-style-type: none"> •Speech not used for communication •Pronoun reversal •Echolalia •Repetition of phrases 	<ul style="list-style-type: none"> •Failure to acquire speech or to maintain speech acquired or to use speech for communication 	<ul style="list-style-type: none"> •First words used 2-4 yrs •Gradual change to sentences •Used word yes fairly well before 6 yrs •Uses "I" fairly regularly •"Possibly" uses echolalia in hollow tone •Understands speech
USE OF BODY AND OBJECTS				
<ul style="list-style-type: none"> •Stares into space for long periods •No use of hands for extended periods •Physically well coordinated •Skillful in doing fine motor tasks •Typically uses objects repetitively •Not destructive of objects •Rocked in crib much as baby •Fascinated by certain mechanical things •Will not readily accept new clothing 	<ul style="list-style-type: none"> •Rhythmical movements of body •Repeats play patterns mechanically •Rituals •Facial grimaces and twisting •Activities lack purpose, behavior not integrated •Disturbed by slight environmental changes 	<ul style="list-style-type: none"> •Self spinning •Jumping •Flapping •Toe walking •Other mannerisms •Lines and patterns objects •Spins objects •Ritual play •Carries, bangs, twirls objects •Insists on sameness of objects •Insists on sameness of events 	<ul style="list-style-type: none"> •Gross and sustained mannerisms, immobility or hyperkinesia (not ties) •Excessive preoccupation with particular objects without regard to accepted function •Pathological attachment to "same surroundings" 	<ul style="list-style-type: none"> •Toe walks •Spins or whirls •Not well coordinated physically •A little awkward, doing fine work •Occasionally uses objects repetitively •Destructive of objects
INTELLIGENCE AND REACTION TO SENSORY STIMULI				
<ul style="list-style-type: none"> •Unusually alert to sound and color 3-4 mos, or •Very disinterested in sounds and colors first 3-4 mos •Parents suspect at least above average intelligence first yr •Unusually strong interest in music •Parents have suspected child nearly deaf •IQ less than 70, 4-7 yrs •Extremely good verbal memory for words repeated often 	<ul style="list-style-type: none"> •Preoccupied with isolated sensory impression. Cannot ignore extraneous stimuli •May solve difficult abstract problems; cannot grasp use of objects •Can classify objects 	<ul style="list-style-type: none"> •Serious intelligence retardation with slits of normal or near normal intelligence function of skills •Abnormal response to one or more type of sensation 	<ul style="list-style-type: none"> •Behaves as if deaf •Covers ears •Distress at noise 	<ul style="list-style-type: none"> •IQ between 70 and 100, 4-7 yrs

Table 10/3: Comparison of Diagnostic Systems (DeMyer, et al., 1971).

psychotic from non-psychotic children but do not distinguish any of the psychotic subgroups.

Good agreement on diagnosis, even concerning subcategories of psychotic conditions in children, is common among people working in close collaboration, as in the case of DeMyer and Churchill. However, this agreement lessens considerably when diagnosticians without constant feedback compare diagnoses, even when relatively structured and standardized diagnostic systems are in use. Nevertheless, this study enables us to infer that any one of the several diagnostic instruments can at least achieve reasonably good agreement in differentiating early schizophrenic and autistic children as a group from non-psychotic children. While more refined definitions of categories are most desirable, it appears that such an achievement may not be possible at present without a significant loss in reliability. Perhaps the course selected by the British Working Party, which simply tried to distinguish schizophrenic and autistic children from other diagnostic groups, is the most prudent one. Finer distinctions may lead to as much confusion as agreement. Nevertheless, the authors believe that the goal of achieving reliable subgroups is of great importance and that efforts in this direction should continue. DeMyer and Churchill's diagnostic subcategories of child psychosis (early childhood schizophrenia, primary autism, and secondary autism) appear similar to other diagnosticians' ideas of 'infantile autism.' Rimland, who would only accept 'primary autism,' is the exception. In the absence of a well-proven biological indicator of the kind which identifies Down's syndrome or phenylpyruvic ketonuria, all authors must include careful descriptions of subjects in clinical reports and research (1971, pp. 175 & 188).

The pendulum does seem to be swinging back in the direction of bio-physiological substrates for many psychotic conditions in early childhood. Early screening systems will have to make provision for testing and monitoring the infant/child's reactions to challenge in both behavioral and physiological parameters, as attested by the several commentaries which follow.

It was hypothesized that reliable and valid psychometric evaluations of young autistic children are possible with measurements at appropriately low developmental levels. A modified 20-min. infant test was administered and readministered to 14 5-yr.-old autistic children. Infant-test scores were correlated with independent clinical judgments and social ages as determined by the Vineland Social Maturity Scale. A test-retest r of .93 and item analyses demonstrated high reliability. 4 of 5 correlations with validating criteria were highly significant. The conclusions are that autistic children (a) are not psychometrically untestable, and (b) may differ from other severely cognitively handicapped children primarily by virtue of having fewer motor disabilities.

...It is felt that the findings of the present study strongly support the contention that so-called autistic children are simply severely cognitively handicapped children whose primary difference from other severely defective children is their relative freedom from motor disabilities.

The overwhelming majority of profoundly intellectually retarded children suffer from what used to be called 'the stigmata of degeneracy,'

that is, physical anomalies. The position taken here is that those rare cases where blatant motor involvement is not associated with cognitive disabilities have been swept into a nosological grouping labeled 'autistic.' The plethora of psychogenic theories that evolved to explain this rare occurrence is understood as a hallmark of the time when dynamic psychiatric formulations flourish wherever definitive physical findings are absent.

The majority of investigations have not demonstrated 'psycho-dynamic' differences between autistic and brain-injured or mentally retarded groups. The major criticism which can be leveled at most of the studies which have found differences is that they did not employ control groups with measured IQs as low as the autistic group's. The argument that the intellectual abilities of autistic children cannot be measured is challenged by the present study. The argument that it is not possible to find populations functioning as low on a cognitive basis as autistics without their having gross physical limitations is exactly the core of the point of view being presented. Those studies which have demonstrated changes in autistic children with operant conditioning techniques are considered as demonstrating that supereffective teaching methods must be used to teach grossly intellectually limited children--and that is what autistic children primarily are (Alpern, 1967, pp. 478 & 485).

An experiment was described in which slow potential responses of five autistic children and five age-matched normal controls were elicited. DC recording of scalp activity was accomplished during presentation of flash and click stimuli followed by photos of the subjects, their mothers, and adult and child strangers. Negative amplitude shifts with stimulation occurred in both groups of children, more when the pictures invariably followed the sensory stimuli than when presented intermittently. The DC responses of autistic subjects did not vary with the content of the pictures. The normal children showed significant differences in negative potential activity related to whether the pictures were familiar to them or not with most negative responses associated with pictures of adult female strangers... (Small, et al., 1971, p. 215).

There is very little if any behavior emitted by a psychotic child which cannot be observed at one time or another in normal children. Strange use of objects, meaningless word play, and spinning and twirling are seen in exploratory play, as forms of amusement when bored, as means of getting attention, etc. When frightened or frustrated normal children also exhibit gaze aversion, avoidance, and crying or tantrum responses, which may include forms of self-abuse. The difference is not that one kind of behavior appears only in psychotic children and another occurs in normal children. It is rather that behaviors which may occupy normal children infrequently and briefly are engaged in more frequently and for longer periods by psychotic children. Although any behavior may be multiply determined it is suggested that one factor which significantly influences the emergence and continuation of 'pathological' behaviors is the success:failure ratio or the degree of mastery of the task at hand. 'Nothing succeeds like success' is probably as true for a psychotic child as for a normal one. Thus, a child is not likely to work at tying his shoe or weaving a potholder if visual-motor impairment precludes success; he

may rather just flip and twirl string. And the child with visual-motor acuity in the presence of a central language disorder might print many words from sight but never write an intelligible sentence. The child does what he can do, and no more.

Yet if brain dysfunction imposes so low a ceiling on a child's adaptive ability that he cannot master the moment-by-moment demands of everyday life, he may be thought of as living in a perpetual 'failure condition.' It is worse yet if caring adults, not appreciating the nature of the child's limitations and perhaps believing them simply due to stubbornness, bear down ever harder with demands for successful performance on tasks which remain quite beyond the child. A significant portion of the readiness of frustration responses and the ubiquity of avoidance and self-stimulatory behavior in psychotic children might thereby be explained.

...Autistic and schizophrenic children then might be characterized not so much by the fact that certain patterns of 'pathological' behavior are seen in them, since these appear in much the same fashion in normal children, but rather by the fact that these patterns emerge at unexpectedly low levels of task complexity, and perhaps immediately after the onset of a 'failure condition'....

...If the 'pathological' behaviors of the failing psychotic child are viewed as signs of emotional upset it may be that the one way in which psychotic children are most nearly 'normal' is in their emotionality! And the demands of a world--either inanimate or, especially, personal--which does not appreciate the severity of their brain-imposed limitations may literally help to drive them crazy with unrelieved frustration and failure--as they might any child (pp. 212-213, & 214).
(Figure 24/4)

Even the schizophrenogenic mother myth may be partially exploded on the basis of the maternal age factors, which appears to be the most salient finding in a study of parents of psychotic, subnormal and normal children.

Due to etiological implications, parental intellectuality defined by 29 descriptive rating scales was compared in 96 families. Parents represented 33 autistic and schizophrenic children, 33 matched normals, and 30 subnormals. Data was obtained from objectively rated interviews, WAIS and other scales. All groups were alike in characteristics they sought in spouses and children, premarital interests, reading preferences, and life style. With the child's age, sex, ordinal position, race, religion and SES held constant, only one significant difference was found between parents of normal and autistic children. The latter emphasized academic success less in autistic than matched normals in their children. All parents of deviant children desired improvement in speech and relatedness, realistically deemphasizing intellectual achievement. Fathers' verbal IQs were significantly higher for autistic than subnormal groups. Parents of normals were significantly younger at child's birth, an unexpected finding implying a neurological link between autism and subnormality (Allen, *et al.*, 1971, p. 311).

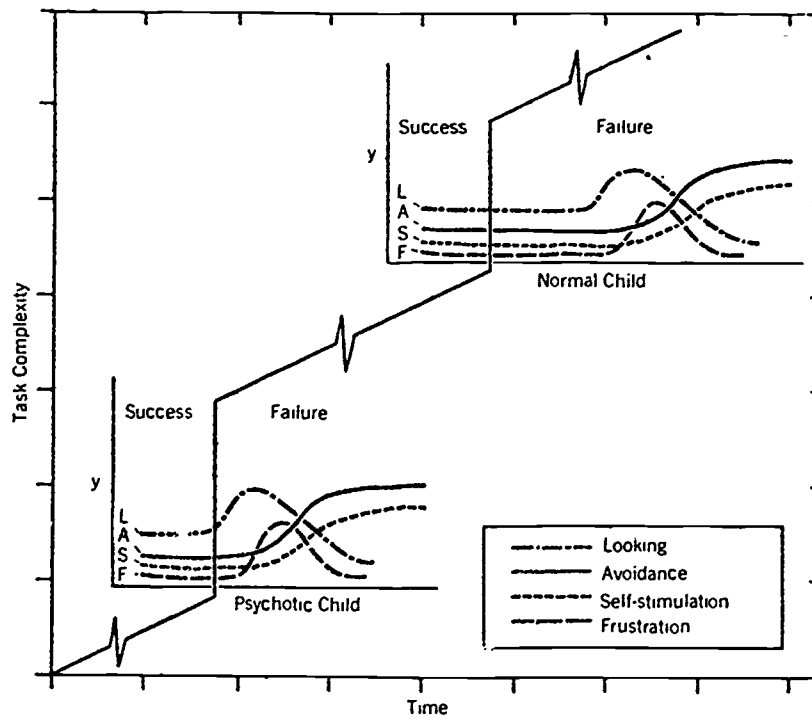


Figure 24/4: For any given adaptive age a level of task complexity will be reached where successful performance turns to failure. Behavior plotted around this transition point produces similar curves in all groups of children

Functional Analysis for Intervention

In a summary at the end of a paper entitled The Psychological Assessment of Children: A Functional Analysis, Bijou and Peterson (1970) weave together a number of the loose ends left dangling and unraveled from the preceding commentaries on various screening and assessment instruments and procedures. Their remarks are not exclusively related to social/emotional factors. Although their emphasis on follow-up may not be apropos to screening per se, it is extremely important in the evaluation of whether or not a screening and assessment procedure is leading to accurate identification of children in such a way that description of their problems is sufficient for instituting remediation and/or prevention. This can only be determined on the basis of the efficacy of the treatment program which is presumably matched to the diagnosis.

This chapter presents a functional analysis of the psychological assessment of children. The task was divided into four parts. The first involves an analysis of the problem that brings the child to the attention of an agency or a professional staff. Behaviors were classified into three categories: behavioral excesses, behavioral deficits, and inappropriate stimulus control. These categories were related in turn to a variety of childhood problems as well as to diagnostic labels.

Since all information about a child and the problem he presents is subject to certain bias or distortion, it was suggested that, whenever possible, direct observation of the child's behavior in the setting where the problem occurs should be used. While the presence of an observer may modify the child's environment to some degree, nevertheless, the information obtained is still considered valuable and has certain advantages over more indirect accounts (interviews and psychological tests) of the behavioral problems.

The second aspect of a functional analysis of assessment concerns an evaluation of those behaviors upon which a treatment program is to be built. Here, one considers which specific problem or problems should be selected for initial treatment, taking into account severity of a particular problem in terms of its debilitating effect upon the child, its aversiveness to the parent, and possible interactions with other behaviors. In addition, one takes into account where the treatment will take place, whether in a specialized treatment situation, such as a clinic, or in a natural setting, such as the home. Consideration must also be given to those conditions which function to maintain the child's behavior in the treatment program. While some surveys and observational data may provide leads to important motivational conditions, a functional screening of potential reinforcers is the best approach for evaluating motivational variables.

In assessing the program to determine the appropriate cognitive abilities and skills, it is essential to evaluate the child's home in terms of its role in stimulating, maintaining, or inhibiting intellectual performances. It is also essential to inventory the child's specific abilities and skills to determine baselines or where in the programs the youngster should begin.

The third aspect of the functional approach to assessment involves evaluation of progress during treatment. While tests and other diagnostic devices are usually administered on a pre- and post-test basis, continuous feedback on the youngster's performance is a basic feature

of a functional approach. The technique for monitoring progress involves: the specification of the situation in which the treatment takes place; the use of a behavior and stimulus code to record the behavior; a recording procedure using a direct frequency count or occurrence in an interval of time, and graphic presentation of the data.

The fourth and final aspect of a functional approach to assessment concerns the evaluation of post-treatment behavior. In contrast to some current approaches, measurement of the efficacy of treatment is best accomplished at the end of treatment. Measures taken during the post-treatment period indicate the operation of environmental conditions that influence the treated behavior.

Nevertheless, follow-up assessments are useful. Among other things, they can provide information on the need for further alterations in the child's environment to recover or to maintain the behavior established in treatment. It was suggested, however, that current techniques such as interviews, personal testimonials, paper-and-pencil tests, self-concept measures, certain rating scales, and personality tests be re-evaluated as measures of the post-treatment status of the individual since they do not yield information on the functional meaning of environmental conditions to the child. While a functional analysis of the child's environment may seem to some to be impractical and costly, there is no other way to obtain adequate and meaningful data on it (pp. 25-27).

CHAPTER VII

COMPREHENSIVE DEVELOPMENTAL SCREENING SYSTEMS

Early Identification and Intervention

This section is primarily concerned with ongoing or proposed endeavors to identify children at developmental risk in a systematic and comprehensive way. The preceding sections have each, for the most part, included only a limited domain of growth and development and generally excluded the others so that no one of them addressed the entire repertoire of vicissitudes experienced by the developing human being. It seems appropriate to begin by quoting some notions advanced by Ingram (1969) in an article he wrote about The New Approach to Early Diagnosis of Handicaps in Childhood.

The ways of recognising congenital handicaps are changing, and the act of diagnosis which depended on the recognition of fully developed clinical syndromes has been increasingly superseded. More and more often handicaps are recognised at routine examinations during infancy or because patients are considered to be 'at risk' of suffering from them, and so are followed up.

The suspicion that a child may be handicapped may increase gradually so that it becomes a certainty as the child grows older, or it may be found to be unwarranted. This changed situation has given rise to new practical problems of clinical management which have not received due attention.

The onus of recognising early that a child is abnormal no longer rests with the parents alone but is shared by family doctors, paediatricians, public health nurses, and others working in the public health services. The suspicion that a child is abnormal can be aroused even before his conception, during the pregnancy, labour and delivery which culminate in his birth, or it may be delayed until abnormalities of behaviour are observed in infancy or in later childhood. Sheridan (1962) quoted experts who suggested that children were 'at risk' of showing physical or mental handicaps if they fell into five main categories:

1. Children with a family history of hereditary disease, such as congenital deafness....
2. Those with a history of abnormalities in prenatal life for example, the effects of maternal rubella.
3. Those with abnormalities of the perinatal period for example, abnormal forms of delivery and prematurity.
4. Children with a history of abnormal behaviour in the post-natal period which might be associated with or cause chronic mental or physical handicap.
5. Children whose developmental progress, as recognised by the mother or by routine periodic developmental screening examinations, deviated from the normal pattern.

Though the value of risk registers has been queried, the value of the earlier recognition of handicap in childhood has not. The concept of diagnosis as a result of growing suspicion during the child's early

life increasingly replaces the concept of diagnosis as an act when he is older and the full clinical manifestations of his disease are apparent (pp. 279-280).

A fairly simple beginning approach to what is being said by Ingram is referred to as the First Identification of Neonatal Disabilities (F.I.N.D.) described by Wulkan:

This agency has vowed not to be reactionary but rather to aggressively provide services as early as possible in the child's life. While increasing emphasis is being placed on prenatal, and in some cases preconceptual (genetic counseling) mental retardation problems, there has been a large gap from the date of birth to the third or fourth year of life of a retarded child.

Functionally, F.I.N.D. operates in the following manner: When the physician identifies a child as mentally retarded, particularly at birth such as with Down's Syndrome or one of the other trisomies, he presents to the family the facts of their child and offers them an opportunity to talk to somebody in more depth about what this means to them and the family. With the consent of the mother, a staff member from F.I.N.D. sees the mother immediately and usually before she leaves the hospital. The purposes of the first visit with the mother are threefold: 1) to provide her with support and help her to initially work through her feelings with regard to her new child. 2) to immediately make the mother aware of resources that are available to the family and to the child. 3) to provide the family immediate service on a homebound basis (no date, p. 1).

Screening as a Part of Total Service System

A somewhat more advanced conceptualization of the problems involved in a screening system is offered by Scurletis and Headrick. They summarize their System of Comprehensive Health Care Screening and Service for Children as follows:

One cannot be so naive as to think that the system we have presented today is the final answer to our problems. What we have attempted to do is to present a model for attacking the problem, some preliminary solutions based on available evidence, and the definition of what, we feel, are critical components in a successful system. One cannot place enough emphasis, however, upon the need for a data system to identify potential users of our services, design service delivery in a way they can be used by people, and direct and coordinate patient flow through the system.

It should be apparent that, within this system, screening becomes an intimate part of the process at every point in the system. Screening is crucial in identifying the high risk, inactive patient at the community level. It is also necessary in order to make decisions about alternate paths through existing services, depending upon the need of the family and child. Ultimately, information about the child must return to the community complex in order for the outreach and follow-up programs to be effective. Unless outreach services are directed by an adequate data system, the whole service system will fail, since

centralized health services facilities can only serve those children and families who are present (no date, p. 8).

In insisting that a screening system be an integral part of an entire health delivery system, Scurletis and Headrick make some salient observations and illustrate them with two diagrams (Figures 25/6 and 26/7).

Other data collected in North Carolina on the maternal and family characteristics associated with postneonatal mortality reveal that the mothers and families who have had the unfortunate experience of a postneonatal death are resistant to preventive health services. ...Using a matched pairs technique, it was found that these mothers (a) are less likely to take their child for a health checkup, (b) are less likely to receive a postpartum checkup in spite of the fact that they (c) have the opinion that their own health is poorer than usual; (d) they are also less likely to have ever received oral polio vaccine and (e) are more accident prone; (f) both these mothers and their male heads-of-household have fewer years of education than those who have not experienced post-neonatal mortality. In summary, we find that we can define some of the characteristics of mothers and families who produce high risk children.

Now let us turn briefly to another kind of data, namely that having to do with constraints that operate in determining the capacity of any community program.... Dr. Julius Richmond indicates that, aside from the obvious constraint of availability of money, any health service in any given community is limited by the following three parameters:

1. The quantity of personnel, both professional and nonprofessional, and their distribution; the facilities, both inpatient and ambulatory; and finally, the technical assistance available to that community.
2. The distribution of the population to be served, as well as the population density; the health professionals and their ratio to population.
3. The quality of all of these factors, both human and technological. In realistically examining the quantity and quality of services rendered, any given community must rely on regional support for more specialized services and central support for highly sophisticated services which are necessary to complete the gamut of care in a comprehensive health care system.

Based upon this information concerning some of the dynamics of health services and the dynamics of high risk identification we can proceed to the development of a potential model of the working structure of our screening and health services system. As you may have noticed, I have not confined myself to screening alone. I do not feel that screening, by itself, is the answer to our problems, whether they be health, social, or educational. Screening must be part and parcel of the overall system of services.

The most important aspect of the community complex is the outreach clinic which identifies and introduces into the total system those individuals who are in need of services and are not obtaining them, either through lack of knowledge or lack of motivation (no date, pp. 3-6).

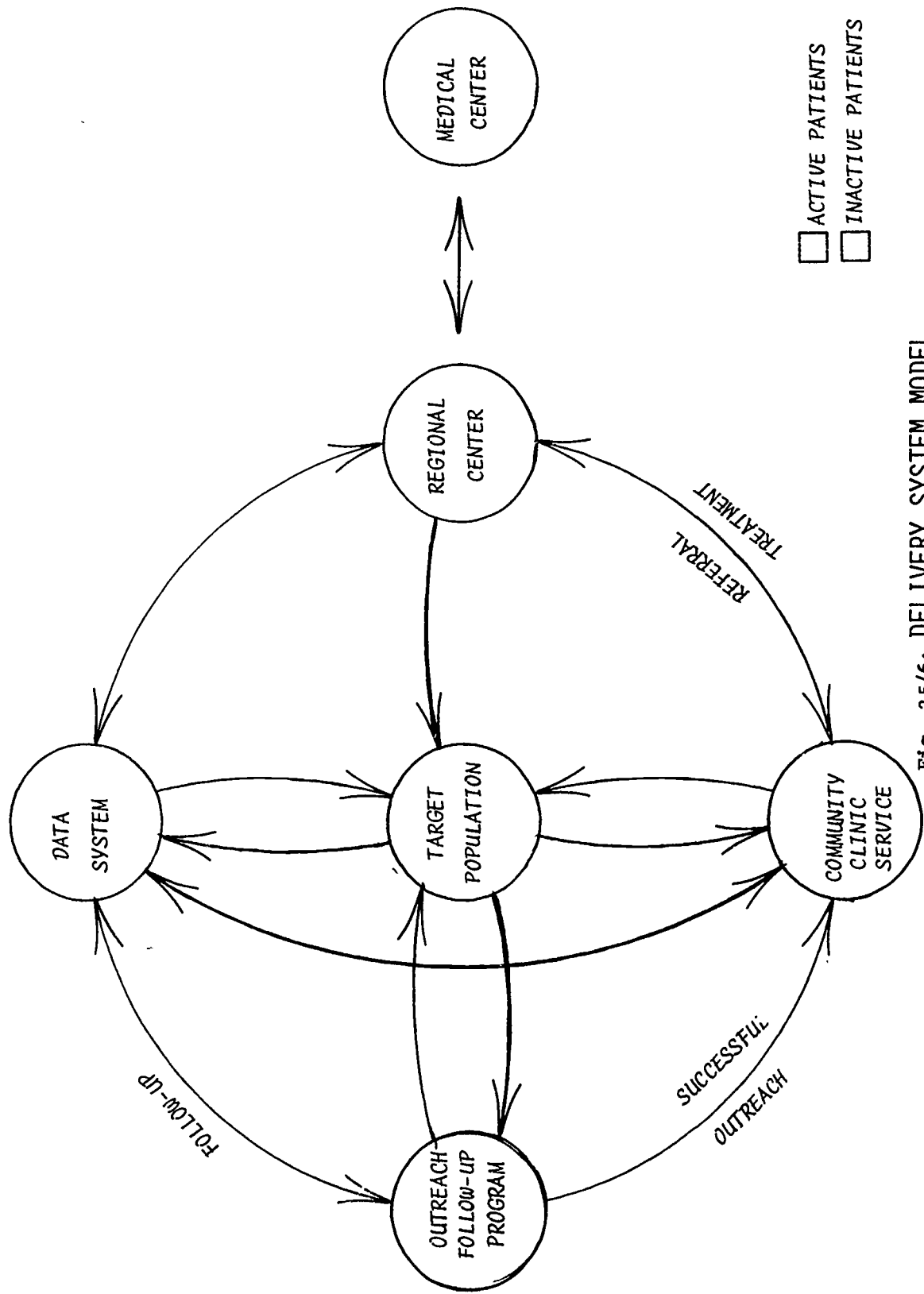
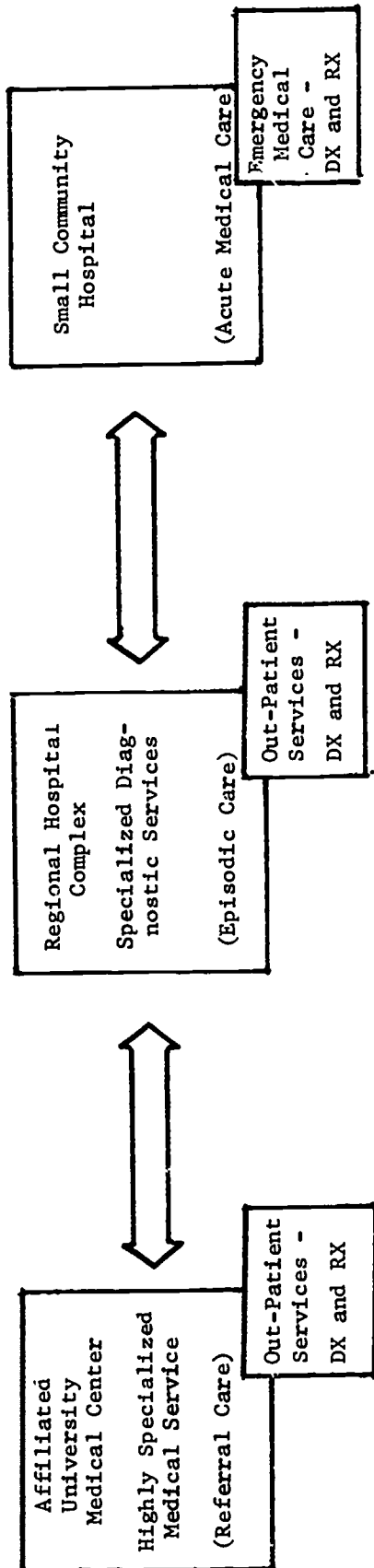


Fig. 25/6: DELIVERY SYSTEM MODEL
(Scurletis & Headrick, 1972)



CENTRAL ROLES

Research - Clinical
 University Graduate Training
 Consultation Outreach to Region

REGIONAL ROLES

Research - Applied
 Laboratory for Community Training Programs
 Local Training Programs
 Continuing Education
 Training of Ancillary Personnel
 Consultation Outreach to Community

COMMUNITY ROLES

Community Education
 Community Service
 Casefinding
 Follow-Up
 Mass Screening
 Continuing Medical Care and Supervision

FIG. 26/7: COMPLEX OF MEDICAL CARE FACILITIES & SERVICES

(Scurletis & Headrick, 1972)

Moving across the nation from North Carolina (above) to Kansas, a preschool multiphasic screening program in rural Kansas is described by Belleville and Green (1971). This system, which is sponsored by the Kansas State Department of Health, was designed to help get planned wellness care to the rural population spread out over the vast area of the state of Kansas. After getting promising results from a preliminary pilot program to identify vision and hearing problems in 3-5½-year-old children and receiving endorsement from the appropriate community agencies, the program has continued to grow.

As the preschool multiphasic programs have expanded, several important realizations have evolved. First, many children enter school with correctable health defects untreated and unfortunately some defects that cannot be corrected, such as amblyopia, for which there is a critical age for detection after which treatment can be of little value--and this period usually occurs before school entry. Second, after the first successful venture, it was apparent that there was a need for a greater variety of screening devices for detecting more of the health needs of children if they were to enter school in a maximum state of receptiveness and growth.

In the three years since the first screening clinic was conducted our goals have broadened, our screening techniques have expanded, and training sessions for local nurses and the volunteers have been initiated. The "goals" now include much more than discovery of obvious physical handicaps. We now are able to detect other deficiencies that Piper (4) in 1968 indicated impeded scholastic performance of children; namely deficiencies of the special senses, mental retardation, emotional and behavioral disorders and physical, social, and cultural deprivation.

The screening techniques now include the Denver Developmental Screening Test, speech and vocabulary screening, hemoglobin and urinalysis screening; and in addition, at most of the clinics immunizations as needed are offered.

...Training sessions are held in every area prior to any clinic. At these sessions not only are the latest techniques of all screening tools taught--but publicity, time, and place for upcoming clinics are planned. In most of the communities, publicity consists of a letter to all known parents of preschoolers, newspaper items, radio and television announcements, and posters for display in local stores, churches, etc. Usually the clinics run from 9:00 to 11:00 A.M. and from 1:00 to 4:00 P.M., and are held in the educational building of a church. (These seem to be the only buildings in rural communities with enough rooms to provide a private place for each screening area. As many as twelve or more rooms have been needed.)

As mentioned above, many volunteers are used. We have been fortunate to secure student nurses from professional and LPN schools, school teachers during summer months, welfare workers, extension and church women, PTA members, and enthusiastic teenagers as volunteers.

Goals of the clinics now include:

1. To secure the identification and correction of all correctable physical defects.
2. To detect, and where possible secure treatment for any developmental lags, emotional or behavioral problems that might interfere with learning. (Parental consent is secured in all cases.)

3. To give teachers and/or school officials sufficient information concerning the findings to enable them to properly place a child in classroom work and activity on school entry.

4. To identify children with defective vision or hearing and refer to the proper medical care with the assurance of follow-up within a reasonable period.

5. To identify children with speech defects that need observation and/or treatment and refer to proper source for such treatment with a similar follow-up.

6. To provide immunization from any preventable communicable disease.

7. To identify children with nutritional needs and make a proper referral or give necessary counselling to parents (Belleville and Green, 1971, pp. 2-5).

Table 11/1 and Figure 27/A list and illustrate the breadth of the screening system and a follow-along card which helps insure continuity of service when indicated.

It is also noteworthy that the Kansas system has been in operation for several years now and, along with many practical suggestions for organizing and implementing the system, it has some instructive data to report.

During the spring of 1971, 818 children were screened in a five-county area with population ranging from 6,000 to 25,000.

In two of the larger counties, a survey was done to determine how many children had had medical supervision since birth. Out of 430 parents questioned, 214 replied that their child had had continuous medical supervision. 216 replied they only went to a physician for emergency care.

Denver Developmental Screening Test--

428 Screened

8 Referrals to physicians

38 Referrals for nursing visits

10% of the children screened needed some type of follow-through
Hearing--

765 Screened

31 Referrals to physicians

7 Retests by nurse or audiometrist

4% of the children screened were referred for further evaluation
and/or treatment

Hemoglobin--

458 Screened

7 Referrals to physicians

44 Referrals for nursing visits for nutrition counseling
and retest

11% of the children screened were referred for medical evaluation
or for nutrition counselling by the public health nurse

Speech--

493 Screened

185 Referrals for retest by speech clinician

37% were referred for further evaluation by speech clinician

<u>Tests</u>	<u>Methods</u>	<u>Follow-through</u>
Vision	<ol style="list-style-type: none"> 1. Hand chart designed for disadvantaged and younger child. 2. Flashcard vision test for children (New York Association for the Blind). 3. Snellen "E" Chart. 4. Titmus Preschool Tester. 	<ol style="list-style-type: none"> 1. Refer to physician. 2. Retest by nurse. 3. It is assumed in all of the follow-through that the local public health nurse will carry the case as long as necessary.
Hearing	Pure Tone Audiometer	<ol style="list-style-type: none"> 1. Refer to physician. 2. Retest by nurse.
TB Skin	Mantoux	All positives are referred to physician.
General Development	Denver Developmental Screening Test	<ol style="list-style-type: none"> 1. Refer to physician. 2. Refer to public health nurse for visits and retests. 3. Refer to school psychologist or counsellor.
Speech	Photo Articulation Test	Refer to speech therapist.
Hemoglobin	Hemoglobin Meter (American Optical Company)	<ol style="list-style-type: none"> 1. 9.5gm. or below-- immediate referral to physician. 2. 10-12gm.--refer to public health nurse and physician notified.
Urinalysis	Labstix	Refer to physician or retest by nurse.
Immunizations	Usual	Booster or start initial series.

Table 11/1: TESTS, METHODOLOGY AND FOLLOW-THROUGH PROCEDURES.
(Belleville & Green, 1971)

PRESCHOOL MULTIPHASIC SCREENING

Copy: School
Card: Parents

Copies: Local Health Department
State Department of Health

Name		Birthdate		
Address		USD No.		
	Test	Retest	Referral	Remarks
Denver Developmental Screening Test				
Hearing				
Hemoglobin				
Immunizations				
Speech				
T B Skin Test				
Urinalysis				
Vision				

KSD H MCH

Kansas State Department of Health .

2-71

Figure 27/A: Follow-Along Card Sample
(Belleville, M. & Green, P.B., 1971)

Tuberculosis Skin Test--

631 Given a Mantoux

No referrals to physicians

Vision--

658 Screened

17 Referrals to physicians

25 Referrals to public health nurse for retests

2½% were referred to physicians for further evaluation and/or treatment

As of August 15, 1971 the follow-through has been completed on 78% of those referred to their physician. We hope that this figure will be raised to 95% by September 30, 1971. For follow-through the children screened are classified into two categories: (1) Immediate referral to physician for further evaluation and/or treatment, or (2) for a retest by public health nurse.

Kansas has a total of 105 counties. In 1969--one clinic was held; 1970--five clinics were held; 1971--fifteen clinics were held (the original five plus ten additional counties); and training for 1972 is now an ongoing process in all areas of Kansas (Belleville and Green, 1971, pp. 6-8).

Screening in a Pluralistic Society

Although intended for purposes other than the design and development of a screening and assessment system and focused on children 5-11 years of age, Mercer (1972) has a number of enlightening findings included in a paper entitled The Origin and Development of the Pluralistic Assessment Project. The study was fundamentally an epidemiological one to determine the prevalence of mental retardation in Riverside, California.

We found that, conceptually, we had to handle each aspect of the study separately. As a result, we evolved two different conceptual frameworks for thinking about mental retardation---the traditional clinical perspective and a social system perspective. The basic assumption of the clinical perspective is that mental retardation is a chronic handicap that exists in the person as an individual characteristic. It assumes that mental retardation has characteristic symptoms which can be diagnosed with the proper diagnostic instruments. From this perspective, the epidemiologist decides whether a person is mentally retarded. If he is clinically retarded, then he is counted as a pathological case in the epidemiology.

There are two models of "normal" which are used simultaneously in the clinical perspective: The pathological and the statistical. The pathological model is based on a disease model which posits that mental retardation is a biological dysfunction typified by particular symptoms. If a person has the symptoms of mental retardation, then he is mentally retarded. The epidemiologist looks for symptoms. There is a strong tendency when using this model to think in biological terms and look for biological signs. The other model for "normal" within the clinical perspective is the statistical model. A person is abnormal if he falls into the tails of the statistical distribution of the population on whatever measure is being used for diagnosis.

.

Two major conclusions from this portion of the study, the clinical epidemiology, are basic to our continuing research. First, we concluded that a one-dimensional diagnosis for retardation in which only an intelligence test score is systematically used as the basis for evaluation is not equitable for persons from non-Anglo backgrounds. There is a real need for a standardized measure of adaptive behavior. Second, we concluded that pluralistic assessment procedures which take the sociocultural characteristics of the individual's background into account when evaluating the meaning of a particular intelligence test score or adaptive behavior score, would produce greater convergence between clinical diagnosis and social system definitions. Such procedures would eliminate the ethnic disproportions which result from present clinical procedures (pp. 2, 7, and 8).

Some of the ethnic implications of screening systems (see also Chapter II) were also pointed out in Mercer's study.

A similar pattern emerged for nominations by ethnic group. Again, the Public Schools, Law Enforcement, and Public Welfare-Vocational Rehabilitation were nominating disproportionately large numbers of Mexican-Americans and Negroes as retardates while the other community organizations were nominating disproportionately more Anglos as labeled retardates (1972, p. 9).

In addition to offering some answers to numerous questions about the interaction of ethnicity, sociocultural and socioeconomic factors, and performance on intelligence tests, this study project is producing several other results relevant to screening and assessment programs in a pluralistic society.

(1) The project will produce an Adaptive Behavior Inventory for Children standardized on representative samples of Anglo, Mexican-American, and Black public school children 5 through 11 years of age which can be used to assess a child's performance in non-academic roles using socioculturally relevant norms.

(2) The project will produce socioculturally relevant norms on the 1973 edition of the WISC for use with Anglo, Mexican-American, and Black children.

(3) The project will produce a Health History and Impairment Inventory standardized on a representative sample of Anglo, Mexican-American, and Black children which can be used to secure a global rating of the Health History and functioning of each child relative to his peers. The rating may be used for preliminary screening to help identify children who may need a medical follow-up.

(4) The project will produce pluralistic assessment procedures based on the above products which will assist in the evaluation of children from non-modal sociocultural settings.

The clinical procedures and normative framework currently used by school psychologists in assessing and placing children in special public school programs has resulted in the placement of many children from sociocultural backgrounds which differ from the Anglo mode for American society into inappropriate educational programs. We anticipate that the pluralistic assessment project will provide one approach to developing a system for taking sociocultural differences into

account in assessing lower status Anglo children, Chicano children, and Black children. Such a pluralistic assessment should result in more appropriate educational placement and programming (pp. 23-24).

As the pluralistic assessment project generates the products and answers the questions it is designed to do, these results will have many applications to earlier screening and assessment efforts as well. The interpretation of all screening data obtained from minority ethnic groups and lower socioeconomic status populations will have to be weighted in accordance with the relative contributions to the variance attributable solely to the environment and which exercise considerable influence on subsequent adaptive behavior. Some of the variables included in fairly interpreting these data are listed in Table 12/3 and illustrated in Figure 28/1 on the following pages. As listed, they would not be appropriate for infants and toddlers and it is submitted that a downward extension of some of these items would not be feasible but they do illustrate some other dimensions which must be taken into consideration.

A Total System for School-Age Children

An exemplary Pediatric Multiphasic Program for children over four years of age is designed to administer a series of screening tests in a single visit and has been conducted by the Permanente Medical Group at the Kaiser Foundation Hospital in San Francisco since 1967. The Pediatric Multiphasic examination requires about an hour and one-half and very systematically obtains data in the following parameters: electrocardiogram; blood pressure and blood pulse; bone age by wrist roentgenograms, anthropometry including various bone diameters, height and weight; visual acuity; respirometry, including spirometry tests for which adaptations for younger children are now being made; audiometry; intelligence tests, including screens for various learning disabilities; drawing tests, including the Draw-a-Person and Bender-Gestalt to look for perceptual-motor and conceptual deficiencies; Tuberculin Tine Test; throat and nose cultures for streptococcus; blood tests using an automated blood analyzer; urine tests allowing some prospective studies; neurological maturity scale; and a behavior inventory, which is responded to by the parent and addresses the areas of sensorimotor development, learning, communication skills, social rapport, interests, creativity, responsibility, and symptomatic behavior. One month after all of the multiphasic testing is completed, the parent returns for interpretation of the results and physical examination by a pediatrician who now has all of the data analyzed by a computer.

An important feature of the pediatric multiphasic program is the number of tests relating to psychological development and behavioral problems. These tests have been specifically developed and arranged and standards established for six-month age intervals. Work is now in progress to permit integration of results of Draw-a-Man, Bender-Gestalt, psychological screening and behavior questionnaire into a single score for presentation to the child's physician.

A pediatric multiphasic program, conducted by San Francisco Kaiser-Permanente Medical Group, combined into a single health service the following three separate elements: (1) a group of screening tests, or phases, administered by nurses or nurse's aides; (2) computer

<u>I</u>	<u>II</u>	<u>III</u>	<u>IV</u>	<u>V</u>
Family Role Performance: (153)*	Neighborhood Role Performance: (82)	Interpersonal Style: (40)	Student Role Performance: (120)	Community Role Performance: (125)
Care of own and family belongings (31)	Independence in movement about the neighborhood (21)	Affection (8)	Learning and study habits (40)	Consumer-Spender behavior (31)
Responsibility for younger children (24)	Neighborhood play and peer group activities (19)	Cooperation (8)	Responsibilities assigned by teachers (17)	Worker-Earner behavior (23)
Care, dressing and health of own body (35)	Work in neighborhood to earn money (12)	Independence (8)	Responsibilities conferred by peers (14)	Independence in movement about the community (35)
Preparation of food and use of equipment (20)	Neighborhood social affairs and activities (12)	Sociability (8)	Social and athletic activities (15)	Social, political, religious, and recreational activities (21)
Family communication, decision making, and scheduling of own time (43)	Volunteer services to neighbors (18)	Stability (8)	Academically oriented activities (34)	Community service and volunteer activities (15)

*Figures represent total numbers of items in each sphere and in each dimension of each sphere for the Pretest Edition of ABIC. Overall total of items equals 520.

Table 12/3: ADAPTIVE BEHAVIOR INVENTORY FOR CHILDREN (ABIC) (Mercer, 1972).

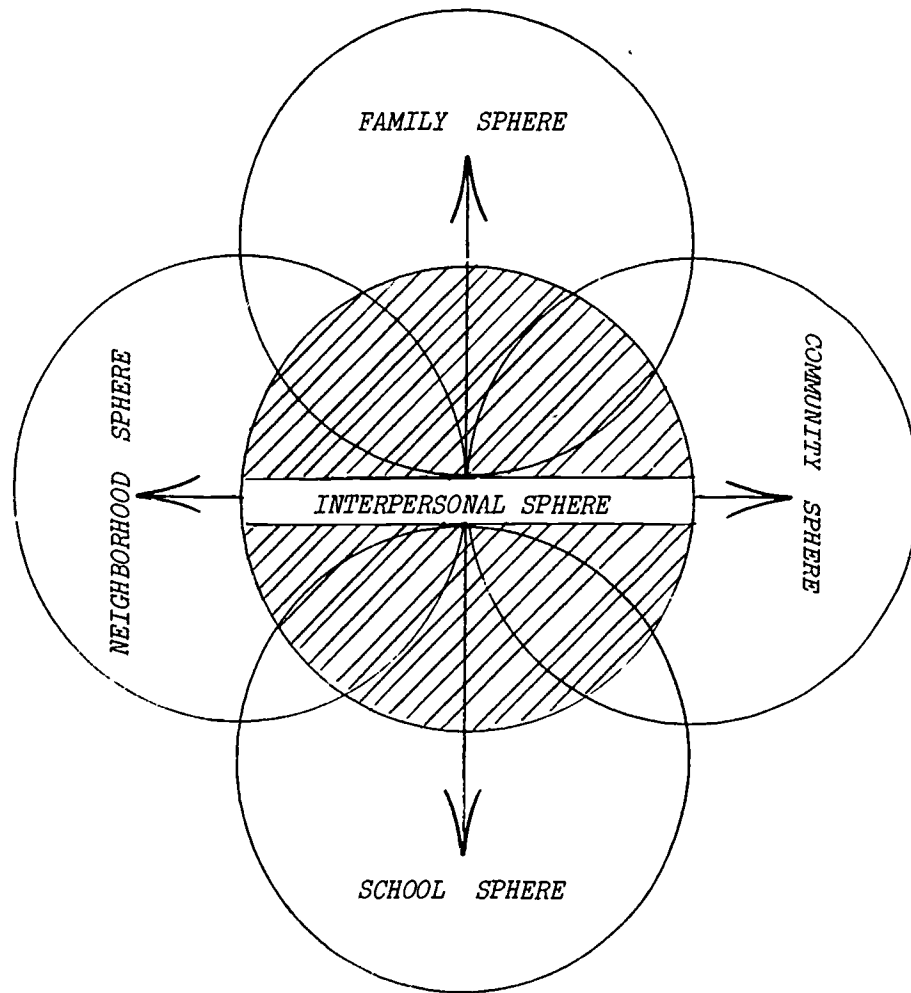


Figure 28/1: Spheres of Social Role Performance (Mercer, 1972).

processing and storage of results of these tests; and (3) a physician's examination approximately one month after the tests are performed. The purpose of the program includes (1) evaluation of this type of examination in the delivery of medical care to children, (2) establishment and verification of new normal values, and (3) an opportunity for developing a variety of longitudinal clinical research studies. Over 5,000 children between 5 and 15 years of age have already been tested; younger children will soon be included in this program (Allen & Shinefield, 1969, pp. 471-472).

When comprehensive screening and assessment systems are planned, there are many helpful considerations contained in the Provisional Guidelines for Automated Multiphasic Health Testing and Services, Vol. 2, Operational Manual, from which several quality control suggestions were cited earlier (Chapter II) of this monograph. For example, the selection of tests for the physical (or other developmental domain) factors must be in keeping with several rather clear-cut criteria.

- (a) Consideration of reproducibility or precision (consistency of repeated measurements); accuracy or validity (true measurement): sensitivity (percent of true positives); and specificity (percent of true negatives).
- (b) Yield rate (of previously unknown, or known but uncontrolled) sufficient to provide an acceptable cost per positive case.
- (c) Minimum physician time for processing.
- (d) Acceptable to the patient (harmless; reasonable time).
- (e) Useful for medical care, or research.
- (f) Completeness (adequately comprehensive to satisfy users' needs; two or three phases, or a clinical chemistry panel of tests alone is not an acceptable AMHTS) (Collen in Collen, et al., 1970, pp. 6-7).

A problem commonly raised in most discussions of massive screening is that a standard method is needed for examinee identification which is unambiguous, immutable, and relatively simple. This becomes particularly critical when automation plays an increasingly larger role in the retrieving and processing of data for a large number of relatively mobile people at random intervals.

There is a definite need to develop a system providing for an identification card which can be used at a computer terminal at registration and also at the other AMHTS stations. Such a system would allow specific test results to be associated with the particular examinee and put right into the computer from each terminal. On-line data processing would thereby be greatly facilitated (Collen in Collen, et al., 1970, p. 35).

Another example of the use of automation and rather sophisticated instrumentation for screening at the secondary or tertiary level and which is applicable to young children is the technique referred to as phonocardiography.

This technique records the precordial heart sounds onto photographic paper or magnetic tape. While it is an important tool in screening large numbers of children, there is less value in screening

adults since the number of murmurs associated with significant remedial lesions in adults is less.

(a) Nonautomated techniques are unstandardized and often difficult to interpret and perform. A health worker other than a physician can be trained to auscultate the precordium for abnormal chest sounds. Considerable time is required for performance of the test.

(b) Automated devices (e.g., "Phonocardioscan") which identify the presence of murmurs are currently acceptable for screening tests of children, but are not sufficiently sensitive to be acceptable for adult AMHTS (Collen in Collen, et al., 1970, pp. 42-43).

The limitations of automated interpretations of electrocardiographs and vectorcardiographs is acknowledged and cited as an area where more adequate computer programs must be developed.

Other comments relevant to massive screening in general which are contained in the manual as specifically related to visual acuity, hearing acuity, and anthropometry are as follows:

Visual Acuity. Distance vision can readily be measured by a trained technician with the Snellen Eye Chart or an equivalent; and also near vision, with the Jaeger method, and color vision with Ishihara plates.

Hearing Acuity

a. Definitions

Tests aimed at evaluating hearing acuity are useful in pre-school and school examinations of children in detecting unrecognized hearing loss.

b. Participant and Procedural Requirements

To be useful, audiometry must be done in "sound-proofed" booths and the procedure must be carefully explained to the participant. Young children and elderly adults are often unable to follow directions carefully, and the results from these tests are often unsatisfactory. Only participants capable of following instructions should be tested.

c. Personnel Requirements

Technicians, if well trained, can satisfactorily administer the test.

Anthropometry

a. Objectives, Definitions, and Uses

Anthropometry serves to quantitate the physical dimensions of the participant as well as confirm developmental age in children. Acceptable measurements include height, weight, the triceps, and subscapular skin folds; and bone age in children as determined by roentgenologic techniques. These measurements are useful in detecting obesity, monitoring disease states, and in the case of children to appraise the status of physical development (Collen in Collen, et al., 1970, pp. 54-56).

Some of the best developed and empirically validated patient data coding and retrieval forms have also been composed for the Permanente Medical Group's Pediatric Multiphasic Testing Program. These forms are workable data-gathering instruments and enable computer print-outs from the correlated storage and retrieval systems to be used and interpreted by a wide

variety of appropriate professionals and paraprofessionals. The standardization of data recording across multiple parameters, some of which are digital and others of which are nondigital, is a slow process. Once meaningful and helpful data are at the fingertips of those desiring it, their subsequent cooperation in collecting data in a standard form is markedly improved.

Multifactorial Developmental Screening Techniques

Since nearly all comprehensive and massive screening programs contain provisions for assessing the developmental progress of children, it is important that some consideration be given to the current status of the multifactorial measuring instruments, methods, and materials now available for doing this. Furthermore, a broad definition of development entails all of the factors previously presented in this monograph. This is especially true with young infants and children who are simultaneously developing very rapidly along several different dimensions, in all of the developmental domains addressed in Chapters III, IV, V, and VI.

The more familiar tests and scales devised by Bayley, Binet, Cattell, Doll, Gesell, Griffiths, Wechsler, and others, are briefly described and discussed in previous chapters of this monograph, since each tends to concentrate its in-depth assessment on only one or two factors of the developmental domain and requires considerable time and training to properly administer, thereby disqualifying each as a primary screen. At least six new instruments warrant exposition and consideration as primary or secondary level screening instruments. These include The Rapid Developmental Screening Checklist, Guide to Normal Milestones of Development, The Developmental Screening Inventory, the CCD Developmental Progress Scale, the Denver Developmental Screening Test, and the Progress Assessment Chart.

A very simple and straightforward checklist consisting of 40 items covering the age range from one month to five years of age was developed by the Committee on Children with Handicaps of the New York Chapter of the American Academy of Pediatrics (Giannini, *et al.*, 1972). Called The Rapid Developmental Screening Checklist, this one-page instrument (see Figure 29), has some brief instructions at the top and is designed to be used by a physician or aide. Once the norms are better established and appropriately adjusted, it might serve as a primary stage screening instrument for a widespread canvassing of a large population in a massive screening and assessment program.

An ingenious device, originally designed by Haynes (1967) for use by nurses dealing with infants and newborn children, serves as a handy reference and perhaps the basis of a primary screening system. Figure 30 shows a representation of the wheel set at twelve months. Tables 13 and 14 reveal the other contents of the front part of the wheel and the following comments further elaborate upon it.

Early discharge of infants from the hospital following delivery has increased the responsibility of the nurse in assisting with earlier recognition of dysfunction and anomalies both before and after hospital discharge. Other factors in increasing this responsibility include the new knowledge about such abnormalities and how

Developed by the Committee
on Children with Handicaps
American Academy
of Pediatrics,
New York Chapter 3
District II

Fig. 29: RAPID DEVELOPMENTAL SCREENING
CHECK LIST

This check list is a compilation of developmental landmarks matched against the age of the child. These are in easily-scored question form and may be checked YES or NO by a physician or his aide, by direct observation.

"NO" responses at the appropriate age may constitute a signal indicating a possible developmental lag. If there is a substantial deviation from these values then the child should be evaluated more carefully, taking into consideration the wide variability of developmental landmarks. (Adjust for prematurity, prior to two years, by subtracting the time of prematurity from the age of the child. E.G., a two-month-old infant, who was one month premature should be evaluated as a month-old-infant).

It is our hope that the early recognition of such lags would lead to early diagnosis and treatment, the results of which can be very helpful to many of these children.

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NAME: _____ D.O.B.: _____ 1st Visit: _____

AGE		YES	NO	DATE
1 month	—Can he raise his head from the surface while in the prone position?	
	Does he regard your face while you are in his direct line of vision?	
2 months	—Does he smile and coo?	
	3 months—Does he follow a moving object?	
4 months	Does he hold his head erect?	
	4 months—Will he hold a rattle?	
5 months	Does he laugh aloud?	
	5 months—Can he reach for and hold objects?	
6 months	—Can he turn over?	
	Does he turn toward sounds?	
7 months	Will he sit with a little support (with one hand)?	
	7 months—Can he transfer an object from one hand to another?	
8 months	Can he sit momentarily without support?	
	8 months—Can he sit steadily for about five minutes?	
9 months	—Can he say "m-ma" or "da-da"?	
	10 months—Can he pull himself up at the side of his crib or playpen?	
11 months	—Can he cruise around his playpen or crib, or walk holding on to furniture?	
	12 months—Can he wave bye-bye?	
15 months	Can he walk with one hand held?	
	Does he have a two-word vocabulary?	
18 months	15 months—Can he walk by himself?	
	Can he indicate his wants by pointing and grunting?	
24 months	18 months—Can he build a tower of 3 blocks?	
	Does he say six words?	
2 1/2 years	24 months—Can he run?	
	Can he walk up and down stairs holding rail?	
3 years	Can he express himself (occasionally) in a two word sentence?	
	2 1/2 years —Can he jump lifting both feet off the ground?	
4 years	Can he build a tower of six blocks?	
	Can he point to parts of his body on command?	
5 years	3 years —Can he follow two commands involving "on", "under", or "behind"?	
	(without gestures)	
4 years	Can he build a tower of nine blocks?	
	Does he know his first name?	
5 years	Can he copy a circle?	
	4 years —Can he stand on one foot?	
5 years	Can he copy a cross?	
	Does he use the past tense, properly?	
5 years	—Can he follow three commands?	
	Can he copy a square?	
	Can he skip?	



to look for them; the better preparation nurses are receiving in growth and development; and the generally expanded role of nurses today. This guide was prepared to help reinforce the basic knowledge and clinical experience nurses should have in order to effectively carry out their broadened function in casefinding. Numerous aspects of appraising the infant or child are reviewed, with special attention to the basic neurological reflex patterns and the maturation of the central nervous system. Criteria for determining whether an index of suspicion actually exists--whether medical assistance should be sought--are indicated for each segment of appraisal.

Protocols for assessing the condition and behavior of the infant or child are offered, including a procedure which can be carried out in the course of bathing the infant. Suggestions are given for discerning the more subtle, as well as the major, deviations from the normal.

While the emphasis here is on the infant and very young child, special suggestions are included to assist school nurses and teachers in the recognition of symptoms which may signal the presence of neurological or other disorders among children of school age.

A new "wheel" device, the Guide to Normal Milestones of Development, is included in this publication to provide a quick recall of the major milestones of development and focus attention upon the factors which may warrant referral to medical attention.

Such a device cannot be expected to do much more than reinforce a sound background in growth and development. Many of the previously cited studies, plus those of Birch, *et al.*, (1962) and Illingworth (1960), emphasize the range of variability which may be found among normal children. Therefore, it is hoped that the facility with which the developmental wheel can be dialed forward and backward, to refer to preceding and following stages, will help the nurse focus upon the overall rate of development rather than the individual stages of any one factor.

The wheel consists of two discs fastened at the center so that they can be rotated one upon the other. A wedge-shaped opening in the top disc permits a view of a section of the bottom disc. On the top disc are listed basic reflex patterns. The bottom disc is divided into 11 wedge sections--one each for the 1st, 2nd, 3rd, 4th, 6th, 9th, 12th, 15th, 18th, 24th, and 36th months of age. As the wheel turns, symbols appear on the bottom disc next to the names of the reflex patterns printed on the top disc; these symbols indicate whether the reflex is present (+), absent (0), evolving or diminishing (±) at that particular stage of development. Table 13 lists the basic reflexes and the symbols for each age.

In addition to the symbols for basic reflexes on each section of the bottom disc is a list of some of the major milestones of development at that age according to the Cattell Infant Intelligence Scale, Griffiths Mental Development Scale and the Composite Developmental Inventory. The last is a set of items designed by Caldwell and Drachman (1964) for appraisal of infants 1 month to 2 years of age, based upon selections from Gesell's Scales. Table 14 lists the developmental milestones found on the wheel under appropriate age headings.

REFLEX	MONTHS										
	1	2	3	4	6	9	12	15	18	24	36
Palmar grasp	+	+	±	±	0*	0	0	0	0	0	0
Asymmetrical tonic neck	+	+	±	±	0	0	0	0	0	0	0
Moro	+	+	±	±	0	0	0	0	0	0	0
Reciprocal kicking	±	+	+	±	±	±	0	0	0	0	0
Rooting and sucking	+	+	+	+	+	±	0**	0	0	0	0
Neck righting (two-step)	0	0	0	±	±	+	+	+	+	+	+
Parachute (protective extension of arms)	0	0	0	0	±	+	+	+	+	+	+
Landau (head up-- back arched a bit in ventral suspension)	0	0	0	0	0	0	+	+	+	±	0

*Reflex grasp may still be present in sleep.

**Rooting and sucking may still be present when hungry or asleep.

Table 13: BASIC REFLEX PATTERNS AND PRESENTING AGES
(Haynes, 1967, p. 53).

ONE MONTH:	Lifts head slightly from prone Head up momentarily when back supported Briefly watches and follows Avoids mildly annoying stimuli (cloth on face) May make some "noise in throat" sounds without definite form
TWO MONTHS:	Head erect, bobbing, when supported in sitting Follows moving person with eyes Imitates or responds to smiling person with occasional smile Vocalizes
THREE MONTHS:	Lifts head and chest when prone Vigorous body movement Better head control Recognizes bottle Coos, chuckles
FOUR MONTHS:	Good head control Rolls side to side Takes object (pencil) held near hand May begin reaching Follows moving object when held in sitting position Laughs aloud Enjoys play
SIX MONTHS:	Sits with minimal support on hard surface Rolls from supine to prone Volitional grasp with whole hand, transfers hand to hand and to mouth (reflex grasp may still be present in sleep) Reaches Babbles in more than two sounds*
NINE MONTHS:	Sits alone, can change position without falling Manipulates two objects simultaneously Says "mama," "baba"--consonant sounds* Unwraps cube
TWELVE MONTHS:	Stands, may step with support Pincer grasp, pellets in and out of cup, retrieves pellet under cup Stacks two blocks Hands toy on request Gives affection May say 2-3 words* Rooting and sucking may still be evident when hungry or asleep

Table 14: DEVELOPMENTAL MILESTONES ON THE "WHEEL"
(Haynes, 1967, pp. 53-55).

Table 14: (cont'd)
Page 2

FIFTEEN MONTHS:	Walks without support Stacks three blocks Jargons--voice up and down--pauses as in conversation* May use 4-5 words* Some self-feeding
EIGHTEEN MONTHS:	Walks, may run a bit, climb up and down a stair Likes pull toys, being read to Makes mark with crayon on paper or table Partially feeds self May be partially toilet-trained--daytime May use 5-10 words*
TWENTY-FOUR MONTHS:	Can throw, kick ball, open door, turn page Engages in parallel play Recognizes familiar picture, knows if it is upside down May use 2-3 word sentences* Improving daytime toilet training
THIRTY-SIX MONTHS:	Alternates feet on stairs Stands momentarily on one foot Rides tricycle Feeds self Puts on shoes Uses simple form board Knows own sex Daytime bowel and bladder control

*Great variability in normal range of language development.

Finally, on the back of the wheel are summarized the conditions or factors which can serve as "indexes of suspicion"--indications that referral to medical attention is warranted:

Overall lag in development of 3 months.

Basic reflex patterns: lack of response; persistence or reappearance of response beyond normal range of variability; or abnormalities in the reflex patterns themselves, as outlined below:

Landau reflex: collapse into inverted U in ventral suspension.

Parachute reflex: asymmetry of response or fisting of either hand.

Neck-righting: immediate and completely obligate trunk and pelvis rotation in response to turn of the head to the right, left, or on both sides.

Rooting and sucking; poor or asymmetric response.

Reciprocal kicking; asymmetric response.

Moro reflex: asymmetric response.

Asymmetrical tonic neck reflex: a completely obligate response to the right, left, or on both sides (i.e., the infant completely unable to "struggle out" of the posture, or a marked and very strong response on one side or the other).

Palmar grasp: asymmetric response.

Other factors: Any major anomaly; three or more minor anomalies; change in vital signs; symptoms of acute illness; bulging or marked depression of fontanels; deviation of head circumference from normal curve; significant deviation in height or weight from normal range of variability for sex; marked extensor tone; opisthotonus; other abnormal posture; constant twitching; convulsion; excessive drowsiness; listlessness; marked hypotonia; high-pitched or very feeble cry; excess grunting; feeding problems; vomiting; persistent colic; hemorrhage, edema, bruises or other signs of trauma; deleterious environmental factors (Haynes, 1967, pp. 61 & 52-56).

A more thoroughgoing version of a developmental screening instrument, spanning 21 weeks to 18 months of age, was created by Knobloch, Pasamanick, and Sherard nearly a decade ago and reported by Haynes (1967). The General Instructions give a good notion of its characteristics and Figure 31 shows its format.

Development proceeds in an orderly predictable manner, with the same variability in behavior for normal infants found in all biologic measurements. By asking some questions of parents, observing the infant's behavior and recording this information systematically, an estimate of the level of function in various areas of behavior can be made which correlates very highly with the maturity age assigned on the basis of a complete Gesell Developmental and Neurologic Examination (Gesell and Amatruda, 1954) from which the items are adapted.

This screening inventory will be of value for serial observations in well-baby supervision as well as for diagnostic problems referred for evaluation. READ THE ENTIRE INVENTORY BEFORE ATTEMPTING TO USE IT.

DO NOT BE ALARMED BY THE LARGE NUMBER OF QUESTIONS. They cover the age range from 1 to 18 months and any one infant can usually be evaluated by 2 or 3 consecutive age levels at most. We have tried

KEY AGES

4 WEEKS
ASYMMETRIC TONIC-NECK-REFLEX

H=History, O=Observation
B=BLOCKS

Patient's Name _____							
Birth Date _____							
Birth Weight _____							
L.D.C. _____	ADAPTIVE						
Age (Weeks) _____							
Student _____							
Date _____	GROSS MOTOR						
Ask Mother after Interview _____	FINE MOTOR						
What age baby do you think your baby is acting like?	LANGUAGE						
	PERSONAL SOCIAL						

12 WEEKS		16 WEEKS—SUPINE		20 WEEKS	
H	O	H	O	H	O
ADAPTIVE					
	Prompt regard of toy dangled in midline at chest level		Wave arms, move body at sight of toy, dangled if on back, or put on table if held in sitting		Bring both hands up towards toy, on back or if supported sitting
	Follow toy, or Ex's hand, in 180° continuous arc, side to side		Regard (look at) toy in hand		Grasp toy only if held near hand (approx one inch away)
	Glauc at toy when put into hand		Take toy to mouth when on back		Look after toy dropped in chest
GROSS MOTOR					
	Head bob forward if held sitting		Head steady, set forward, sitting		Head erect, steady, held sitting
	Symmetric posture head, body seen		Symmetric postures predominate		No head lag when held by hands and pulled to sitting
	Hold head up 45° when in prone (on abdomen) sustainedly		Hold head 90°, look directly ahead in prone (on abdomen)		Push whole chest off bed, prone
FINE MOTOR					
	Hold hands open or close loosely		Scratch finger, clutch at clothes		Scratch on tabletop, or on bed in prone (toy in sight not essential)
	Hold toy put in hand with active grasp		Bring hands together in midline and play with own fingers		
LANGUAGE					
	Coo and chuckle		Laugh out loud		Squeal like a little pig, voice up high
	"Talk" back just if you nod head and talk to him		Breathe heavily, in play		
PERSONAL SOCIAL					
	Look at examiner predominantly		Initiate smile just when people come up and stand beside him		Smile at self if close to mirror
	Hold up, or look at own hand		Recognize bottle just on sight		Put both hands on bottle when feeding
	"Pul" it clothes				

KEY AGES

24 WEEKS 28 WEEKS ONE HAND APPROACH & GRASP 32 WEEKS

H=History, O=Observation

24 WEEKS		28 WEEKS ONE HAND APPROACH & GRASP		32 WEEKS	
H	O	H	O	H	O
ADAPTIVE					
	Reach & pick up or take toy with both hands		Reach & pick up or take toy with one hand only		Pick up one small toy and thrn second one
	Reach for toy dropped within reach		Transfer toy easily, hand to hand		Hold these two prolongedly
	Put toy in mouth when held supported in sitting		Bang toy up and down when sitting supported		Secure toy by string if string contacted by hand
GROSS MOTOR					
	Grasp feet when lying on back (in supine)		Lift head from bed if on back		Sit 1 minute erect unsteady on hard surface
	Roll to abdomen, get both arms out from under chest		Sit if put on hard surface leaning on hands		Stand, hands held shoulder height
			Stand if chest held under arms		Pivot in circle, prone, using arms
FINE MOTOR					
	Pick up small toy and hold in center of palm with all fingers		Pick up small toy, hold to radial side palm with 2nd & 3rd finger		Try to pick up crumb by eaking with thumb, 2nd & 3rd fingers, usually little arm movement
			Put whole hand on crumb, rake it		
LANGUAGE					
	Grunt and growl (deep sounds)		Say "Mum-nim-mum" esp. crying		Make single consonant sounds, "da, ba, ga, ka"
	Initiate "conversation" with toys or people		Make same vowel sound in series, "ah-ah-ah, uh-uh-uh, oh-oh-oh"		
PERSONAL SOCIAL					
	Know strangers from family		Feet to mouth when lying on back		Bite & chew toys, not just lick
	Smile and talk to self if put close to mirror		Reach out & pat self if put close to mirror		Persist in reaching for toys out of reach

36 WEEKS		40 WEEKS PICKS UP CRUMBS & THREADS		44 WEEKS	
H	O	H	O	H	O
ADAPTIVE					
	Drop one of two toys picked up to take third one offered		Play inside cup with toy you put there, touch & manipulate it		Take toy out of box or cup
	Hit toy in hand at toy on table		Hold small toy & try to or pick up crumb at same time		Put small toy inside cup or box if shown, but not let go of it
	Hold toy in one hand & play with attached string with other		Poke with index finger at things		Poke at crumb inside bottle
GROSS MOTOR					
	Sit 10 plus minutes steady on hard surface		Sit erect & steady indefinitely		Stand at furniture without leaning against it, lift one foot up and sit own
	Stand at furniture & not lean against it if put there		Go, not fall, forward to prone		
			Crawl (creep) on hands & knees		
			Pull self to standing		
FINE MOTOR					
	Pick up small toy in ends of fingers		Put small toy down, take hands off		
	Pick up crumb, thumb & index finger		Pluck crumb up promptly, usually with thumb and index finger		
LANGUAGE					
	Say da-da, ba-ba, without miming		Say and mean "na-na" and "da-da"		
	Initiate cough, tongue click, etc.		Have one other "word"		
	Know own name		Play nursery trick just if asked		
PERSONAL SOCIAL					
	Hold own bottle, pick up if dropped and finish it		Play nursery trick only if you do it first, doesn't understand meaning of words (does above)		Hold out toy to you, but not let go of it
	Feed self cracker, do good job				Reach for image of toy in mirror

Figure 31: Developmental Screening Inventory (Knobloch, et al., in Haynes, 1967, pp. 83-85).

Figure 31: (cont'd)
Page 2

		KEY AGES					
		48 WEEKS		52 WEEKS		56 WEEKS	
				TRIES TO PILE OBJECTS			
		H	O	H	O	H	O
		H=History, O=Observation					
ADAPTIVE	Play with one toy after another of a group in same way, in sequence [e.g., drop to floor, move to another spot on table]			Try piling one small toy on 2nd just presses or it falls off			Put toy into cup or box just if you point and ask him to
	Exploit crumbs only, ignore bottle			Put toy in cup or box if you show him first each time			Imitate scribble with crayon after you do it
GROSS MOTOR	Hold furniture & walk around it			Walk with only one hand held			Forget to hold on, stand alone momentarily
	Walk if both hands held at shoulder height for balance						If standing up, take few steps alone, fall headlong
FINE MOTOR	Pluck crumb easily with thumb & index finger, not resting arm or hand on tabletop						Pick up two small toys in one hand at same time, deliberately
LANGUAGE			Say 2 "words" plus ma-ma & da-da			Say 3 or 4 "words"
			Lift up of toy into your hand if you hold hand out for it			When asked to, look at object (ball, shoe, light, T-V set, etc.)
PERSONAL SOCIAL	Take toys off table to another surface [e.g., floor] deliberately in play			Help in dressing—push arm thru sleeve if you get it started			Use slight casting motion and play ball with you, throwing it towards you
				Offer toy to own mirror image			
		15 MONTHS		18 MONTHS			
		H	O	H	O	Record MATURITY LEVEL in weeks or months, and the DIAGNOSTIC CATEGORY. (Can assign intermediate levels e.g., 35 weeks)	
		LOOK SELECTIVELY, IDENTIFY PICTURES					
ADAPTIVE	Pile 1 small toy on 2nd [tower 2]			Dump crumb out of bottle—may show			N=Normal, or advanced Q=Questionable A=Abnormal MATURITY LEVEL DIAGNOSTIC CATEGORY Adaptive _____ Gr. Motor _____ Fine Motor _____ Language _____ Pers. Soc. _____ Examiner's Name _____
	Get 5-6 [of 10] small toys in cup or box, doesn't put all 10 in			Scribble when you hand him crayon, i.e., spontaneously			
GROSS MOTOR	Stroke crayon in air (imitates) after you draw vertical stroke			Imitate stroke on paper after you draw vertical stroke			
	No longer creep or crawl			Run stiff-legged			
FINE MOTOR	Get up in middle of floor and walk alone			Rarely fall when walking			
	Collapse & catch self when falls			Climb into adult chair			
LANGUAGE	Drop crumbs into bottle just if you point and ask him to			Walk upstairs if you hold 1 hand			
	Help turn pages of book			Turn pages of book 2-3 at once			
PERSONAL SOCIAL	4-6 words, including first names			Stack up 3 small toys [tower 3]			
	Talk foreign language—jargon			Point to picture, if ask, dog, bab			
	Pat at pictures in book			Look back & forth as you point from 1 picture to other in book			
	Indicate wants by pointing or vocalizing [grunt, "uh-uh-oh"]			Walk or crawl, pulling string toy			
	When fed leaves dish on tray			Hug and love doll, stuffed animal			
				Use spoon to feed, spill food hit			

to phrase the items as clearly as possible; specific explanations for some are listed in the instructions. It will help to understand them if you look at the adjacent age levels, e.g., lift vs. hold at 8 and 12 weeks in Gross Motor Behavior; offer the parents both alternatives. ASK THE QUESTIONS AS THEY ARE STATED.

START by asking questions appropriate to the chronologic age of the child. If the answers are negative, drop to a lower age level then work back up. It is best to cover ONE AREA OF BEHAVIOR AT A TIME rather than one age level at a time. Remember that the infant may be slow in one area and normal in other areas. Keep asking questions above the child's chronological age until no more positive answers are obtained. When you start your interview TELL THE PARENTS SOME QUESTIONS ASKED WILL BE ABOVE THE CHILD'S LEVEL OF ABILITIES.

Record the parents' answers (H=History Col.) and your observations (O=Observed Col.) on each visit, to the left of each item. For behavior which depends on your observations only, the history column is blocked out. Record responses +(Present), -(Absent), or X(Unknown). If an infant is seen every 4 weeks there may be some overlap in behavior; confusion can be avoided by recording in different colors. Failure to progress normally will be obvious if significant overlap between visits persists.

Blocks are provided for recording the age level at which the child is functioning and the diagnoses. In each of the five areas of behavior, assign maturity levels in weeks, or months, based on your clinical judgment of the age levels your recorded history and observations describe best. You can interpolate between the adjacent age columns, e.g., 35 weeks, since a 32 week infant adds 36 weeks behavior gradually over the next 4 weeks. DO NOT FORGET TO TAKE THE PARENTS' HISTORY INTO ACCOUNT. This is particularly true in language behavior, which may not be exhibited during the examination. We have found parents' reports to be very accurate when clear-cut specific questions are asked.

Assign a diagnostic category in each area on the basis of your age levels. With just these items, expect to be able to divide the infants into three diagnostic categories: (A) definitely abnormal, (Q) borderline or questionably abnormal, and (N) normal, or advanced. Do not expect to make a precise diagnosis. REMEMBER THAT THERE IS NORMAL VARIATION AROUND THE AVERAGE OF 100 AND THAT THE AGE PLACEMENT OF AN ITEM IS THAT AT WHICH ROUGHLY 50% OF INFANTS ACHIEVE SUCCESS. If an infant has a history of normal language behavior, at least at 36 weeks and beyond, it is dangerous to make a diagnosis of mental deficiency, even though adaptive behavior is retarded. Be suspicious of the presence of abortive grand mal convulsive seizures.

Age in weeks must be counted on the calendar; there are 13 4-week periods per year. Don't forget to SUBTRACT THE WEEKS OF PREMATURITY from the chronological age (Knobloch, et al., in Haynes, 1967, pp. 77-78).

Boyd (1969) introduces the manual for the experimental form of the CCD Developmental Progress Scale with a number of remarks which are germane to all such scales and thereby give a helpful appraisal of the state of the art.

Developmental scales are not new. Attempts have been made by many individuals, representing many disciplines, to record and measure the typical development of a child in whatever area of functioning came closest to the interest and training of the person doing the research. Gesell and his coworkers, beginning approximately a quarter of a century ago and continuing to the present time, studied the orderly sequence of human growth and development in many areas of function and published normative data. Doll more specifically described social development and devised the Vineland Social Maturity Scale to measure it. Bayley carried out research on early childhood development for many years, terminating in the publication of the Bayley Scales of Infant Development consisting of three parts measuring mental behavior, motor behavior, and examiner-rated scales measuring general infant behavior. Over the years other investigators contributed both original data and the modifications of some of the earlier scales; however, most of the scales, both original and modified, focused on a label of one sort or another usually expressed by numbers such as a developmental age or quotient. In addition, each new scale made its claim to accuracy and precision but had to admit to a constant numerical error of measurement. One result was compounded confusion, especially when the examiner was insufficiently trained in statistical measurement to understand the limitations of numbers, and the phenomenon of individual difference, and the perplexity of the consumer was further elaborated when he was forced into explaining hopefully with meaning and accuracy, but usually with doubt and confusion, age or quotient scores to a concerned parent.

In 1963, Gunzburg, in England, produced the Progress Assessment Chart to describe, pictorially, developmental progress in four main areas of growth and training: Self-help, Communication, Socialization, and Occupation. In 1966, Frankenburg and Dodds, basing their material on careful standardization of fine and gross motor skills, language skills, and personal-social skills on over 1,000 normal Denver, Colorado children from two weeks to six years of age, constructed the Denver Developmental Screening Test which permitted the developmental growth of a child without deriving either an age or quotient score. In recent years, the American Association on Mental Deficiency has encouraged the development of more realistic measures of adaptive behavior and research is continuing in this direction. In short, there is increasing awareness of the need for practical and practicable material on child growth and development which can be meaningfully applied by both the professional and the parent as a valid foundation on which immediate and long-term training procedures can be built.

As with the Denver Developmental Screening Test and Progress Assessment Chart, the purpose of the CCD Developmental Progress Scale, utilizing previous research findings of many workers, attempts to portray the developmental level of functioning in a pictorial manner, enabling the user to see at a glance comparative levels of functioning in the areas of Motor Skills, Interpersonal-Communication Skills, and Self-Sufficiency Skills, and also to identify, quickly and clearly, those skills below the general level of the child's functioning which, for one reason or another, may not yet have emerged or been trained and which should, therefore, receive special attention. The division of the scale into three parts is an attempt to combine in one

scale, areas of concern usually reported by several disciplines, and frequently overlapping. No items in this scale are of such complexity as to require specialized professional training; there is no attempt, however, to have the CCD Developmental Progress Scale replace the professional clinical judgment of the various clinical disciplines. The skills of the speech pathologist in studying specific organic and functional disabilities remain a province of that discipline; the skills of the occupational and physical therapist in studying muscle functioning will not be supplanted by this scale; in determining intellectual functioning this scale will not replace the use of the traditional intelligence test administered by the trained psychologist. The CCD Developmental Progress Scale, on the other hand, may be given by any discipline among the helping professions (assuming reasonable care in following the instructions) or may be reported as a composite of the findings of several disciplines, pulled into one report, and pictorialized on one page, with the possibility of the follow-up study specifically relating to the development of desirable behaviors rather than changes in scores (pp. 1-3).

The following cites some of the specific features of the CCD Developmental Progress Scale, which consists of 150 items some of which are immediately and directly observable and measurable and others of which are ascertained through parent interview:

This scale, as a totality, does not yet have statistical evidence of validity and exists presently as an experimental procedure. However, the selection of items has followed a procedure which should allow the assumption of both validity and practicality. No item was placed in the scale unless it met two criteria: First, there must be research evidence indicating that the particular behavior or skill inherent in the scale item typically emerges within the general age level to which it is assigned; the general criteria for selection of an item on this basis was that between 50% and 75% of children of that age level demonstrate the skill. Thus, one should be able to assume essential validity of the total instrument since each item has been proved to have developmental validity. Secondly, no item was selected for the scale unless the skill directly or indirectly has "survival value"; this item has been defined as a behavior which enables more efficient, and less dependent, immediate daily living or which is a prerequisite for, or leads to, the development of later behaviors which improve the efficiency of living. The CCD Developmental Progress Scale is, then, not a study of all development in and for itself, but an attempt to measure practical and useful development skills.

Consistent efforts have been made to make the administration of this scale casual, informal, and simple. No items have been included which require complex materials or the purchase of elaborate paraphernalia; for the most part, the scale can be presented with a few simple objects such as paper and pencil, a rattle, a tennis ball, a small bottle, candies, three coins, and some blocks. The setting in which the child is examined should be kept simple and with a minimum of extraneous materials. The entire atmosphere of presentation of materials should be both casual and interesting.

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It should be noted that absence of a skill which should, on the basis of other skills, be present does not automatically call for an immediate training program. Absence of a skill should lead one to ask, "why is it absent?" If there is a sensory limitation or if the skill is not possible because of a physical disability, the treatment process might be very different from a situation in which no physical or sensory deprivations are present and in which the primary emphasis can be the determination of an adequate training program for the development of the skill. With the above limitation clearly stated to the person to whom the results might be shown, this recording sheet should be useful to show directly to the parent or teacher with the aim of centering attention on needed behaviors and their attainment rather than upon scores, ages, or quotients.

The recording sheet, it will be noted (Figure 32), also includes a section labeled Mental Skills. This is not a part of the CCD Developmental Progress Scale itself, but is included for comparison purposes if the examiner wishes to use it. Any standardized intelligence scale which gives an approximate mental age or from which a mental age may be derived may be used to fill in the age bar, enabling a comparison between motor, interpersonal, self-sufficiency and traditional mental skills (pp. 3-4, 6-7).

A review of the literature indicates that validity and reliability studies done on developmental scales are not widely undertaken or reported and the results are frequently not impressive. An outstanding exception to this is the Denver Developmental Screening Test which has been subjected to extensive and intensive reliability and validity studies.

In terms of the reliability of the DDST the following conclusions were reached:

Tester-observer agreement and test-retest stability of the Denver Developmental Screening Test (DDST) were evaluated with 76 and 186 subjects, respectively. The correlation coefficients for mental ages obtained at a 1-week interval were calculated for 13 age groups between 1.5 months and 49 months. Coefficients ranged between .66 and .93 with no age trend displayed.

1. Tester-observer agreement for individual items was greater than test-retest stability.
2. The test-retest stability of the DDST is as high or higher than similar reliabilities for such diagnostic tests as Bayley's Revised Scale of Mental and Motor Development.
3. The only apparent differences between DDST items having high and low test-retest stability was that a greater percentage of items with high stability could be passed by report.
4. The high test-observer agreement, stability of test items and validity of the DDST, and the ease with which the DDST can be learned, administered, and interpreted make this a useful tool for screening for developmental deviations in preschool-aged children (Frankenburg, 1971a, pp. 1315 & 1325).

Of course, regardless of how reliable and easily administered a test is, it is far more crucial to be certain that it is measuring what it claims to be measuring and is therefore valid.

Fig. 32:CCD DEVELOPMENTAL PROGRESS SCALE (Boyd, 1969)

DATE Year _____ Month _____ Date _____ NAME _____
 BIRTH _____ UNIT NO. _____
 AGE 6 mos. _____

Experimental Form

	1	2	3	4	5	6	7	8
Follows object	Takes cubes	Builds tower of 2 blocks	Builds bridge of 3 blocks	10 pellets in bottle	10 pellets in 23" bottle	10 pellets in 20" bottle	10 pellets in 18" bottle	Arranges material neatly
Rolls over	Sits without support	Walks alone	Rides bicycle	Catches ball, bounced 2/3	Plays outdoors safely	Plays outdoors skill	Rides bicycle	
Grasps object	Cruises	Walks backward	Balances on 1 foot 1"	Balances on 1 foot 5"	Balances on 1 foot 10"	*Prints 1-20 few reversals	*Prints 1-20 no revers. 1/2"	
Bear weight	Stands alone	Stoops & recovers	Cuts with scissor	Hops 1 foot	*Draws Man 4 parts	*Draws Man 6 parts	Cuts carefully	
Transfers objects	Pincer grasp	Scribbles	Copies circle	Copies cross	Copies square	Copies triangle	Copies vertical diamond	Uses tools to construct

MOTOR SKILLS

*-On back of drawing sheet

	1	2	3	4	5	6	7	8
Responds to bell	Says- mama, dada	Plays ball	Show-mouth, eyes, hair, nose 1/4	*Word list 9/22	*Word list 14/22	*Vocabulary 6/9	*Names animals 1' 9	Names days of week
Babbles	Imitates sounds	Uses 3 to 5 words	Blocks-give "just one"	Block-on, under, from, back 3/4	*Analogies 2/3	*Prints first name	*Knows & writes date	
Follows person	Responds to no-no, bye-bye	Indicates specific wants	Uses plurals- blocks, shoes	Do-sleepy, cold, hungry 2/3	Do-street, lost 1/2	Made of-fork, door, shoe 3/3	Reads 1.5 grade level	Reads 2.5 grade level
Smiles	Reacts to strangers	Mimics chores	Helps in house	Show "longer" 3/3 or 5/6	Show "smooth-er" 3/3 or 5/6	Show R-eye, L-eye, R-leg, L-arm 4/4	When-break-fast, bed, afternoon 3/3	Tells own address
Turns to voice	1 Word-not mama, dada	Soliter- play	Cooperative play	Separates- without fuss	Tells age	Competitive games	Answers phone takes message	Plays group games

COMMUNICATION- INTERPERSONAL SKILLS

*-On back of this sheet

	1	2	3	4	5	6	7	8
Reaches for object	Drinks from cup	Feeds with spoon	Eats with fork	Feeds-pour, cuts with fork	Brushes own teeth	Names-penny, dime, nickel 2/3	Spreads own bread	Cuts own meat (knife)
Reaches for toy	Uncovers face	Chews food	Gets own drink	Identifies red, yellow, blue, green 3/4	Couns-4 and 3 blocks 2/2	Couns-10 and 8 blocks 2/2, 4-1, 3-2, 2/3	Tells time, quarter hour	
Occupies self	Works for toy	Drinks without help	Washes, dries own hands	Toilet trained cares for self	Washes own face	Blows own nose	Bathes self	Makes change
Feeds cracker	Gets to sitting	Overcomes obstacles	Avoids-street, knives, height	Buttons self	Runs about within block	Runs about, crosses streets	Cows to bed unassisted	Reads and follows signs
	Gets to sitting	Removes clothing	Dresses with help	Dresses without help	Laces own shoes	Errands outside home	Ties own shoes	Makes self presentable

SELF SUFFICIENCY SKILLS

	1	2	3	4	5	6	7	8

MENTAL SKILLS

In view of the widespread use of the Denver Developmental Screening Test (DDST) for screening the development of preschool aged children, a study was undertaken to evaluate the validity of the DDST. 236 subjects were evaluated with the DDST and the following criterion tests: Stanford-Binet, Revised Yale Developmental Schedule, Cattell, and the Revised Bayley Infant Scale. Correlations of mental ages obtained with the DDST and the criterion tests varied between .86 and .97. Scoring the DDST as normal, questionable, and abnormal agreed very highly with IQs or DQs obtained on the criterion tests.

Coincidence for Stanford-Binet and RYDS with the DDST were 100 and 97 percent, indicating that abnormalities on these two criterion tests were usually identified by the DDST. The coincidence rates of 77 and 58 percent for these two tests indicate that 23 percent (Stanford-Binet) to 42 percent (RYDS) of normal children were erroneously called abnormal on the DDST. This is an acceptable level of performance for a screening test when it is realized that 81 percent of the total cases are correctly classified, and errors are in the direction of referring a few extra normal children for complete evaluation.

Of more concern in screening is that the fact that a number of children rated abnormal on the Bayley and Cattell were rated as normal and questionable on the DDST. This is particularly surprising since some of the highest correlations were obtained between these two tests and the DDST mental age. Here the coincidence rates of 88 and 94 percent indicate highest agreement between children called normal on both tests.

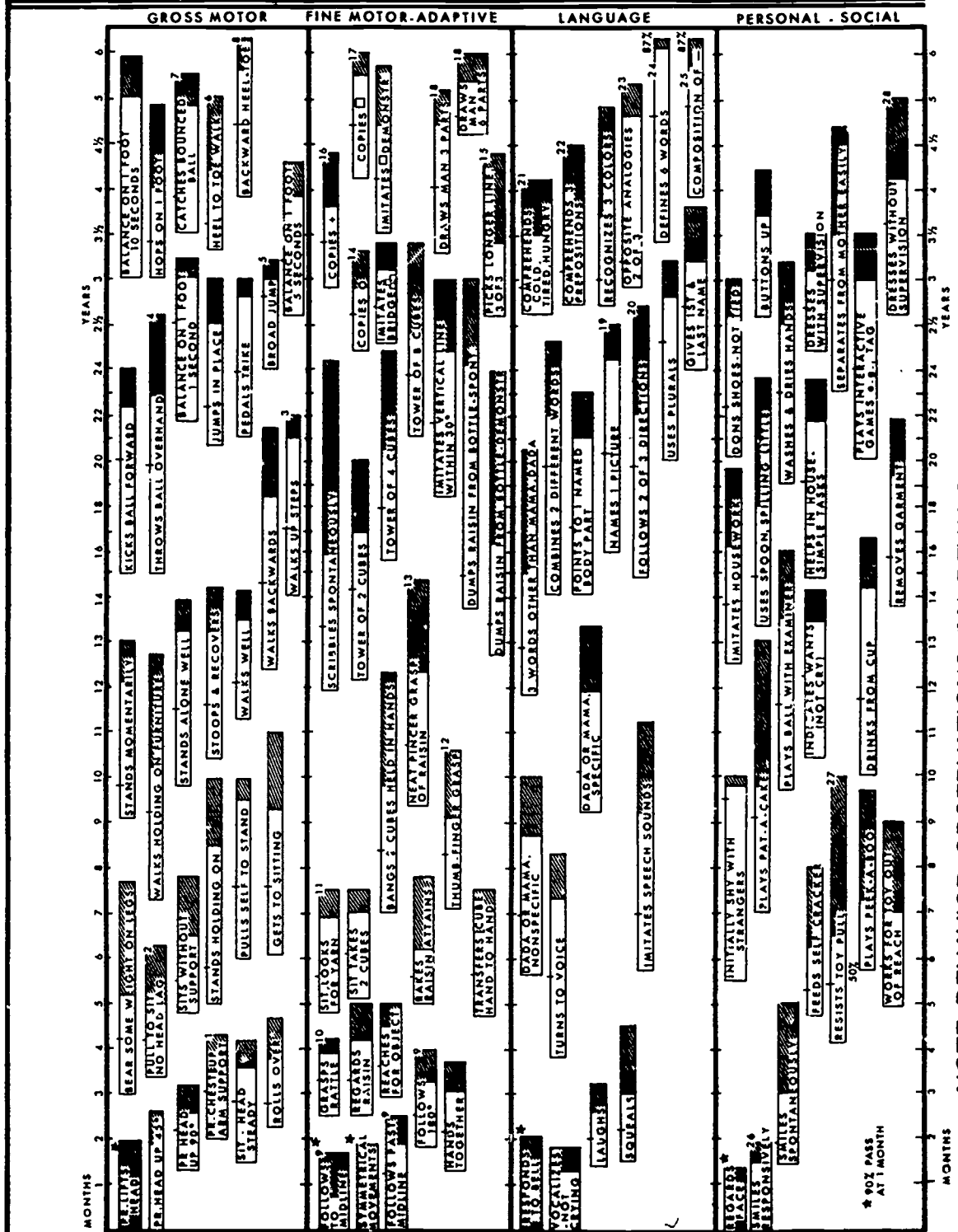
It seems likely that the explanation for this degree of disagreement, especially between DDST and Bayley, may arise from the different ways in which mother's report is used in scoring. Thus, on the DDST many items can be credited as passed on the basis of mother's report, even though the behavior cannot be observed in the testing. On the Bayley, however, only items passed on the basis of test-observation are used to calculate a score. Since mothers' reports are used only to evaluate the adequacy of test results and are not credited in the calculation of a score, this would tend to produce lower scores on the Bayley. Thus, the observation of a great amount of disagreement in classifying the youngest age group is not surprising. Depending on how the test is used, this finding may or may not be of great concern. One might say that best results are obtained after 30 months of age. If, however, one is concerned with picking up children with developmental deviations in the first year, one must be prepared for the finding that a normal classification on the DDST will in approximately 13 percent of the cases, conceal a child who would have obtained an abnormal rating on the Bayley.

The overall impact of data...however, is to lend strong support to the use of the DDST as a screening test for identifying developmental deviations. The consistency with which children with low IQs are identified without grossly calling "deviant" children who actually are normal is especially encouraging at the upper ages...(Frankenburg, et al., 1971b, pp. 475 & 483-4).

And yet Boyd (1972) suggests that the DDST (Figure 33), which is quite similar to the CCD in format and content, is more appropriate for younger ages while the CCD Scale may be more appropriate for older ages, based upon the number of items contained in each test for different ages (Table 15).

Figure 33:
DENVER DEVELOPMENTAL SCREENING TEST
PERCENT OF CHILDREN PASSING
Pr=PRONE Sit=SITTING

Date _____
Ward _____
Name _____
Hosp. No. _____
Address _____



NOTE BEHAVIOR OBSERVATIONS ON REVERSE SIDE

(c) 1969 - W.K. Frankenburg & J.B. Dodds, University of Colorado Medical Center

	Denver Scale		CCD Scale	
	Number of Items	Cumulative Total	Number of Items	Cumulative Total
Birth - 6 Months	25	25	15	15
6 Months - 12 Months	21	46	15	30
12 Month - 18 Months	14	60	15	45
18 Months - 24 Months	10	70	15	60
2 Years - 3 Years	13	83	15	75
3 Years - 4 Years	12	95	15	90
4 Years - 5 Years	5	100	15	105
5 Years - 6 Years	5	105	15	120
6 Years - 7 Years	0	105	15	135
7 Years - 8 Years	0	105	15	150

Table 15: Comparison of Number of Items at Different Age Levels between Denver Scale and CCD Scale (Boyd, 1972).

There are some striking similarities between the DDST and the CCD; one of the co-authors of the DDST, Dodds (Frankenburg and Dodds, 1967), was a student in psychology at the University of Oregon, where Boyd developed the CCD. Of course, the universality of developmental processes would dictate fundamentally similar content on all such scales, as seen in those contained herein and to be found in other older or less promising (or unknown) scales not included. After further discussing the comparison of the two scales, Boyd goes on to present some compelling reasons for using parental reporting, in spite of its potential pitfalls.

I am also including a copy of the comparative table between the Denver Developmental Screening Test and the CCD Developmental Progress Scale, which attempts to portray the overlapping nature of these two instruments and the reasons why the Denver Scale is more appropriate for the younger ages, while the CCD Scale may be more appropriate for the older ages.

As you will note, and as we discussed, the CCD Scale is, in many ways, an attempt to 'up-age' the Denver Developmental Screening Test, and in no way is an attempt to supplant or replace the Denver. In fact, we are teaching both scales to our medical students and suggesting that they select the instrument which comes closer to the functioning age of the child in order to get the most accurate description.

The CCD Scale chooses three areas rather than the four designated by the Denver Scale; fine and gross motor abilities are confined under one heading with the assumption that one can tell by the nature of the task whether an observed deficiency is primarily in the upper or lower extremities. The Communication-Interpersonal combines some of the language aspects of the Denver Scale with certain of the personal-social category. The Self-Sufficiency category utilizes and expands the personal-social category of the Denver, but makes one fairly important distinction: almost all of the material in the self-sufficiency category is derived from the report of the parent rather than actual examination. The intent here is to derive a description of the typical behavior which can be contrasted with the demonstrated motoric and comprehension abilities measured in the other two categories of the CCD Scale. The purpose is to enable a description to differentiate the child who has a motoric or comprehension weakness which necessarily affects typical behavior from the child who does not have such weaknesses, but who demonstrates lesser self-sufficiency skills primarily as a result of parental training (or lack of it). My purpose in stressing this point is to make it possible to specify which child needs treatment and which child needs training. Of course, I realize that this instrument is only a screening device, but the direction, at least, can be indicated.

The fact that the Self-Sufficiency section is based in large measure on the report of the parent constitutes not only, in my opinion, a major strength of the CCD Scale, but also a potential weakness. Obviously, if we are to get accurate reporting of the child's typical behavior, the questions must be asked in such a way as to elicit a description of the behavior which typically occurs, and questions must not telegraph the socially desirable answer. If the questions are asked as a check-list, very frequently we find a

spuriously high ability level in self-sufficiency, as contrasted with the other two categories, largely because of the mother's defensive assumption that the doctor would not have asked the question if he did not believe the child should perform the task and her consequent tendency to rationalize that perhaps the child 'could.' This constitutes one of the major aspects of training, but, in my opinion, not an insurmountable one. We find that our medical students, for example, are all too inclined at the beginning to want to 'give the child credit' or 'not count something against him' which is not his fault (such as tendency on the part of the mother to do things for him which he might actually be capable of doing for himself). With appropriate review of interview techniques and discussion of the meaning of the responses, however, we have been able to acquire sufficient good interviewing and sufficient reliability of scoring to believe that the technique merits continued use (Boyd, 1972, pp. 1-2).

Most of the other validation and/or experimental studies conducted which employed the DDST are generally supportive of the instrument in terms of face and concurrent validity. However, in line with the preceding remarks in this section and in Chapter VI, concern was expressed about its predictive validity, particularly with minority ethnic groups in poverty settings (Sandler, *et al.*, 1970 & 1972). One large study involved 1629 preschool children, about equally distributed in age from early infancy through five years, with a significant swing toward lower SES, as determined by Hollingshead's Two-Factor Index of Social Position (1957) (which takes both income and educational level of parents into consideration). This study also partially questions the validity of the DDST as normed and scored for this population.

According to the President's Committee on Mental Retardation (1969), three-fourths of the nation's mental retardation is found in rural and urban low-income, disadvantaged areas. Only 6 percent of the children in the study showed less than normal development as determined by the DDST. This is perhaps less than what one would expect for a population of children having approximately 80 percent in social classes IV and V. This finding of low incidence of developmental delay in the study population suggests that the anticipated incidence was high for the project area.

On the other hand, it may be hypothesized that the DDST was not detecting developmental delay sufficiently within the age limits of the study population. It may also be possible that the effects of disadvantaged rural conditions are cumulative in nature and not recognizable as a developmental deficit until school age. In any event, it is recommended that there should be a continued search for effective screening techniques and a rescreening of children within the same age limits, in order to obtain further data regarding the incidence of developmental delay and handicapping conditions within the project area (Black, 1970, p. 58).

The validation of screening instruments and systems has been undertaken with older preschool and elementary school children (Bakalis, 1972; Denhoff, 1969; Hoffman, 1972; Meier, 1971; Sandler, 1972; & Wyatt, 1971) and might prove instructive for designing studies with infants and younger children.

This study explores the effectiveness of selected screening instruments in detecting emotional disturbance and learning disabilities among preschool disadvantaged nursery school children.

The concern of the investigators is focused upon the existing need for valid and reliable instruments which can be easily and economically used in assessing the developmental functioning of young children. A first-step approach to early prevention and remediation of learning failures is considered to be growth in the awareness of the individual needs and capacities of the preschool child. Effective screening instruments, which identify the vulnerable and developmentally deficient child are required in the effort to help all children who can benefit from specialized psychoeducational programs.

Three screening instruments, the Kohn Social Competency Scale, the Kohn Symptom List and the Myklebust Pupil Rating Scale (Screening for Learning Disabilities) will be used in this study. A random sample of 600 preschool disadvantaged children, attending federally funded preschool programs in urban Philadelphia will be evaluated by their teachers according to the items on these scales. The investigators will explore the validity of the teachers' judgments of the presence or absence of developmental problems using reference criteria which includes the Wechsler Preschool Primary Scale of Intelligence and a modified version of the Demyer Psychiatric Examination.

It is expected that study results will be of direct and applied value in planning programs for young children (Sandler, 1972, p. 1). (Figure 34/1)

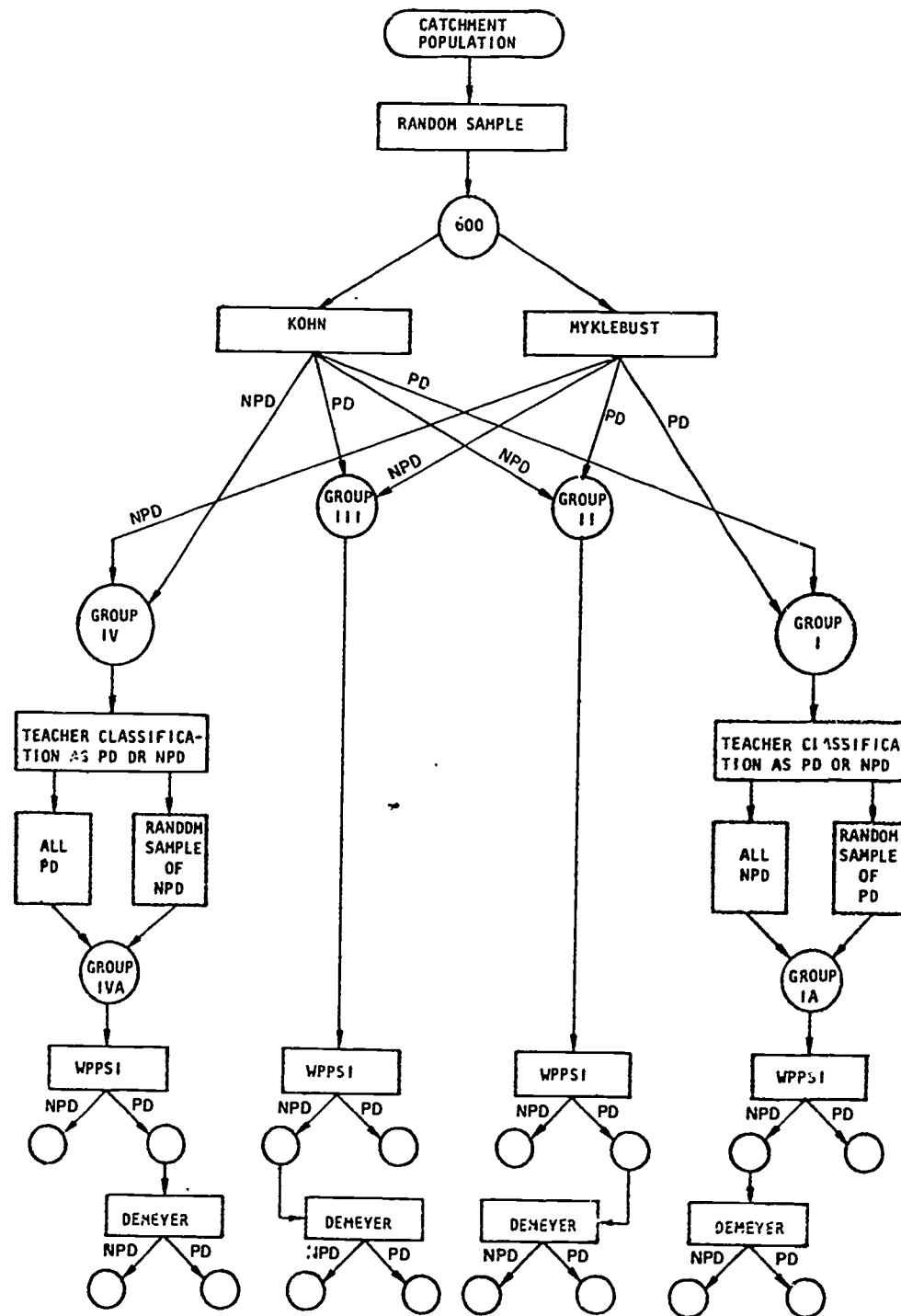
Beyond the Paralysis of Analysis

When a satisfactory comprehensive developmental screening system has been field tested and thoroughly debugged, it is only useful if it plugs into practical intervention programs. Several successful prevention/remediation programs have been proposed or reported in the literature (e.g., Appalachian Regional Commission, 1970; Gordon, 1970; Honig & Lally, 1972, Lovell, 1968; Painter, 1968; & Williams, 1972), but it is beyond the purview of this monograph to mention, let alone elaborate upon, them, since that would comprise another monograph of at least this magnitude.

One noteworthy project is designed to employ a comprehensive screening system as a means for identifying and properly channeling a subpopulation of preschool children at high risk of subsequent school failure into remedial/prevention service systems.

The Brookline Early Education Project is a proposed comprehensive program for guiding the educational development of the child from birth to four and a half years. Preschool education as it exists today (i.e., private nursery schools or compensatory education programs for disadvantaged children) does not meet the needs of most children in this age range.

The Brookline Project will develop a program which will assess each child's strengths and weaknesses and provide programs to meet these specific needs early in life. The primary purpose of the diagnostic program is to attempt to insure each family that no child will progress through the preschool years with an undetected educational handicap. The following paper is a description of the diagnostic



PD = Probable Disability
NPD = No Probable Disability

FIGURE 34/1: MODEL OF RESEARCH DESIGN

screening procedures we will use. These procedures are based upon what we consider to be the best assessment techniques available in medical, psychiatric and educational practices today.

Goals for the Brookline Early Education Project Diagnostic Program:

- A. To develop an effective screening procedure which will evaluate physical, emotional, and intellectual development of children in the 0-4½ age group.
- B. To identify a 'high risk' population which is likely to exhibit educational underachievement in the public school system.
- C. To identify the specific discrepancy in development which is likely to cause the educational underachievement, i.e., physical, emotional, or intellectual.
- D. To put parents in touch with a comprehensive, child-oriented service structure (Kaban, 1972, pp. 3-4).

This project, which is under the overall direction of Burton White at Harvard University, is obviously an experimental pilot program which will test out a number of different alternatives for establishing an effective screening procedure. A generic description of the diagnostic procedures, which are rather conservative in light of the preceding remarks on infant testing, is contained in the second draft of the project description just prior to a detailed description and analysis of the various procedures under consideration.

There are two primary methods for the early identification of children who might exhibit physical, emotional, or intellectual deficiencies in development:

- a. The identification of 'high risk' families.
- b. Diagnostic screening of the child.

Except for cases of extreme pathology, educational deficiencies cannot be detected reliably during infancy (0-18 months). In our work with families of such young children, our diagnostic efforts will focus on the identification of 'high risk' families. In order to make this diagnosis, we will rely heavily on medical histories, general background information, and school records. For older children, the number of medical and psychological procedures available to assess development increases. We will use these direct measures of development as well as the historical data to evaluate a child's development (p. 9½).

The draft then discusses specific techniques for identifying high risk families, the kind of birth data that will be collected, school information data which will be used, and then the specific techniques for diagnostic screening of the child, including a standard pediatric examination, visual, auditory, special neurological, dental, and psychological tests including the battery of Harvard Preschool Project Tests, some of which are discussed briefly in previous chapters of this monograph, plus certain interview schedules. As shown in Table 16, there will be an effort made to determine the relative efficacy and cost benefit of three different protocols projected to cost between approximately \$830 per program per child in Program I, to \$580 for Program III. Table 17, shows a schedule of procedures and staff which are included in accomplishing the most elaborate Program I. It is hoped, of course, that an even more efficient and economical combination can be reached by using the most efficacious subsections of these three

<u>Pediatric Examinations</u>			<u>Denver Developmental Screening Test</u>			<u>Preschool Project Tests</u>		
<u>Program I</u>	<u>Program II</u>	<u>Program III</u>	<u>Program I</u>	<u>Program II</u>	<u>Program III</u>	<u>Program I</u>	<u>Program II</u>	<u>Program III</u>
3 mon	3 mon	3 mon	6 mon	6 mon	6 mon	12 mon	12 mon	12 mon
9 mon	9 mon	12 mon	12 mon	12 mon	24 mon	18 mon		
15 mon	15 mon	18 mon	24 mon	24 mon		30 mon	30 mon	30 mon
27 mon	27 mon							
36 mon	36 mon	36 mon						
48 mon	48 mon	48 mon						

<u>Social Competency Rating</u>			<u>Visual and Auditory Screening</u>		
<u>Program I</u>	<u>Program II</u>	<u>Program III</u>	<u>Program I</u>	<u>Program II</u>	<u>Program III</u>
18 mon	18 mon	18 mon	6 mon	6 mon	6 mon
24 mon	24 mon		18 mon		
30 mon	30 mon	30 mon	30 mon	30 mon	30 mon
36 mon	36 mon		42 mon		
42 mon	42 mon	42 mon	54 mon	54 mon	54 mon
48 mon	48 mon				
54 mon	54 mon	54 mon			

Table 16: COMPARISON OF PROCEDURES ACROSS THREE PROGRAMS
(Kaban, 1972, p. 25).

<u>Age</u>	<u>Procedure</u>	<u>Staff</u>
	Interview Birth Data	Psychiatric Social Worker Public Health Nurse
2 week	Prectl Neurological Exam	Pediatric Neurologist
3 mon.	Pediatric Examination	Pediatric Resident
6 mon.	Denver Developmental Screening Test	Graduate Student
9 mon.	Visual & Auditory Screening Pediatric Examination	Optom. and M.D. Pediatric Resident
12 mon.	Denver Developmental Screening Test	Graduate Student
	Preschool Project Tests (3)	Graduate Student
15 mon.	Pediatric Exam	Pediatric Resident
18 mon.	Visual & Auditory Screening Preschool Project Tests (3)	Optom. and M.D. Graduate Student
	Social Competence Rating	Graduate Student
24 mon.	Denver Developmental Screening Test	Graduate Student
	Social Competence Rating	Graduate Student
27 mon.	Pediatric Exam	Pediatric Resident
30 mon.	Visual & Auditory Screening Preschool Project Tests (3)	Optom. and M.D. Graduate Student
	Social Competence Rating	Graduate Student
36 mon.	Pediatric Exam	Pediatric Resident
	Stanford-Binet Test	Graduate Student
	I.T.P.A.	Graduate Student
	Social Competence Rating	Graduate Student
42 mon.	Visual & Auditory Screening Dental Exam	Optom. and M.D. Pedodontist
	Social Competence Rating	Graduate Student
48 mon.	Pediatric Exam	Pediatric Resident
	WPPSI	Graduate Student
	Social Competence Rating	Graduate Student
54 mon.	Visual & Auditory Screening Social Competence Rating	Optom. and M.D. Graduate Student

Table 17: SCHEDULE OF PROCEDURES AND STAFF FOR PROGRAM I
(Kaban, 1972, p. 22).

programs. Moreover, it is believed that such studies as this one will lead to refined procedures which will be more sensitive and specific with younger infants and children.

One of the most logical approaches to testing the validity and reliability of an early screening and assessment system is to do it in conjunction with some of the poverty programs for young children, which predictably would have an unusually high yield in comparison to the entire U.S. population. The Office of Child Development is responsible for three programs which seem eminently well suited for such pilot work; these include the Parent-Child Centers, Home Start Programs, and Head Start Programs widespread throughout the U.S.

A particular case in point is the La Junta Parent-Child Center program, where an early screening, assessment, and intervention project for young children at moderate to high developmental risk is being undertaken. A 1971 Needs Assessment Survey conducted by the La Junta Parent-Child Center staff revealed that there is no systematic and regular program to identify high risk children, who are frequently in high risk families, any place in the entire Arkansas Valley, let alone in the La Junta Parent-Child Center catchment areas (Las Animas, Ordway, and Rocky Ford, Colorado). The National Parent-Child Center goals all focus on identifying and, insofar as possible, providing for the many unmet needs of poverty children, from conception through five years of age, and their families. An important objective of the Advocacy Component of the Parent-Child Centers is that it will subsequently act as a catalyst and coordination resource for establishing exemplary delivery systems or intervention programs to meet these identified needs. The La Junta Parent-Child Center program, as the next logical level of sophistication in needs-assessment determination, has designed a systematic and staged approach to ferret out children whose optimum growth and development is at risk due to various congenital anomalies or sub-optimum family and environmental conditions. As can be seen in Figure 35, this pilot project has seven stages which are presumably self-explanatory in light of preceding discussions.

The Advocacy Component of the La Junta Parent-Child Center has several home-visitor and parent-educator staff members who can make the home contacts and carry out Stages I and II. In addition to the culture of poverty considerations and the ethnic minority complications, it will be necessary to translate the procedures into Spanish and have Spanish-speaking persons available to administer them to the several Spanish-speaking families and to interpret the results. The Parent-Child Center also has a trained child development specialist, who will conduct the Stage III evaluations insofar as possible, with the option of getting certain specialized tests accomplished on a consultative basis from specialists in the area or members of the JFK Center staff. Those children who continue to manifest positive findings at Stage III will be referred to the JFK Center at the University of Colorado Medical Center in Denver (nearly 200 miles away) for total developmental evaluations and subsequent intervention planning and follow-up. A subsample of 20 children will receive all procedures, Stages I through IV, to establish the selectivity and sensitivity of the screening and assessment system (Meier, 1971); some of these 20 children presumably will also require a certain amount of intervention, which is depicted on the schematic diagram in Stages V through VII. An important observation about intervention closes this section.

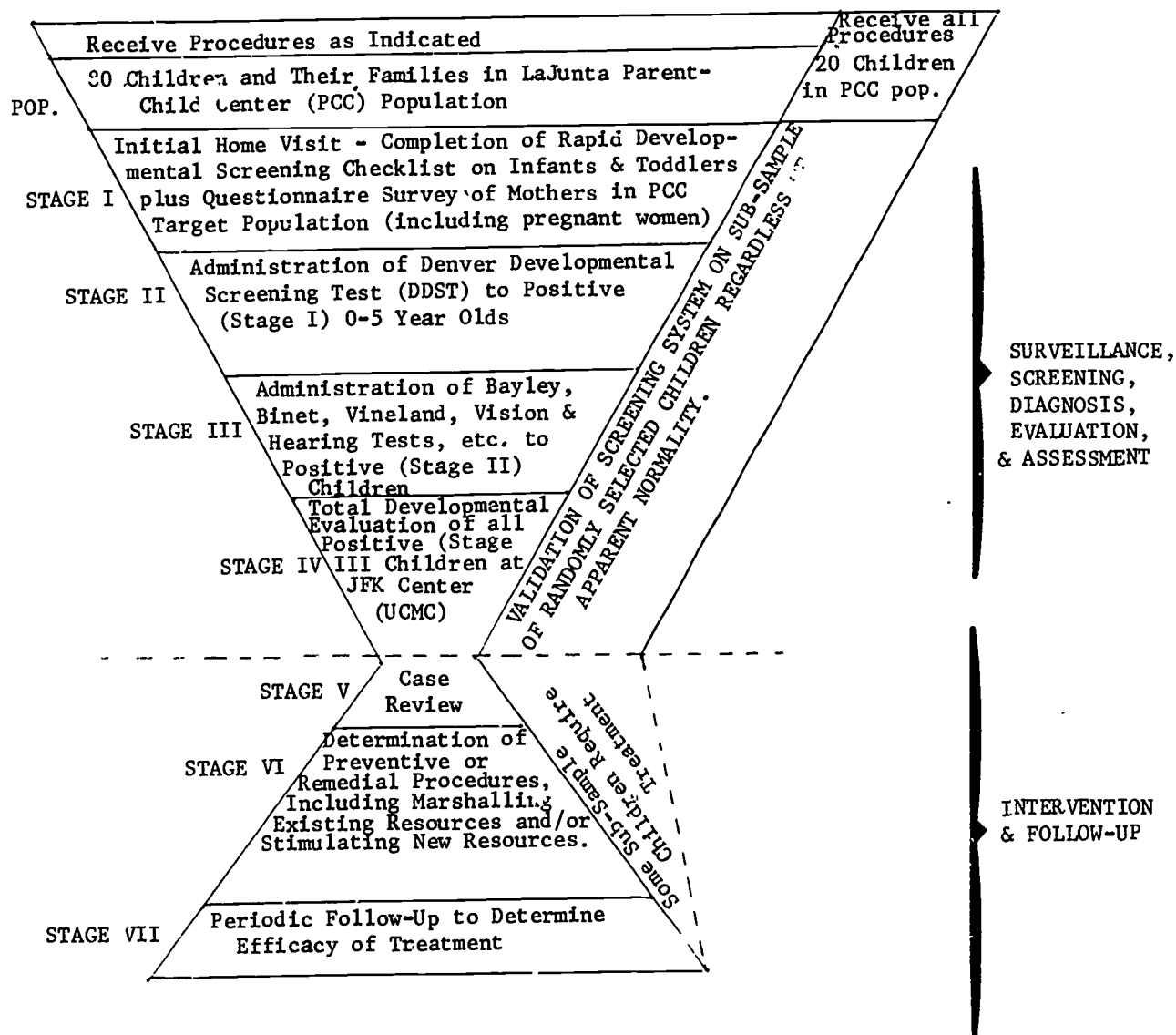


Figure 35: Early Screening, Assessment and Intervention for Young Children at Moderate to High Developmental Risk (Meier, 1972).

Preliminary findings of current preschool programs for the disadvantaged (Weikart 1967) suggest that the experiences offered by the environment to the disadvantaged child are inadequate for continued normal intellectual development after age one, and that projects which deal with the enrichment of the environment of the children at ages three, four, or five are remedial rather than preventive. Inasmuch as the damaging effects of a poor postnatal environment are already apparent in the second year of life, it appears necessary to provide enrichment programs much earlier than is currently the practice. Much work needs to be done to evaluate the effectiveness of preventive projects in this period of life.

The establishment of day-care centers for infants and young children would make it possible for all agencies that serve children to pool their resources to provide more efficient physical and mental health services as well as provide cultural and educational stimulation for the children and their parents. This might be one effective way to stem the tide of problems which are overwhelming the schools.

We found it reassuring, for instance, that IQ changes from two to 10 years in our predominantly Oriental and Polynesian populations were very similar to those hypothesized by Bloom (1964, p. 72) as the probable effects of stimulating versus deprived environments on the development of intelligence. Bloom's speculations were based on longitudinal studies of predominantly middle-class Caucasian children (Werner, Bierman, & French, 1971, pp. 138-9 & 140).

Some Manpower Considerations

As noted in several of the aforementioned screening and assessment programs, the use of aides and paraprofessionals becomes a critical ingredient in order to conduct such massive programs on an economical basis. In several places in this monograph the fact that paraprofessionals can and must be employed in these programs is mentioned. An encouraging 6-year survey entitled Evaluation of the Resources of a Pediatric Out-Patient Department indicates that such health aides can be very helpful and relatively inexpensive primary agents in the overall screening program.

To investigate new means of delivery of care to inner city, disadvantaged, minority group children, a large sample of the population initially was surveyed ecologically and demographically.

The population's problems were: 50% were unimmunized, 25% under five years were iron deficient, 75% of all visual problems were undetected, 25% of the ER visits were for fragmented care of chronic illness, only 1% of ER visits were for serious illness. The families were large, reading ability of the mothers was at the 6th grade level, 32% had positive tuberculin tests, 30% were unemployed. Each year 150 children under fifteen years of age presented as pregnant.

To deliver a type of care which would solve these problems comprehensively, the following resources were investigated:

(1) Multiphasic screening for health defects in the ER: vision, immunization, hearing, family planning, nutrition (hemoglobin), audiology, dental problems.

(2) Health survey and supervision of chronically ill children and their entire families, utilizing professionals (public health nurses) and paraprofessionals (indigenous health aides).

(3) Similar survey and supervision of pregnant children (<15 years) and their families.

(4) This led to evaluation of the potential ability of indigenous health workers.

Health aides could be trained to perform the six screening procedures in one month but required continuous supervision and retraining by a professional, especially in the field of vision testing and identification of dental caries. The mobility of the population made evaluation of the impact of screening difficult. However, in one year, 13,000 children were immunized; 271 cases of tuberculosis identified; 976 parents referred to family planning, 154 referred for dental care; 51 anemic children identified; 444 suspected visual defects noted. Most success in correcting the problems occurred when the problem could be corrected within the Outpatient Department itself, e.g., immunizations. Referral to a resource outside the Outpatient Department, e.g., vision, family planning, dental, depends on patient compliance and results in fragmented, unsuccessful care. This should be considered in setting up a screening program, involving referrals outside the immediate screening area. Cost of screening was 47 cents per patient (Wingert, unpublished Summary, p. 1).

The use of indigenous and paraprofessional personnel in the screening process is gaining increasingly wider acceptance (Frankenburg, *et al.*). Not only is it an economical means of accomplishing the task but also it leaves a residual of trained and skilled people in the community for ongoing services.

Most significant was the surprisingly warm acceptance and unconditional hospitality extended to the screening technicians when they visited the homes in the project area. A total of only 21 parents expressed resistance to having their child screened. In many cases, parents who were concerned that the screening technician might not have their child on her list would either call the health department or 'drop in' on the screening of a neighbor child. The anticipated hostility toward a screening technician making extemporaneous visits to rural Appalachian homes was no major problem. The success of this aspect of the screening process can be attributed, in part, to the following considerations: (1) All screening technicians were native to Appalachia; (2) screening and interview techniques were deliberately planned to be unpretentious and honest (a previously proven technique that came naturally to most of the screening technicians); (3) many parents considered the visit a free service to enable them to know how their child was progressing developmentally; (4) publicity on the project was wide and varied; and (5) the best publicity appeared to be word-of-mouth from neighbor to neighbor, resulting from the goodwill generated by the screening technicians (Black, 1972, p. 55).

With the advent of refined programmed instruction, it may be possible to train large numbers of paraprofessionals in screening and assessment techniques far more efficiently than is now the case. For example, the Cartwrights have perfected a computer-assisted instruction course in the early identification of handicapped children for teachers of handicapped preschool and primary children. The mobile computer-assisted instruction

system enables training to be disseminated to large numbers of teachers residing in remote areas.

The CARE course uses a wide variety of instructional strategies to assist students in reaching the course objectives. All of the strategies are interactive and all require active involvement on the part of the learner. The most prevalent strategy used in the course is the tutorial approach. This approach simulates the master tutor engaging in an interactive dialogue with an individual student. The tutor presents information, asks penetrating questions, and carefully analyzes the student's responses to the questions. On the basis of the student's demonstrated understanding or lack of understanding of a given concept, the tutor provides alternative courses of instruction, remedial sequences of instruction, or even enrichment material. The tutor can move a capable or well-informed student through a course of instruction very rapidly. Similarly, the tutor can tailor a sequence of instruction to meet the needs of a student who is not as capable or does not have a good background of experiences or preparation. The sophisticated CAI system can perform the chores of dozens of tutors rapidly and efficiently. The net effect is that hundreds of teachers in the CARE project have been individually tutored in certain special education skills.

The second major mode of instruction used in the CARE course is the inquiry approach. This type of activity is used in the latter stages of the course to draw together all the concepts acquired by the teachers throughout the course. This strategy includes simulation of regular classroom problems as well. In essence, the inquiry and simulation approaches as used in the CARE course are directed problem solving strategies. Teachers are told that they have access to information about a class of first-grade children. One or more of the children in the class may be handicapped or have an educational problem of one kind or another. It is the teacher's task, in effect, to screen the class for children with educational problems, identify those children with potential or existing problems, and deal with the problem by modifying the child's educational program or making an appropriate referral. The teacher begins the screening by looking over the complete cumulative records of the children in the class. The student may ask the computer for additional information. Not all the information the student receives is accurate; in fact, many false leads are given to lure the unwary teacher into making the wrong decision. The computer system will lead a teacher down the wrong path for awhile and then explain why that particular line of reasoning is not appropriate for that specific child. Eventually, as a result of skillful questioning on the part of the CAI system coupled with the appropriate line of questioning by the teacher, a decision is reached by the teacher to refer a child or to modify the child's program. The teacher's decision is evaluated by the system and then the teacher's plan for referral or program modification is evaluated by the CAI system.

When a teacher completes the course, he has actually constructed several case histories of children with problems and has made educational decisions related to the best plans for dealing with these problems (1970, pp. 9-10).

The results of this system, albeit focused on a different target group of trainees suggests that such a computer-assisted instructional series could and should be developed to assist in the training of vast numbers of paraprofessional persons who would be needed in a national screening and assessment program.

It was the purpose of this project to develop a complete college level computer-assisted instruction (CAI) course dealing with the identification of handicapping conditions in children. The end product was a CAI course called Computer Assisted Remedial Education (CARE). The purpose of CARE is to give educational personnel the knowledge and skills necessary to deal effectively with children who have educational problems. Under separate funding arrangements, the CARE course is now being offered for three college credits to inservice teachers in the various parts of Pennsylvania and other states.

Several stages of development were required to produce the CARE course. First, an intensive review of the relevant literature was carried out in the early stages of the project. Approximately 2,000 journal articles and over 50 books were reviewed by the various course authors and graduate assistants in order to identify the most current thinking in the field. Subsequent course curriculum development was based on the literature review with assistance from consultants. As the course authors prepared the sequences of instruction, the educational programmers translated the Coursewriter II language for use with the IBM 1500 Instructional System. Both authors and programmers tested course sequence for smoothness and credibility before a pilot group of students took the course for debugging purposes. After the pilot group took the course, extensive revisions were made, and a second pilot group assisted in the evaluation of the CAI program. These pilot groups plus other formative evaluation procedures have been instrumental in producing a CAI course which is internally valid and error free.

Summative evaluations have shown that students who take the CAI course score significantly higher in achievement and take about one third less time to cover the same objectives than students instructed in the conventional lecture-discussion method (Cartwright & Mitsel, 1971, p. 43).

A series of training packages, including prescribed behavioral competencies to be demonstrated on videotape for microtraining purposes (Meier, 1968 and 1970) could be developed and employed by a network of training institutions, such as represented by the Association of University Affiliated Centers.

Hypothetical Community and Future Endeavors

As stated at the outset, this monograph only contains selected and representative, but in no way exhaustive, examples of the state of the art in screening and assessment of young children at developmental risk. The Boston Screening and Assessment Conference addressed this issue and resulted in delineating some of the specific steps toward implementing a national comprehensive screening and assessment system, based on the consensus that the state of the art does warrant such a massive undertaking. No effort is made in this monograph to incorporate the voluminous proceedings from the conference itself, since the technical papers and a summary of the Boston

Conference are two additional publications (1973) to serve that purpose. Then, marshalling the resources required for mounting this effort for the welfare of all young children, and ultimately the entire nation, remains as the great challenge. Regional and local planning conferences to design and implement some model systems based on typical or hypothetical communities will enable all of the technical and demographic variables to emerge and be given due consideration.

This report describes the background of two political subdivisions and a region--a city called Dixon, its county called Tiller, and the surrounding metropolitan area.

The report's contents are based on a health training model entitled Dixon, Tiller County developed by the Communicable Disease Center (CDC), U.S. Department of Health, Education, and Welfare. Most of the descriptive material and statistical data is drawn directly from the CDC report. However, an effort has been made to select information and data that are relevant to child health and child development. In several places the Dixon, Tiller County material has been augmented to highlight this special area of concern.

This hypothetical community was developed to provide a frame of reference for the participants in a workshop of the identification and treatment of developmental disorders among preschool children which the President's Committee on Mental Retardation plans to sponsor. As such, it is hoped the report will provide an adequate base on which to plan a model screening and treatment system for preschool children.

The task of the workshop participants will be to outline in as much detail as possible the programs and activities that should be established to discover and treat developmental disorders among preschool youngsters in Dixon County. The Committee's ultimate objective in sponsoring such a workshop is to stimulate a demonstration project in one or more metropolitan areas to implement a comprehensive approach to early identification and treatment of children with a wide range of developmental disorders (Nocks, 1971, p. 1).

The next logical steps, which are suggested in the other Boston Conference Proceedings, will have to be accomplished at the local and regional level. It is intended that this state-of-the-art monograph serve as a point of departure and reference.

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Developmental Domain	Page 1	Test or Procedure*	Developer(s) Author(s)	Age Range ²	Reliability	Validity	Time ⁵	Cost per Child ⁶	Administration ⁷	Recommended Stage ⁸	
PHYSICAL	30	Automated Multiphasic Health Testing Services	Collen & Cooper	Over 4 yr.	A ³	A	70	30 ⁵	Mix	Ter.	
	34	Biochemistry & Cytogenetics	Guthrie	B-3 mo.	A	A	u ⁴	<1	LT & EE	Sec.	
	38	Amniocentesis	O'Brien	C-B	A	A	60	20	P	Sec.	
	40	Metabolic	Howell, Holtzman & Thomas	B-3 mo.	A	A	<30	2	LT & EE	Sec.	
	41	Ultra-Micro Automated System	Ambrose	B-3 mo.	A	A	60	1	Mix	Sec.	
	42	Nutritional Status	Fomon	B-30 mo.	A	U	20	1	PP	Sec.	
	44	Gestational Age	Iubchenco	B-1 mo.	A	A	5	2	PP	Sec.	
	49	Statistical Mortality Morbidity	MCH	B-12 mo.	A	A	Neg ⁹	Neg	P	Pre-Pri	
	51	Statistical Epidemiology	Tarjan, et al.	Pre-B	A	A	Neg	Neg	P	Pre-Pri	
	55	Data System	Scurletis, et al.	Pre-B	A	A	Neg	Neg	PP	Pri	
	57	Prevention	de la Cruz & LaVeck	Pre-C	U ⁴	U	U	U	P	Pri & Pre-Pri	
	58	Apgar Rating	Apgar	B	A	A	6	1	P	Pri	
	59	Vision	Press & Austin	Over 30 mo.	U	U	Neg	1	PP	Pri	
	61	Eye Screening	Barker & Hayes	B-5 yr.	U	U	Neg	>1	PP	Pri	
	62	Electro-Oculograph	Petre-Quadens	1-6 yr.	A	U	120	10	LT & EE	Ter.	
	64	Hearing High-Risk Register	Hardy	C-3 yr.	A	U	Neg	Neg	PP	Pri	
	67	Hearing Screening	Young, Downs & Silver	9-12 mo.	A	A	5	2	PP	Pri	
	71	Potential Battered Children	Kempe & Helfer; Walworth & Metz; Gil	C-2 yr.	U	U	U	U	P	Sec.	
	73	Vocalization Analysis	Filippini & Rousey	B-12 mo.	U	U	40	20	PP	Sec.	
	75	Behavioral & Neurological Assessment Scale (1)	Brazelton	B-3 yr.	A	U	40	30	P	Ter.	
	75	Neuro-Developmental Observation	Ozer & Richardson	Over 5 yr.	U	U	20	15	PP	Sec.	
	INTELLECTUAL/COGNITIVE	80	Attention to Discrepancy	Kagan	B-12 mo.	A	U	30	20	LT, EE	Ter.
		83	Ordinal Scales of Cognitive Dev.	Uzgiris & Hunt	B-3 yr.	U	U	60	30	PP	Sec.
		86	Infant Intelligence Scale (CIIS)	Cattell	B-30 mo.	A	A	25	15	P	Sec.
		86	Bayley Scale of Infant Dev.	Bayley	B-30 mo.	A	A	45	25	P	Sec.
88		Kuhlmann-Binet Infant Scale	Kuhlmann	B-30 mo.	A	A	30	15	P	Sec.	
88		Griffiths Mental Dev. Scale	Griffiths	B-4 yr.	A	A	30	15	P	Sec.	
89		Gesell Developmental Scale (Revised Yale)	Gesell, et al.	B-5 yr.	A	A	40	30	P	Sec.	
92		Ivanov-Smolensky	Luria	B-24 mo.	A	U	20	15	LT	Ter.	
93		Habituation	Lewis, et al.	B-13 mo.	A	A	30	15	PP	Sec.	
93		Psychophysiological	Crowell	B-3 mo.	A	A	80	50	Mix	Ter.	
LANGUAGE	98	Playtest	Friedlander	3-12 mo.	A	A	50	25	LT; EE	Ter.	
	99	Infant Cry Analysis	Ostwald, et al.	B-3 mo.	A	U	30	15	LT; EE	Tcr.	
	104	Expressive Language	Reyes, et al.	2-4 yr.	A	A	40	20	PP	Sec.	
	108	Receptive Language	Marmor	1-3 yr.	A	U	30	15	PP	Sec.	
	108	Early Language Assessment Scale	Honig & Caldwell	3-48 mo.	A	U	30	15	PP	Sec.	
SOCIAL/EMOTIONAL	114	Behavioral & Neurological Assessment Scale (II)	Brazelton, et al.	B-3 yr.	A	U	30	15	PP	Sec.	
	114	Behavior Problem Checklist	Quay & Peterson	B-4 yr.	U	U	30	20	P	Sec.	
	116	Rimland Diagnostic Check List	Albert & Davis	B-4 yr.	U	U	30	20	P	Sec.	
	116	Behavior Checklist	Ogilvie & Shapiro	3-6 yrs.	A	U	45	30	P	Sec.	
	117	Quantitative Analysis of Tasks	White & Kaban	1-6 yrs.	A	A	60	30	PP	Sec.	
	118	Behavior Management Observation Scales	Terdal, et al.	B-4 yr.	U	U	60	20	PP	Sec.	
	118	Vineland Soc. Maturity Scale	Doll	B-18 yr.	A	A	25	10	PP	Pri/Sec.	
	118	Preschool Attainment Record	Doll	B-7 yr.	A	U	30	15	PP	Pri/Sec.	
	119	Behavioral Categorical System	DeMyer & Churchill	2-5 yr.	A	U	30	20	P	Sec.	
COMPREHENSIVE SYSTEMS	125	Psychological Assessment: Functional Analysis	Bijou & Peterson	B-Adult	A	A	U	U	P or PP	Ter.	
	128	First Identification of Neonatal Disabilities (FIND)	Wulkan	B-12 mo.	U	U	U	U	U	All	
	128	System of Comprehensive Health Care Screening & Service	Scurletis & Headrick	C-4 yr.	A	U	U	U	Mix	All	
	132	Preschool Multiphasic Program	Belleville & Green	B-4 yr.	A	A	U	U	Mix	All	
	136	Pluralistic Assessment Project	Mercer	5-11 Yr.	U	U	U	U	U	Sec.	
	140	Pediatric Multiphasic Program	Allen & Shinefield	Over 4-yr	A	A	120	30	Mix	All	
	143	Rapid Developmental Screening Checklist	Giannini, et al.	B-5 yr.	A	A	5	1	PP; P	Pri	
	143	Guide to Normal Milestones of Development	Haynes	B-3 yr.	A	A	15	5	PP; P	Pri	
	150	Developmental Screen. Inventory	Knobloch, et al.	5-18 mo.	A	A	20	10	PP; P	Pri	
	153	CCD Develop. Progress Scale	Boyd	B-8 yr.	A	A	30	15	PP	Pri	
	156	Denver Develop. Screening Test	Frankenburg & Dodds	B-6 yr.	A	A	30	15	PP	Pri	
	16	At Risk Register	Albernan & Goldstein, Sheridan; Oppe; Walker	Pre-C	A	A	Neg	Neg	PP;LT	Pre-Pri	
	19	Risk Factors (Kauai Study)	Werner, Bierman & French	Pre-C to 12 Yr.	A	A	Neg	Neg	PP	Pre-Pri	

NOTES: 1. Number of first page discussing topic in Screening and Assessment of Young Children at Developmental Risk (by Meier, J.H., Wash., D.C., Gov't. Printing Office, 1973).

- C=Conception; B=Birth.
- A=Adequate, i.e., >.75, when reported or estimated (only concurrent and face validity - not predictive).
- U=Unknown - in any category indicates that data are either unavailable, too variable, or sparse.
- Minutes required for administration and interpretation - estimated average with normally developing child.
- Estimated total in dollars including time and materials under optimum conditions.
- P=Professional trained to administer test(s); PP=ParaProfessional, properly trained; LT=Laboratory Technician; EE=Elaborate Equipment (in laboratory and usually not portable); Mix=Combination of preceding. A trained professional is required to interpret test results.
- Recommended Stage in Screening System - Pri=Primary; Sec.=Secondary; Ter.=Tertiary; Pre=Before.
- Neg.=Negligible amount of time or cost per child.

*When supporting data for this index are not found in monograph¹, consult References, pp. 175 ff.

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