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ABSTRACT

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Six papers discuss some of the current issues in the field of mental retardation and human development. Epidemiology of mental retardation from a sociological and clinical point of view is analyzed by Jane R. Mercer, based on studies of mental retardation in the community in Pomona, California. The role of genetics and intra-uterine diagnosis of genetic disorders in relation to mental retardation is discussed by Henry Nadler. William K. Frankenburg reviews the importance of early identification of developmental problems, essential characteristics of screening tests, and some available developmental screening tests, particularly the Denver Developmental Screening Test. Ira J. Gordon considers the effects of early educational intervention programs on early development, focusing upon the family as a target and upon programs that are research programs rather than service efforts without research or evaluation. New directions in reformulation efforts of teacher education are outlined by Nicholas J. Anastasiow. Louis Z. Cooper discusses rubella in terms of developmental problems and family health services. (KW)



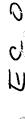
# Current Issues in Menta! Retardation

Selected Papers from
The 1970 Staff Development Conferences of
The President's Committee on Mental Retardation



The President's Committee on Mental Retardation

Washington, D.C. 20201



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# CURRENT ISSUES

# IN MENTAL RETARDATION AND HUMAN DEVELOPMENT

Selected Papers

from

THE 1970 STAFF DEVELOPMENT CONFERENCES

of

THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

Edited by Donald J. Stedman

U.S. DEPARTMENT OF HEALTH. EDUCATION

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The 1970 Staff Development Conferences of
The President's Committee on Mental Retardation

#### INTRODUCTION

In the spring of 1969, this Editor was asked by the President's Committee to develop and implement a plan to provide for the further professional in-service training of the PCMR staff and other key staffers in federal agencies concerned with mental retardation. New developments in research laboratories, service programs, training activities and other areas made it necessary, PCMR felt, to renew and update administrators of important MR programs. The staff personnel needed renewal. Subsequent interviews with staff members confirmed this need.

The first task was selecting a method of developing and holding inservice training sessions for busy and talented people.

From the scart it seemed important that the climate for the training program be informal but businesslike. The topics had to be front-edge stuff presented by highly skilled but articulate and interesting people. Time was necessary for interchange with "experts" as well as colleagues in other agencies; some of this time in private where "stupid" questions could be asked or notions validated. The retreat-conference style was chosen but with one fundamental difference--it ran on a predictable and orderly schedule. Superb presentations, permissive interaction, forums, private discussions, organized competitive recreation, good food, serious discussions, equality and informality pervaded the three conferences held. They were a success on three counts: (1) they were overwhelmingly applauded in private evaluation letters afterwards by meeting-weary and somtimes hyper-critical bureaucrats, (2) all of the "experts" presenting proclaimed a personal-professional gair from interaction with participants (a surprise bonus), and (3) the knowledge dicrease was evident from reports of participants in their later work. An additional, relatively unmeasurable, but frequently reported outcome was a significant increase in the quality and quantity of communications between participants and their agencies with other participants and their agencies. This was perhaps predictable since it is widely known that an increase in social linkage between systems increases business-professional interactions within and between those systems.



The first session was held at the Capitol Hill Hotel in Washington, a short walk from HEW buildings and in close view of the PCMR, the second at the Belmont Conference Center near Baltimore, and the third at Airlie House near Warrenton, Virginia. Each conference was better than the previous one. One more conference would have over-saturated the group.

The topics and presenters were carefully chosen. The primary responsibility for these choices was mine. For better or for worse, the decision on such things, as with a university investment counselor, should remain with one person who "knows the field." A committee will yield to the sage of the group and prevent the construction of an orderly mix of talent and participant group. It's a gamble but it can pay off. Special thanks that this one did go to Fran Lynch, now head of the Developmental Disability Division in RSA.

Certainly, prime topics and great presenters were left for future series. We missed nutrition, human behavior ecology, rehabilitation, the "new" special education, psychopharmacology, law and ethics, and many more. That's the "beauty" of working in the MR field--it provides for a rich confluence of disciplines and bright people, working together to solve a complex problem.

What follows now is a summary of six presentations, in a new sequence, and with some permitted but necessary editorial work to make the papers seem less informal than they really were.

Donald J. Stedman Nashville, Tennessee

May, 1971



The Epidemiology of Mental Retardation in an American City

#### Jane R. Mercer

The studies of mental retardation in the community which we have been conducting at the Socio-Behavioral Laboratory at Pacific State Hospital in Pomona began with an investigation of the families of hospitalized mental retardates. In the initial study, we were interested in determining what characteristics differentiate families who re-accept their mentally retarded children after a period of hospitalization from families who do not. Two groups of families were studied. One group had withdrawn their mental retardates from the hospital and taken them home to live in the community. The second group of families was selected by choosing, from the hospital population, patients who matched those re-accepted by their families in age, sex, ethnic group, length of hospitalization, and IQ.

As we interviewed the parents in this initial study, we became increasingly aware of the differential perceptions of mental retardation which exist in the community. We found, for example, that the families who had taken their children home from the hospital were significantly more likely to be lower-status families. A middle-class family rarely took a child home once he had been institutionalized.

We asked each parent the following question: "We know that a lot of people have told you that .... is retarded, but we would like to know what you think. Do you believe that he/she is retarded?" We frequently found that lower-class parents, with a great sigh of relief, would say, "Nobody ever asked my opinion before, but we never really felt that .... was retarded. We felt that .... was the problem, but not mental retardation."

I remember one response in particular. A Mexican-American mother with a 22-year-old son replied, "There is nothing wrong with Benny. He just can't read or write." She had migrated from Mexico. She could not read or write in English. She was not sure what had happened while Benny was gone but believed that he had had a job at the state hospital, working in the kitchen. She wanted to know if I could get his job back for him because he was having trouble finding work.

We also found that there were different routes into the hospital. A child from a lower-class family was more likely to have been placed by a governmental agency, over his parents' protests, while a middle-class child was more likely to have been placed by his family after a family decision. Such placements tended to be permanent, while the lower-class child was more likely to return to the community.



Many of the persons in that study were in their early twenties. Among those who had been released from the hospital, we found some who had jobs, were married, and had children. We had to be careful in our interviewing to avoid revealing their former hospital status to associates who were not aware of their past. Their matched, mainly middle-class, counterparts were still in the hospital.

We asked each parent what he saw in the future for his child and found very significant differences between the two groups. The lower-class parent was very likely to be surprised at the question. "Well, he will probably get a job, get married like everyone does. What do you expect? He will grow up." The middle-class samily was likely to reply, "He will probably spend the rest of his life in the hospital." If they had their child at home, they usually expected him to continue to be dependent on the family. Differential social definitions seemed to be related to differential outcomes and social system definitions appeared more complex than clinical definitions.

The Riverside Project, which followed this initial family study, was visualized as the first comprehensive community epidemiology of mental retardation to be done in the United States. The purpose of the project was to study one fairly large American city and attempt to secure an overall view of mental retardation in that community from both a traditional clinical perspective and a sociological perspective. The community chosen was Riverside, a city with a population of 100,000, about 50 miles east of Los Angeles.

Riverside was chosen because it is a self-contained community, not a suburb of Los Angeles. People who live there work there. It has an upper class that goes back to early settlement days as well as a middle and lower class. The population is about 8% Negro and 13% Mexican-American. Thus, it has a relatively complete social structure. In addition, Riverside has a large enough population to produce a sizeable number of retardates for study but small enough so that a field survey could develop a comprehensive picture of the social and clinical characteristics of its population.

I do not have time today to discuss the intricacies of the field-work, but we have been collecting data for about seven years and we have now gathered quite a bit of follow-up data in addition to the original cross-sectional study. Today, I will discuss a few of the findings from the large original study which are most relevant to national policy. There will not be time to talk about the various follow-up studies.

The original project was conceptualized as a clinical epidemiology in the traditional medical sense. We planned to locate persons with the symptoms of mental retardation, count them, see who they were and where they lived, and calculate prevalence rates for various subpopulations of the community. We used two approaches to case finding.



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First, we did a field study in which we screened all members of a representative sample of the households in the community. Secondly, we did an organizational study in which we asked all the major organizations in the community to give us information about mental retardates whom they were serving. Most community studies of mental retardation in the United States have been organizational studies. There have been a few field surveys. We decided to do both.

We found that, conceptually, we had to handle each aspect of the study separately. As a result, we have 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. All of the discussions at this conference today have been from a clinical perspective.

There are two models of "normal" which are used simultaneously in the clinical perspective. The one definition of "normal" is based on a pathological, disease model which comes from the field of medicine. This model posits that mental retardation is a biological dysfunction typified by particular symptoms. If a person has the symptoms, 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 Social System Epidemiology

For the organizational study, we operated from a sociological perspective and defined mental retardation, not as a handicap nor as a disability, but as a social status and a role that a person plays in the community. Persons holding the status of mental retardate in one or more of the social systems of the community are the labeled retardates.

The notion of a social system is a basic conceptual tool which sociologists use in thinking about society. For example, we can describe this conference as a social system in which people hold different positions. Some people hold the status of speakers or as representatives of different governmental agencies. At the moment, we are occupying different positions in relation to each other in this social system. Right now, I happen to be occupying the status of speaker. My role is to explain to you what I have been thinking and doing these last four or five years. You are occupying the status and playing the role of audience. On another occasion you may be up here speaking and I may be holding the status of audience.



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From a social system perspective, mental retardation is defined as an achieved social status, a social position which a person can achieve just as surely as a person can achieve the status of teacher or of social worker. Thus, we can describe how a person becomes mentally retarded just as we can describe how a person becomes a teacher. If we regard mental retardation in this way, we can ask, "How does a person become mentally retarded in the community? How does he get labeled by other people as a mental retardate?"

We went to over 240 agencies in Riverside and asked them to give us the names of every individual whom they knew who was mentally retarded and to share with us whatever information they had about them. The first question each organization asked was always, "What do you mean by mental retardation?" Our answer was always the same, "We are studying the meaning of mental retardation and do not want to define it for you. We want to know what you mean by mental retardation. We would like you to use your professional judgment and whatever standards your agency uses and tell us who is mentally retarded." There were no refusals. Everyone was willing to use his professional judgment and tell us who was mentally retarded.

This process resulted in a list of 2500 names, with many duplications. In some instances, individuals were nominated 12 to 15 times. On the other hand, many persons were nominated by only one organization. When we sorted out the duplicates, our register of 2500 persons shrunk to approximately 1000 unduplicated cases. We divided this list of persons into two registers, persons nominated by clinical organizations and persons nominated by nonclinical organizations. Clinical organizations are those which have either medical doctors or psychologists on their staffs to diagnose and identify mental retardates. Such persons are the "legitimate labelers" in the community. They have the legal right to diagnose mental retardation. It is the clinical register which I will be discussing today.

We compared the age distribution of persons on the clinical register with the age distribution of the population of the community. We found a large overrepresentation of school-age persons, some underrepresentation of preschool children, and a large underrepresentation of persons past school age. If we assume that mental retardation is a chronic illness, this kind of age curve is hard to explain. It could be argued that it is difficult to identify preschool retardates who are not yet mature enough for their disabilities to be apparent, but what happens to persons over 20? Do they die? Do they all move out of town?

In our follow-up studies, we were able to locate most of the persons on the clinical case register four years later. We found that many retardates who had been labeled in the public schools had merged back into the community. By the time they were in their middle twenties, nobody was labeling them as retarded anymore. Was there any purpose in ever calling them retarded if as adults they disappear into the



community? Those persons who remained labeled as adults had significantly lower IQs and significantly more physical disabilities than the rest of the labeled population.

Another variable which we investigated was socioeconomic status. In working with agency records, we found that one piece of information that we were always able to secure for everybody was an address. With an individual's address, we could identify the census block on which his residence was located. Using census statistics, we could determine the median value of housing on each block and place an individual in the proper housing value decile as a measure of his socioeconomic status.

There was a great overrepresentation of persons on the clinical case register from the lowest four housing-value deciles and a significant underrepresentation of persons from the top six deciles when the distribution of socioeconomic status on the register was compared to the distribution of socioeconomic status in the community. There were significantly more people from low socioeconomic circumstances being labeled as retarded by various agencies in the community.

There were also significantly more persons from ethnic minority groups being labeled as mentally retarded. Although 80% of the general population of Riverside are English-speaking Caucasians, hereafter called Anglos, only 53% of the labeled retardates on the clinical register were Anglos. While the community was 10% Mexican-American, 32% of the labeled retardates were Mexican-Americans, three times as many as would be expected from their percentage in the population of the community. Seven percent of the community population was Negro, but 22% of the labeled retardates were Negro, three times as many as would be expected.

Most Mexican-Americans and Negroes in Riverside are from low socioeconomic levels. Therefore, these disproportions in labeling could be the result of the generally low socioeconomic status of minority groups. We controlled for socioeconomic status by comparing only those persons who were in the lowest three deciles with each other. Fifty-three percent of the low-status community population were Anglos but only 19% of the low-status persons on the clinical register were Anglos, a large underrepresentation even when socioeconomic status was controlled. On the other hand, 29% of the low-status persons in the community were Mexican-American but 61% of the low-status, labeled retardates were of Mexican-American heritage, a large overrepresentation. When socioeconomic status was controlled, Negro disproportions disappeared. Approximately 18% of the low-status population of the community were Negro and 17% of the low-status retardates were Negro. This finding was consistent throughout the study and appeared in the field survey as well as in the agency survey. Controlling for socioeconomic status tended to eliminate disproportions for the Negro population. Such controls reduced but did not eliminate disproportions for the Mexican-American population.



In order to better understand the labeling process, we studied the characteristics of persons labeled as mental retardates by different types of community agencies. We grouped the formal organizations in the community into eight categories: public schools, law enforcement, public welfare-vocational rehabilitation, Department of Mental Hygiene, private organizations for the mentally retarded, private service organizations, medical facilities, and religious organizations. When we studied the age distributions of persons nominated by various agencies, we found that every agency in the community except public welfare~ vocational rehabilitation was nominating disproportionately more schoolage children and significantly fewer adults than would be expected. All agencies, except medical facilities, were also nominating disproportionately fewer preschool children. Medical facilities, however, were nominating many more preschool children than their proportion in the population. Thus, emphasis on school-age children was a general characteristic of labeling in most community organizations.

We studied the sociceconomic characteristics of persons being nominated by various organizations and found that public agencies, i.e., the public schools, law enforcement, public welfare-vocational rehabilitation, were the organizations which were nominating disproportionately large numbers of persons from low socioeconomic levels. Medical facilities, religious organizations, Department of Mental Hygiene, and private organizations were labeling retardates from all socioeconomic levels in approximately the same proportion as they appeared in the community. Therefore, we concluded that the socioeconomic disproportions characteristic of the clinical case register were primarily the result of nominations from public agencies.

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.

We were interested in the level of the norms used by various agencies in defining mental retardation, and looked at the average IQ of persons nominated as retardates by different formal organizations in the community. Law enforcement agencies and the public schools had the largest percentage of their nominees with IQs about 70, 53.5% and 46.1%, respectively. The average IQ for persons nominated by law enforcement agencies was 70.3 and that for the public schools was 67.4. At the other extreme, private organizations for the mentally retarded nominated only 14.3% with IQs above 70 and the Department of Mental Hygiene nominated only 11.5% with IQs above 70. A similar pattern emerged for physical disabilities. Again, law enforcement and the public schools nominated more persons with no reported physical disabilities than any other agencies, 70.8% and 62.0%, respectively. At the other extreme, only 25% of those nominated by private organizations



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for the mentally retarded, 16.3% of those nominated by medical facilities, and 10.9% of those nominated by the Department of Mental Hygiene, were without reported disabilities. We concluded that law enforcement agencies and the public schools have the most stringent norms and were nominating less clinically deviant persons than other community agencies.

We concluded our study of community agencies by analyzing the organizational network linking these eight groups of agencies to each other. This analysis revealed that the public schools clearly hold a commanding position in the community constellation. They nominated the most persons as mental retardates and had significant overlapping cases with six other types of agencies. Because of the centrality of the public schools in the labeling process in the community, we decided to do an indepth analysis of how a student achieves the status of mental retardate in the public schools.

For this purpose, we studied the characteristics of all of the children referred to the Pupil Personnel Department of the Riverside Unified School District during one school year, over 1200 children. We followed them through the various stages in the labeling process and found that there are eight clearly defined stages. After a child enrolls in the public schools, he is usually assigned the status of a "normal" student in the classroom. This is an ascribed role to which a child is automatically assigned if he does not have visible physical handicaps. Usually the next step in achieving the status of retardate in the public school is for the child to fail a grade, that is, he achieves the status of a "retained student." Over 70% of the children eventually placed in classes for the mentally retarded had failed at least one grade prior to placement.

If, after being retained, a child is still not meeting the expectations of the teacher, she is faced with the problem of deciding whether to give him a "social promotion," and thus keep him in the regular class, or to discuss the matter with the principal. If she takes the matter to the principal, the child moves to Stage 4 in the labeling process. He becomes an "academic problem." At this juncture, if the teacher and principal decide that he is a "reading problem," "speech problem," or "underachiever" he may retain his status as a "normal student" in the regular classroom. However, if they decide he is a "case to be evaluated," he will then be sent to the school psychologist for diagnosis and move to Stage 5 in the labeling process.

There are several ways in which a child may still escape being labeled, even if he is referred for psychological testing and evaluation. School psychologists, who do not have time to give individual intelligence tests to all children referred to them, must decide which children to test. If a child is not tested, he cannot be labeled a retardate.

We found that there were no ethnic or socioeconomic biases in the labeling process up through the selection for testing. That is, lower status children and children from ethnic-minority backgrounds were not referred or tested in disproportionately large numbers. However, at



the point when the IQ test was administered, sociocultural factors became important. Significantly more lower-status children and children from ethnic minorities scored below 80 on the IQ test. From this stage in the labeling process onward the disproportions characteristic of the clinical case register emerged. Significantly more children from low-status homes and ethnic-minority backgrounds failed the IQ test, were recommended for placement, and were ultimately placed in the status of retardate than would be expected from their proportion in the population.

# The Clinical Epidemiology and Field Survey

In the other aspect of our study, the clinical epidemiology and field survey, we selected a representative sample of 3000 housing units from the community, approximately 10% of the population. We screened all persons in each housing unit under the age of 50 for possible mental retardation, approximately 7000 persons. For purposes of the field survey, we defined mental retardation using the definition of the American Association on Mental Deficiency. A mental retardate was defined as an individual who is subnormal in intellectual performance and adaptive behavior when compared to his age peers. These deficiencies might be related to biological abnormalities, but evidence of organic involvement was not mandatory to an evaluation as a mental retardate. Intellectual subnormality was operationalized by using the Stanford-Binet LM for older children and adults and the Kuhlmann-Binet for young children.

There are no standardized measures of adaptive behavior which are applicable to the general population of the community. Therefore, we developed a series of 28, age-graded, scales for this purpose. The Adaptive Behavior Scales for young children contain many items modified from the work of Gesell and Doll. The scales for school-age children and adults consist of a series of questions concerning social role performance.

Physical disabilities were rated on the basis of responses to questions about visible organic abnormalities with which the respondent, usually the mother, would be familiar and which she would be able to report, i.e., ambulation, vision, hearing, presence of seizures, selfhelp, and so forth.

From these three operations, we generated an eight-fold typology for screening the population in the field epidemiology. Table 1 depicts typology.

Type 1 mental retardates are those who fail all three scales, they are the physically disabled mental retardates. Type 2 mental retardates are those who fail both the intellectual dimension and adaptive behavior, but do not have serious physical disabilities. They are the nondisabled mental retardates.



"Normal" Population

Table 1
Typology of Mental Retardation

		• • •		
	Failure Mandatory for a Diagnosis of Mental Retardation		Failure Optional for a Diagnosis of Mental Retardation	Clinical Types (Hypothesized)
Type	Intellectual Performance	Adaptive Behavior	Physical Disability	
Menta	<u>l Retardates</u>			
1	Fail	Fail	Fail	Severely & Profoundly Retarded - TMR
2	Fail	Fail	Pass	Moderately & Borderline Retarded "Familial & Undifferen- tiated" - EMR
One-D	imensional Retar	dates		
Qua	si-Retarded			
3	Fail	Pass	Fail	Theoretical Type - No Cases Anticipated in Epidemiology
4	Fail	Pass	Pass	Persons not Socialized to American Middle-Class Skills, Knowledge, & Motivational Patterns
Emo	tionally Maladju	sted		
5	Pass	Fai1	Fail	The "Physically Disabled who are also "Physically Handicapped"
6	Pass	Fail	Pass	Emotionally Maladjusted
Nonre	etarded - "Norma	s"		
7	Pass	Pass	Fail	The "Physically Disabled who are not "Physically Handicapped"



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Pass

Pass

Pass

You will note on Table 1, that a two-dimensional definition of mental retardation generates a new type of individual not identified in one-dimensional taxonomies, those who fail the intellectual dimension but pass adaptive behavior. Under a two-dimensional definition, such persons are not mentally retarded but would be labeled as mental retardates under a one-dimensional typology. We have called them the quasi-retardates.

A third group in the typology consists of those who pass the IQ test but fail adaptive behavior. We hypothesized that this group would consist of emotionally maladjusted persons. However, this category is not of central importance in the epidemiology and I will not discuss them further at this time. Types 7 and 8 consist of persons who pass both the IQ test and adaptive behavior. They are the "normals."

There were two phases to the field survey. In the initial interview, phase one, all members of each housing unit were screened using the Adaptive Dehavior and Physical Disability Scales. Usually one respondent answered for all members of each household. In most cases, the respondent was the spouse of the head of household who answered questions for those individuals in the housing unit to whom she was related. Unrelated individuals were individually interviewed.

In phase two, a subsample of the phase one sample was selected for intelligence testing. This subsample was designed to select a disproportionately large number of those persons in the population who have a high risk of having the clinical symptoms of mental retardation.

We analyzed the data using three different cutoff points for subnormality: the AAMD cutoff which defines anyone more than one standard deviation below the mean for the population as subnormal; the educational criterion which defines anyone with an IQ of 79 or below as subnormal; and the traditional criterion which defines the lowest 3% as subnormal. We found that, regardless of the cutoff used for defining subnormal, disproportionately more low-status persons and persons from ethnic minority backgrounds were identified as clinically retarded. When socioeconomic status was held constant, the disproportions for Negroes tended to disappear. Disproportions were reduced, but not eliminated, for Mexican-Americans.

When we compared the characteristics of the mentally retarded (Type 1 and 2) with the quasi-retarded (Type 3 and 4), we found that the clinically retarded came from significantly lower socioeconomic levels; had parents with significantly less education; were more likely to come from families in which the head of household was divorced, separated, or widowed; and were more likely to live in deteriorated housing. On the other hand, the quasi-retarded were more likely to come from homes in which English was spoken all the time and in which the head of household was born in the South. We found that the quasi-retarded were more likely to be Mexican-American and Negro than the clinically retarded and that they were significantly more likely to



be performing their educational, occupational, and family roles in a manner indistinguishable from the rest of the population. We concluded that a two-dimensional definition of mental retardation is a viable concept worthy of conceptualization because it does differentiate a group of persons who show adequate social competence even though they have low IQs.

Another question was addressed by the study. Does it make any difference which criterion level is used as the cutoff for subnormal-the traditional criterion of the lowest 3%; the educational criterion of the lowest 9%; or the AAMD criterion of the lowest 16%? We found that the issue is not important for middle- and upper-status Anglos. Their rates of clinical retardation were not materially increased by raising the cutoff level. However, rates for low-status Anglos, Mexican-Americans, and Negroes were greatly inflated when the higher criteria were used.

We also found that rates of clinical retardation based on the traditional criterion were closely approximated rates from other major epidemiologic studies of mental retardation than did rates based on the educational or AAMD criteria. The traditional criterion also most closely approximates the actual rate of labeling in the community of Riverside as revealed in the clinical case register. Therefore, we concluded that there is a significantly higher level of diagnostic consensus among clinicians and researchers in the field of mental retardation when the traditional criterion is used than when either of the other cutoff levels is employed.

We looked at the actual social-role performance of adults screened in the field survey as "borderline retardates" and compared their performance to that of persons identified as clinical retardates at the traditional criterion level. We found that most of those adults who failed only the educational or AAMD criteria were filling the usual complement of marital, occupational, and community roles played by adults. Unlike those identified as clinically retarded under the traditional criterion, there was little in the role performance of the adult "borderline retardate" that would warrant calling him either subnormal or mentally deficient. Therefore, we concluded that the traditional criterion approximates the actual labeling practices of the community and produces more convergence between clinical and social system definitions of deviance. At this criterion level persons are least likely to be labeled as retarded who, as adults, will be able to fill a normal complement of social roles.

Another question addressed by the epidemiology was that of the relationship between sociocultural factors and clinical retardation. Both in the field survey and in the social system survey of community agencies, persons from ethnic minorities and lower socioeconomic levels were disproportionately represented among those identified as mentally retarded. Using a two-dimensional definition of retardation and adhering



to the traditional 3% cutoff level reduced these disproportions but did not completely eliminate them.

Using data for Mexican-Americans and Negroes in the field survey, we did a stepwise multiple regression in which IQ was used as the dependent variable and 18 sociocultural characteristics of the family were used as independent variables. It was possible to predict 37% of the variance in Mexican-American IQ scores from these sociocultural factors and 27% of the variance in Negro IQs. When a similar analysis was done for elementary school children in the Riverside Unified School District, 15% of the variance in Full Scale WISC IQs of 598 Mexican-American elementary school children could be accounted for by 17 sociocultural characteristics of their families. Nineteen percent of the variance in the Full Scale WISC IQs of 339 Negro children could be accounted for by sociocultural background characteristics.

Mexican-American elementary school children with higher IQs tended to come from less crowded homes and have mothers who expected them to have some education beyond high school. They had fathers who were reared in an urban environment (over 10,000 population) and had a ninth-grade education or more. They lived in a family which spoke English all or most of the time and was buying its home.

The primary variables for Negro children were similar to those found for Mexican-American children. Instead of overcrowding, the size of family emerged as the most important single variable for Negroes. Educational expectations for the child appeared as the second most significant variable after the common variance with size of family was taken into account. Marital status of the head, socioeconomic index score for the occupation of the head of household, and whether the family is buying or renting its home appeared in that order. Thus, the more a Negro child's family resembled the modal sociocultural configuration of the community, the higher the child's IQ on the WISC.

The five most predictive background characteristics in the multiple regression were used to form an index. Each child was given one point for each of his family background characteristics which were like the dominant society on the five primary sociocultural variables predicting Full Scale IQ for his group. Each Negro and Mexican-American elementary school child was assigned one of five groups according to the extent to which his family background conformed to the modal configuration for the total community of Riverside. The mean Full Scale IQ for that group of Mexican-American children whose families were most like the dominant cultural configuration was 104.4. The mean Full Scale IQ for the Negro children whose homes most resembled the modal cultural configuration of the community was 99.5. Differences between both means and the national norms for the test can be accounted for by chance.

On the other hand, those children in the group least like the sociocultural mode for the community had a mean IQ almost one standard deviation below the norms for the test. The 127 Mexican-American



children with 0 or 1 characteristic like the sociocultural mode had a mean Full Scale IQ of 84.5 and the 47 Negro children in that category had a mean Full Scale IQ of 82.7. The average child in this sociocultural group would qualify as a borderline retardate.

It is not possible in this presentation to explore all of the details or the ramirications of this study. However, the major conclusion reached was that pluralistic diagnostic procedures which take the sociocultural characteristics of the individual's background into account when evaluating the meaning of a particular IQ 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 which do not take sociocultural factors into account. The larger report, The Eligibles and the Labeled, presents the argument in much greater detail and makes some specific proposals for implementing such pluralistic procedures.

#### Editors note:

A new article on this topic was published in April, 1971 by Dr. Mercer in the <u>Peabody Journal of Education</u>, entitled "Sociocultural Factors in Labeling Mental Retardates." Reprints are available from Dr. Mercer or the <u>Journal</u> Editor, Peabody College, Nashville, Tennessee.



# Human Genetics and Intra-uterine Diagnosis

#### Henry Nadler

In the last decade, one of the major changes in investigations as well as active care in the area of mental retardation has been the appreciation of the role of genetics. There was a great deal of information as to the conceivable mode of inheritance for many genetic disorders which led to mental retardation, but the actual scope of this was not really appreciated until the last 10 or 15 years. There are a number of advances which have occurred in this period of time concerning intra-uterine diagnosis of genetic disorders.

The first step in terms of methodology was the development of human cytogenetics. Eleven years ago Dr. LeJeune was able to show that Down's syndrome or mongolism was caused by an extra chromosome. We have learned much about cytogenetics such as its relationship with mental retardation, fetal wastage. One in every 125 live births in the country now has a chromosomal abnormality which, in fact, in many instances will have some appreciable effect upon the ultimate life of this child.

The second thing that happened, again an older concept but one put into use more recently, was the concept of inborn errors of metabolism, biological defects which are single-gene defects in which the patient is unable to synthesize a particular enzyme or protein. The deficiency of this material in some ways, in most cases unknown, leads to a particular disorder. This concept was first proposed by Gerard almost 70 years ago. The number of disorders seems to double almost every 10 years.

A third advance, again an old technique recently applied, was the work of Dr. Lila, Dr. Freda, and others in developing amniocentesis, the procedure whereby a sample of amniotic fluid is withdrawn from the amniotic sac surrounding the baby. These investigators were able to show that the procedure could be accomplished with a great deal of safety to the mother and fetus late in pregnancy and, thus, a genetic disorder could be detected in utero. Not only could a diagnosis be made but the patient, i.e. the fetus, could be treated. Unfortunately, the only active intra-uterine treatment possible after diagnosis of a genetic disorder is the intra-uterine transfusion of blood to protect the baby from developing congestive heart failure. The baby must then be worked up to a stage where he can be delivered and able to compete with his environment, even at a premature level.

The vast majority of genetic disorders which lead to mental retardation (and also those that do not lead to mental retardation) do not have any successful form of therapy to significantly modify the natural history of the disease.



If we look at the whole group of chromosomal abnormalities or aberrations, there is no active treatment to prevent the mental retardation or multiple congenital malformations seen. Many metabolic disorders, such as Tay-Sachs disease, and a number of the degenerative neurological disorders, have no successful therapy. Some disorders, on the other hand, do, and we will spend some time with them later on, because they open up a different concept. An example of the latter is galactosemia, in which the substitution of a diet restricting galactose is frequently life-saving for the infant in the first few months of life.

We thought if a diagnosis of disorders could be made early in utero, we would have two conceivable options. (Both early diagnosis and early treatment are important in any period; but, they would be most important early in pregnancy or before conception, and we have no methods of doing either selectively before conception.) At the present time, the emphasis is placed on diagnosis of disorders in which there is no treatment, and the only option left to the parents is interruption of pregnancy. In the future, one hopefully will have the option of early diagnosis for treatment's sake, in which one could then treat the affected disorder in any number of ways and therefore prevent the morbidity of the particular disease.

About 1965 a number of groups in the country started doing amniocenteses. The person who I think was most responsible for taking a good look at the ability to do amniocentesis is Dr. Jacobson who, being an obstetrician, had an advantage of working daily with pregnant women. Also, practicing in Washington, D. C., he had the advantage of an extremely liberal abortion law. At the time, it might not have been very liberal, but it was liberally interpreted, and they were able to do a number of therapeutic abortions.

Within the uterus there is a sac in which the baby is held; circulating around the baby is a fluid which, in late pregnancy, partly consists of fetal urine. In many instances this fluid is an accurate reflection of what is going on in the fetus.

The first step in sampling the amniotic fluid is to separate it into a cellular fraction and a supernatant fluid fraction. The latter is the material which is used to detect Rh incompatability. Based on the change in optical density, which happens to be the amount of bilirubin in amniotic fluid, one can detect if the fetus is hemolyzing his red cells in utero and producing a great amount of bilirubin, and therefore might be at great risk.

Let us look at the adrenogenital syndrome. It is an autosomal recessive disorder, which means that both parents are carriers and they have a one in four chance of having a child with the particular disorder. In this instance there is a block of steroid synthesis in the adrenal gland, and the female children are born frequently with hypertrophy or enlargement of the clitoris. They may in error be



called boys. They may die in early infancy because they lose great amounts of salt. Sometimes they have a number of crises when they have lost salt and, as a result, later on they may be mentally retarded.

Diagnosis of this syndrome has been made late in pregnancy by Dr. S. B. Yeffcoate on the basis of finding abnormal amounts of steroid compounds in the ammiotic fluid supernatant fraction. These were normal substances found in ammiotic fluid, but found in much larger amounts than normally seen. Unfortunately they were only able to do this at the 39th week of pregnancy, and it required large volumes of ammiotic fluid, thus it had little potential usefulness. More recently, attempts to detect it early in pregnancy have been made without reliable results.

Despite the fact that diagnosis has not been reliably done, there has been more discussion of treatment of this potential disorder than any other in utero. The reason is that after birth one treats the children in a number of ways. One is to give cortisone, whereas another is to supplement salt and/or steriods which retain salt in the body. In this particular disorder people have proposed that if one were to make the diagnosis early in pregnancy, cortisone could be injected into the amniotic fluid or into the fetus, perhaps preventing the clitorial hypertrophy.

This rationale is not particularly good, because in utero the patient does all right, and other than the clitoral hypertrophy which can be surgically corrected, there does not appear to be any intrauterine damage. It would probably not be the best one with which to start.

More recently, a great deal of work has been done in looking at enzymes. There are some six or seven genetic disorders which can be detected simply by looking at the amniotic fluid supernatant to see whether an enzyme is present or absent. Perhaps the most exciting work going on here that will have some effect on mental retardation, a significant effect, is work which again was proposed a long time ago and is finally being carried out.

A number of years ago, Dr. Rabin of Wisconsin suggested that if one looked at lipid levels one might find free fatty acids and other compounds in ammiotic fluid by which prediction of the premature infant likely to develop respiratory distress syndrome would be possible. As most of you know, this is the single most common cause of death for the premature infant. There is a great deal of discussion in the literature about the effect of this anoxia on survivors. There are some suggestions that children who have had respiratory distress syndrome, small premature infants, are more likely to have choreoathetosis, and possible more likely to have mental retardation.



If one could accurately predict which children would develop this syndrome, it might help the obstetrician. Dr. Rabin, Dr. Nelson, and most recently Dr. Gluck in San Francisco suggested that during the development of the fetal lung there is production of a lipid-like material, surfactant, which might parallel the production of lipids in ammiotic fluid. If one obtains a sample of ammiotic fluid after 36 weeks and finds a particular compound, lecithin, present in large amounts, the fetus upon delivery as a newborn will not develop respiratory distress syndrome. If he has a deficiency or relative deficiency of lecithin, he will. This has proved very accurate in their hands but might not be so accurate in widespread use.

How is this information used? There are women who have diabetes, toxemia of pregnancy, or who have had one Caesarean section for one reason or another. Induction of delivery or the second Caesarean section should be performed at a time when a premature infant who has difficulty in survival will not be delivered. Up to now this time has not been possible to calculate.

In the case of the infant of the diabetic mother, one would like him to be old enough to avoid being a premature infant but not to stay in utero so long that he might die in the last couple of weeks of pregnancy. This is a difficult decision, and has always been an uncertainty.

In these cases, an ammiocentesis could be performed to determine the lecithin level in the ammiotic fluid. If normal levels are found, it would suggest that the child would not develop respiratory distress syndrome. Labor could be induced or the Ceasarean section be performed to deliver a baby who, although small, is not at risk for this complication of prematurity.

Attempts to segregate virus from the ammiotic fluid generally have been unrewarding. Recently a group in Toronto has suggested that they found particles in ammiotic fluid on electron microscopy, presumably in women who have had rubella, and that this represents rubella infection. This is unconfirmed.

Most of the work on intra-uterine diagnosis has taken advantage of the fact that the fetus at all stages of gestation sheds cells. He may shed them from his trachea; he may shed them from his skin; he may shed them from his bladder late in pregnancy. A number of things can be done with these cells. They can be used directly for cytology, directly for biochemical analyses, and there are now some 18 enzymes which can be detected directly after amniocentesis. Twelve are associated with inborn errors of metabolism, most causing retardation or death in early infancy. Most of the work which has been done is the cultivation of these cells, either for direct biochemical studies after they are grown, or for cytogenetic or chromosome analysis.



The optimal time for an amniocentosis is somewhere between 12 and 14 weeks. During this interval, the amount of amniotic fluid triples, and the removal of a large amount of amniotic fluid would be safer for the infant and subject him to less risk. Early diagnosis is important. If one detects a genetic disorder for which there is no treatment and the parents decide they would like to terminate the pregnancy, it must be early enough for therapeutic abortion to be performed. As you know, there are some state laws that suggest that abortions cannot be performed after 20 weeks; in others it is 24; in still others, 28. An early diagnosis, not only for legal reasons but also for the parents' sake, should be as early as possible.

The procedure is performed in the out-patient department of the hospital. Under local anesthetic a needle is placed through the abdomen into the uterus. It is similar to a spinal tap or sample of blood and is quite easy to do. The needle is placed into the uterus, the stylet removed—a small amount of ammiotic fluid is withdrawn. The woman stays there for about 15 or 20 minutes or so and then goes home.

There has been a good deal of discussion about amniocentesis, but not much information about the risks to the mother. Early diagnosis is of no use if the mother or the fetus is subjected to any appreciable risk. The original work done in this field was difficult to interpret. If one did an amniocentesis, what were the risks if the baby survived?

It is in the group of patients for whom ammiocentesis is used to determine the outcome of the pregnancy, the vast majority of whom will come to term and deliver babies, that we will be able to assess the risks to the fetus, and the risks to the mother. What are the potential risks? We can separate them into maternal and fetal.

The risk to the mother might be infection; this was a significant problem when ammiocentesis was first being done. Another risk is hemorrhage. A third would be a more subtle point: could you sensitize the mother because of blood group differences between the mother and baby? There is some suggestion that this might occur, certainly later in pregnancy and conceivably early in pregnancy.

The other main group of risks revolves around the fetus. First is spontaneous abortion because of the procedure. Second there is the chance of placing a needle into the fetus directly thus causing the child to be born with some abnormality. Another risk is congenital malformation. Could you increase this risk? This has concerned many people, but there is no great likelihood of it as amniocentesis is performed after the fetus has completed structural development.

There is another question, almost impossible to answer, which conderns the possibility of a subtle damage. Could the child lose five IQ points as a result of this procedure, or ten? I do not think this question will ever be answered.



What are the indications for amniocentesis? We are going to have to define which populations are at appreciably enough risk to warrant even a low risk of amniocentesis.

One group consists of chromosomal translocation carriers, women or men who have a chromosomal rearrangement themselves. They are, in general, normal yet they run a very significant risk of having a child with a particular chromosome abnormality. For this group the main risk is mongolism, Down's syndrome. For instance, a woman who is a D/G translocation carrier has a risk as high as one in three. Some estimates have suggested it could only be 20 percent. The point is, somewhere between 20 percent and 33 percent in each pregnancy is the risk of that baby having Down's syndroms.

A second group which we have elected to use to study is a population of women past the age of 40. If we consider both mongolism, with roughly one out of every 600 births in this country being a baby born with Down's syndrome or mongolism, and maternal age what do we find? We find that the woman aged 25 has a risk in the order of 1 in 2,000 of having a baby with mongolism. At age 35, the risk is 1 in 250. At age 40, her risk is 1 in 100, or 1 percent, and when she reaches age 45, it is 2 percent or one out of 50, for that chromosomal abnormality alone.

This tells us if we were to do ammiocentesis on all women past the age of 40, we could routinely expect to pick up about 2-plus percent of instances in which the fetus had a significant chromosomal abnormality for a disorder which would lead to significant mental retardation or multiple congenital malformations.

There is another group, women who have had a previous child with Down's syndrome, who have a recurrence risk somewhat greater than the general population but not an appreciable risk in terms of numbers. One might suggest that the usefulness of ammiocentesis is not to pick up the occasional child who is going to have trisomic Down's syndrome, but really for peace of mind for the mother who is going to be very much concerned during that pregnancy. Ammiocentesis in this case may assure her that she has a normal child.

One result obtained from amniocentesis is the determination of sex. Why is this important? There are a number of disorders inherited in an X-linked recessive fashion. If a woman with a one in four risk of having a baby with a particular disorder and the defect is carried on one of the X chromosomes of the mother, her risk is actually one in two for her sons and zero for her daughters. By determining the sex a diagnosis has not been made but precision of your counseling has been increased.

There are many X-linked and metabolic defects. How can you cope with this in terms of chromosomal aberrations in 1970? You can pick up those defects I call primary abnormalities in terms of numbers.



In that group is the little girl who has XO, i.e. is missing an X. In the vast overwhelming majority of cases essentially all of them will be of short stature, probably will have amenorrhea and not menstruate and not have children.

The Klinefelter male is presumably 1 percent of all institutionalized patients at state institutions for the retarded. He is an XXY male, or a variation of this.

All the abnormalities in chromosomes can be detected as well as Down's syndrome--characterized by an extra chromosome. Most of these are syndromes in which children die early. For example, 90 percent of the children with an extra D chromosome die by 3 weeks of life, and another chromosome abnormality causes death in 90 percent of the afflicted children by 6 months of age. Finally there are cases where parents are missing parts of chromosomes.

These women who are translocation carriers can be detected as women to be at risk. They could and should have management as of this time.

As to women past the age of 40, the limiting factor here is the number of centers set up at present to handle amniocentesis. It has been suggested that the age level be reduced to 35, when the risk curve first starts to go up. We have been reluctant to do this because of patient numbers, and the possible risks of amniocentesis.

- DR. FRANKENBURG: Have you found any triploid X's?
- DR. NADLER: Fortunately not.
- DR. FRANKENBURG: Why do you say "fortunately"?
- DR. NADLER: That would be a very difficult one to counsel because there are a wide variety. There are one or two who are retarded, and others who are perfectly normal, and so on.
- DR. FRANKENBURG: We have followed 15 or 20 patients with extra X chromosomes; there are four or five Klinefeller's, et cetera. We have followed them for three or four years, and they are all developing normally. There are some that are a little bit slow, but if you examine the environment of the child you can easily explain that.
- DR. JACOBSON: Of course, in this you see infertility and reproductive problems coming in. Many of us saw the triple X's while studying mothers. There is no question that they have a high proportion of abortion and infertility and other problems. Most intelligent parents ask of this situation not, "What will my child be like?" but, "What will my grandchildren be like?" That is why I think Dr. Nadler says this is a difficult situation in counseling.



DR. BELMONT: I am not clear what kind of criteria you use to manage for the vast majority, who tend to be of normal intelligence. What are the problems for the genetic counselor who is faced with the knowledge that there is a slim likelihood of that child's being retarded? How do you deal with the parents?

DR. NADLER: Counselors differ in philosophy, as do physicians in general. I belong to the school of information. That is, I define for the parents what is known, and I would describe for them what we do know about XXY.

We do know that there is an increased likelihood of mental retardation percentage-wise. This does not mean that many of the babies with XXY syndrome will not have normal intelligence. We do know that they are infertile. We do know that a significant percentage of them at puberty will develop gynecomastia (breast development) and will have to have breast surgery, not only for cosmetic reasons but for an increased incidence of carcinoma of the breast in these patients.

You are forced, just as a physician is at any time, I think to give them the information for the test you conduct, and then they will try to come to a decision. Sometimes it is an extremely difficult decision, especially when you are talking not about diagnosis after birth, but about diagnosis in utero.

DR. BELMONT: Do we have a frame of reference as to how parents make decisions in situations like this? I am asking if you are confusing the parent with the available information.

DR. NADLER: First of all, this is a biased population because generally when they come to you they have already made a decision. They are having an amniocentesis now because they are highly concerned and moderately certain that they are going to terminate the pregnancy if necessary. Apart from that, the question you have asked is the one a doctor faces every day in his practice: what is the proper kind and amount of information to transmit to parents? Sometimes what you transmit will depend on the ability of the parents to comprehend.

You do influence people as a counselor. You do influence them by simply saying the same things in slightly different ways: "You have a three out of four chance of having a perfectly normal child," or "You have a one in four chance of having a defective child." Both figures are identical. The inference of the two is different. So, the counselor does influence them. I share your concern, but I know of no better way than what I have been doing to inform people.

There are other defects. There are genetic disorders that are not primary chromosome abnormalities, such as Bloom's syndrome and Fanconi's anemia. These are disorders in which the patients frequently die in childhood. They usually have a high incidence of malignancies, usually lymphomas or leukemias. They have a higher incidence of immune defects, and also a high frequency of chromosomal breakage.



It was questioned whether I could make a diagnosis in utero for those disorders of chromosomal breakage, and I think the answer is no. We have seen chromosomal breaks in perfectly normal amniotic fluid, and have no idea what it is. We have seen, in the best example of chromosomal breaks and rearrangements that we have had, a woman who had rubella in the first trimester of pregnancy. She was terminating the pregnancy and we were sent the amniotic fluid. Upon examination of the cells and chromosomal breakage, many viral particles were detected. Finally, we have also seen chromosomal breakage in the fluid of a woman who was in a radiation accident. She walked into her husband's lab while he was working with isotopes, and there was an accident. She was at that time six weeks pregnant, and we were sent the fetus and amniotic fluid. Both the fetus and amniotic fluid cells had chromosomal breakage.

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What we have discussed so far are genetic problems, or problems resulting in congenital malformations or mental retardation on the basis of a chromosomal aberration. With chromosomal aberrations, the extra piece of chromosome, or the whole one, or the missing one has very drastic multiple effects upon the child. Most chromosomal abnormalities are not compatible with life; are found in abortion material early in pregnancy, and are, in essence, discarded.

What is to stop us from using early in utero diagnosis to initiate therapy? What is to stop us in the case of a galactose mic from developing a method to remove galactose from the environment of the fetus? The only thing that prevents us is our own ingenuity.

Perhaps the child with cystic fibrosis could be treated. Some are born with intestinal obstruction; if you can diagnose this, you may be able to take advantage of it. The fetus swallows. You can give medicine by giving it in the ammiotic fluid. You can give digitalis, which has been done in cases of heart failure. You know you have a drug that will clear out maconium, and you know that the fetus swallows, and perhaps he will swallow it and protect himself. On the other hand, you might find that maconium floating around in the ammiotic fluid is detrimental.

I think it is our own lack of ingenuity in ways of approaching disease at the present time which has precluded us from trying to actively treat the fetus during the period of time he is in utero. My own personal opinion again is that I think more happens to influence the normal life span of an individual in terms of significant events during these nine months in utero than at any other comparable period. And I will be very surprised if, when your President's Committee meets ten years from now, you do not have people sitting around and discussing the merits and problems of intra-uterine treatment of many disorders, not only genetic and metabolic, but infectious disease, etc.



I would like to discuss briefly other approaches to intra-uterine diagnosis. The obvious one is a direct visual approach to the fetus, and there are two ways of going about this. In this approach we are not so much looking for single-gene defects or chromosomal abnormalities but for so-called multi-facturial characteristics.

We are talking about a mother of a child with myelomeningocele and hydrocephalus, a woman who had a three in a thousand chance when she first became pregnant, but once she had had that child, she had a chance of three in a hundred. We are talking about the woman who has a baby with hydrocephalus alone, the woman who has had children with cleft lip and cleft palate, who are missing extremities, and so forth. If these could be detected early in utero, you might be able to treat it, or might again just have to provide this information and conceivably terminate the pregnancy.

There has now been made an instrument two millimeters in thickness which can be placed into the uterus. Pictures have been taken with direct visualization. It is difficult to move the fetus, and unfortunately it still requires a small hysterotomization. I am sure this will be improved very quickly. The problem again is safety and reliability.

Another approach is to take advantage of fetal development physiologically, and I think this has been a very positive feature of intrauterine diagnosis. In the last four years, I think we have learned more about normal fetal development in many parameters because of these studies.

DR. BERING: What about the couple having a difficult time conceiving or bringing a child to term? Have you done studies on this group?

DR. NADLER: We have done them on many women who have had spontaneous abortions but have not found anything. There are some women who are spontaneous aborters, who have a chromosomal abnormality which causes spontaneous abortions. For most spontaneous abortions we have no way of knowing whether it is environmental, maternal, or fetal factors which are responsible for that abortion.

MRS. GOODMAN: Have you made any investigation about the age of the father?

DR. NADLER: We do not mean to blame the mothers all the time. Unlike chromosomal abnormalities, there are some single-gene defects which increase with age of the father. The achondroplastic dwarf--whom you see in the circus or who wrestles on television--is a particular case which occurs more frequently with increasing paternal age.

DR. BEGAB: You indicated earlier it is unlikely we would ever reach a routine stage of ammiocentesis for pregnant women.



DR. NADLER: It is dependent upon the refinements.

DR. BEGAB: In terms of this last group that has been highlighted, the group over 40, let's say, where you are concerned with not only the higher incidence of mongolism but all sorts of abnormalities, wouldn't it be a desirable procedure to routinely apply to that high-risk group?

DR. NADLER: That is a very loaded question, because I obviously believe it would be.

I would caution you that only an obstetrician should do this test. The procedure, quite honestly, is very simple and anybody in this room with two minutes of training could do it.

However, there are two possible problems. First, in case of complications you would want somebody skilled to be available. It is the same as with delivering babies. You know most of you could deliver all the babies except for one or two percent when you really want someone who is skilled; that is why you go to an obstetrician.

The second reason is this: if the obstetrician does it, he is morally committed to do something about the result. Once an obstetrician commits himself to do the ammiocentesis—he may not realize it at the time—he finds he has a moral commitment to that patient, in the case of abnormality, because he has taken part in the management of it.

DR. FRANKENBURG: In response to the question of whether you should do this with all mothers over 40, I would say that I think it would be very important that we collect some data to determine the accuracy of the procedure, determine the risks and everything else involved, before implying to the public at large that this should be done.

DR. NADLER: As of 1970 the problems are that most laboratories or most places in the country do not have great expertise in handling either the procedure of ammiocentesis or the cultivation of cells, thus more inaccurate diagnoses can be expected. You can expect more complications of the procedure when it is done by them as opposed to when it is done by those who are skilled in it.

The population we work with is divided into two groups. All patients who come to Chicago are seen originally by me, where we take the usual genetic history. We will go through and make sure the people have the disease they are supposed to have—it is difficult to try to monitor for A when they had B. We try to have an accurate diagnosis of the disease, which may mean obstetrical records from the mother's obstetrician, pediatrician, and so on. They may have a child in an institution in California and we have to get records on the child. Then, we discuss with the family the natural history of the disease if they do not know it. We discuss with them the potential risks of this procedure, the potential risks of diagnosis, and we also discuss quite



openly what their feelings are about therapeutic abortion: "If you have a fetus detected in utero who is carrying an abnormality, what have you thought about doing?" If they do wish to have the test done in Chicago, they are sent to one obstetrician who does all the tests. He examines the woman and makes sure that she is of proper gestational size, and so on. Either I will see the child in the hospital after he is born, and appropriate biochemical tests will be done if needed, or they may bring the baby to the hospital for examination in the first few weeks of life and we will see him then. These examinations are all done by me.

In the case of patients from outside of Chicago, we get records from the obstetrician and are forced to rely on the evaluation of the pediatrician who has seen the infant in that period.

DR. LIPSITT: Has it ever occurred that a therapeutic abortion is contraindicated despite the fact that you judge the fetus to be at high risk and the mother wants the abortion?

DR. NADLER: We have found that situation in a woman who had rubella early in pregnancy. There is a positive advantage to having people with expertise see somebody before an abortion. It is not the easiest decision in the world to make, and there are some people who have competence in evaluating such a family.

There is a legal problem which exists with intra-uterine diagnosis. For example, the pregnancies that have been terminated in Illinois have been done legally, but really illegally. We have no abortion law in Illinois which has fetal abnormality or malformation as a condition, so a psychiatrist comes into the hospital, sees the woman, and they get around the law in this circuitous, ridiculous route, but she has her pregnancy terminated by a licensed physician in a licensed hospital.

I do not want to argue the pros and cons of abortion, they are not really relevant. As I said before, we are trying to provide a way in which accurate diagnosis can be made in the case of those people with risk factors. Then, if they wish to, they can take advantage of that diagnosis. We are not suggesting that this is a routine screening procedure; it cannot and will not be for a long period of time, if ever. There will undoubtedly be some people who will not wish to have their pregnancies terminated. This is an individual decision, and will continue to be.

Finally, I hope that what we have done--by "we" I mean all the people who have worked in these areas--is provide a method by which we can offer the opportunity to have children born who really have their optimal potentials intact. I think this is what it is all about.



# Developmental Screening of Preschool-aged Children

## William K. Frankenburg

Before launching into a discussion of early developmental screening, I think it would be important to review some theories of the development of intelligence, and then to offer an operational definition of mental retardation—so as to define what is being screened. Next we shall focus on the importance of early identification of developmental problems and the essential characteristics of screening tests. Available developmental screening tests will be discussed briefly in terms of these characteristics. With this as a setting we shall then discuss the Denver Developmental Screening Test (DDST).

# Theories of Development of Intelligence

One of the first theories of intelligence was the notion of "fixed" intelligence. This theory was prevalent prior to World War II. The theory originates in the days of Galton, who was a friend of Charles Darwin. Galton reported observing that in London most of the prominent people came from very few families. He therefore assumed that intelligence is inherited and therefore measurable with specific sensory tests.

Binet considered these tests to be too simple and too specific. He considered it more important to assess the overall intelligence of children. He defined intelligence as the faculty of judgment, and he felt that past experiences played a role in shaping judgment.

The next prevalent theory is best described as that of "predetermined development." The foremost individual expounding this theory was Dr. Arnold Gesell, a physician and psychologist. This theory is based on the notion of unlearned behavior. Gesell wrote about the progressive morphogenesis of patterns of behavior. He stated that infancy is a time when all individuals realize their inheritance. He interpreted intelligence as being an unfolding process which occurs more or less automatically. He also explained that one can't advance from one stage to the next unless one has gone through the previous stage. The present application of this theory is the treatment expounded by Doman and Delacato.

The third theory is that of interactionism. In this theory the fertilized ovum is in an adaptive process or interacts with its environment. The genes control the biochemical process of metabolism and the chemical conditions that surround the cell have a controlling effect upon how the genes are expressed. The genotype therefore provides a controlling directive and sets limits for the range of the phenotypic



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(expressed) variation. The environment may alter the direction within these genetic limits. The intelligence of a child is therefore an expression of his inheritance and his past experiences. Piaget has worked extensively in developing his own theory of interactionism. In his theory there are two basic processes. The first is that of assimilation, which is the incorporation and the utilization of stimuli from the environment. The second is that of accommodation or the fitting of unfamiliar experiences into the available organization and reshaping the organization in the light of new experiences.

# Definition of Mental Retardation

As you are aware, mental retardation, mental deficiency and mental subnormality are elusive terms because they represent a complex symptom with many different causes, many of which are not always understood.

The American Association on Mental Deficiency defines these terms as subaverage intellectual function which originates during the developmental period and is associated with impairment in adaptive behavior.

If one accepts the interactionist theory, it is readily apparent that not every individual who is retarded in later life can be identified at the time of birth. If one defines mental deficiency on the basis of the intelligence quotient, the poor are disadvantaged because they have not had the opportunities of the more affluent.

For purposes of this discussion, I have chosen to define mental retardation as subaverage intellectual development or impaired function in the adaptive process.

# Importance of Early Screening and Identification

When considering screening for mental deficiency it is important to consider the optimal age at which to begin screening. If one accepts the premise that mental development and intelligence is an ongoing process of interaction, one realizes that screening for mental deficiency is a continuous process much like the screening of growth retardation. The pertinent question to be asked is "What is the optimal age to begin the screening process?"

There is abundant evidence in support of the value of early identification of children with developmental problems. Some of this evidence is related to the theory of critical periods of development.

You have all heard discussions about rubella or German measles and its devastating effect upon the fetus if the mother contracts rubella during the first trimester of pregnancy. Other studies have demonstrated that permanent intellectual impairment can occur in children suffering from a protein deficiency. The most severe and long-lasting effects are associated with a deficiency occuring during the first four years of life.



Dr. Peter Chase at our medical center (Colorado) has undertaken a study of malnutrition in children. He compared the development of 19 children who had malnutrition with a group of 16 normal children. The development of the children suffering malnutrition was slightly delayed in comparison to the development of the controls.

Within the group of 19 malnourished children, there was a marked difference between the 10 children who were treated after four months of age and the 9 in whom the malnutrition was corrected prior to four months of age. The developmental quotient, which is an expression of rate of development, was 70 or borderline defective for those begun on treatment after four months; 95, which is normal, for those begun on treatment before four months; and 99, also normal, for the controls.

The controls in this study were selected by matching on age and social class. As you are aware, problems of malnutrition are complex because the socioeconomic factors responsible for malnutrition may also be responsible for impaired development. In South America, children who suffer from malnutrition have a higher incidence of illness and under-stimulation. Each of these factors is related to the other and thus has multiplying effects upon the child. For this reason, I believe that malnutrition must be studied by utilizing ecological methods. Whatever the interrelationship of these factors, it nevertheless is suggestive that the first four months may be the most critical postnatal months in the development of the child. In phenylketonuria (PKU), with rare exception, the children who are treated early have much more normal intelligence than the children who are diagnosed late. In our clinic we are following about 60 PKU children. All the PKU children born to untreated phenylketonuric mothers have suffered irrevers the brain damage and growth impairment prior to the time of birth. The PKU children treated prior to three months of age had a mean developmental and intelligence quotient of 86. The average DQ/IQ for children treated after three months of age was only 46. control subjects had the following average normal quotients: siblings, 103; mothers, 110; and the fathers, 109.

Treatment is necessary before three months of age to prevent deterioration of IQ, but cessation of treatment after four years of age is not associated with a deterioration of IQ. These data demonstrate three critical periods: the prenatal, the first three postnatal months, and the first four years of life. The data also demonstrate the interactionist theory in which the child's environment—in this case the body chemistry—may modify the child's phenotype (intelligence) and the body chemistry may be modified (through dietary treatment) to modify the child's eventual phenotype within certain genetic limitations.

Results of treatment of congenital cretenism (thyroid deficiency) also demonstrate a direct relationship between early onset of treatment with normal IQ, late onset with low IQ. Thyroid deficiency not manifesting itself until school age is not associated with a deterioration of intelligence.



One explanation for critical periods in the early prenatal and postnatal life of the child is probably associated with the growth of the brain. The rate of brain growth is most rapid at the times of the aforementioned critical periods.

The newborn baby has a brain that is already 40% of its adult size. In addition, it doubles its birth size by two years of age. By the time a child reaches four years of age the rate of brain growth has rapidly decele\_ated.

The rate of growth of other body organs follows markedly different patterns. Studies by Spitz, Bowlby, and Provence have demonstrated similar critical periods in relation to maternal deprivation.

Another reason for the early identification of children with developmental problems is that parental awareness of these problems may prevent subsequent emotional problems which may be produced by parental misunderstanding of a child. An example is the child who, due to lack of comprehension of what is asked of him, is assumed by his parents to be lazy or stubborn.

Though from the foregoing one might conclude that Parly identification of mental deficiency is important, prevalence rates of mental deficiency indicate a general failure in early identification. Goodman reported a study of a metropolitan area in which the incidence of retardation was one-half of one percent for children below five years of age. The rate was 2.2% at five years, 4% at six years, and 8% at 10 to 13 years. Studies by Scheerenberger in New York and the report of the Mental Deficiency Commission of London have also demonstrated a marked increase in the incidence of mental retardation at the age when children enter school.

The increased incidence among school-aged children is due in a large part to better case finding methods. Dr. Barbara Korsch demonstrated in a study that pediatricians in pediatric training and those having over five years of pediatric experience did not differ significantly in their ability to estimate the IQs of children. Furthermore they tended to overrate the intelligence of retarded children and to underrate the intelligence of handicapped children. It has also been my experience that the pediatrician's failure to use a reliable method of developmental assessment on a routine basis has led to the failure of identification of retarded children. If the pediatricians, who are supposed to be knowledgeable in growth and development of children, fail to identify these children, there is little likelihood that these children will be identified before they enter school.

There has been an increasing public awareness of the importance of early recognition of children with developmental problems. The President's Committee on Mental Retardation has noted that early case finding should be one of ten top priorities in mental retardation. The Academy of Pediatrics in its Standards of Health Care of 1968 published



recommendations regarding the screening of children for developmental problems. Standards set for health programs such as Headstart, Children and Youth Projects, and Maternal and Infant Care Projects all call for screening children for developmental problems. The 1968 amendment to the Social Security Act also calls for early screening of children for handicapping conditions.

Despite the foregoing, I think there has been little support on the part of the government towards the developmental problems. Thus, the providers of health care are legislated to provide a service but not given the means, in terms of methods and money, for carrying out the legislations.

Before reviewing available developmental screening tests it is important to review briefly the essential features of good screening procedures.

One important feature in large-scale screening programs is <u>economy</u>. There must be economy of screening equipment. There must also be economy in terms of training personnel to administer the test. The easier it is to learn the screening procedure, the larger the manpower pool that can be utilized in screening. Screening procedures requiring a large amount of time to administer are obviously not economical.

The screening test must have clearly defined limits of what is normal and what is suspected to be abnormal. That is to say, the test should yield comparable results from one time to the next. It must be reliable.

The screening test must be <u>sensitive</u>. A test with a high degree of sensitivity has a high degree of efficiency in picking out the individuals having a particular malady. A screening test must also have a high degree of <u>specificity</u>—the ability to call normal all those who do not have the malady. In other words, a screening test having a low degree of sensitivity will result in not identifying a large number of children with the malady. This situation is referred to as underreferral. Tests having a low degree of specificity will result in classifying children abnormal when they actually are normal. This is, therefore, an over-referral. It is unlikely that any screening test will have 100% sensitivity and 100% specificity. For most screening tests which can generate a series of results, one has to select a cutting or referral point which is somewhere between 100% sensitivity and 100% specificity.

The consequences of under-referral and over-referral will vary depending upon the malady being screened, the age of the child, and the local resources available to perform diagnostic evaluations and treatment for the particular malady. Therefore, depending upon the above factors, it should be possible to derive a cutting point scmewhere between points A, sensitivity, and B, specificity, so as to have maximum benefit.



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### Review of Developmental Screening Tests

One developmental screening assessment tool is called the Communication Evaluation Chart. The authors of this test have assembled it by selecting developmental, hearing, and language items from various tests. Each item is placed into a specific age category.

Another developmental screening test was assembled by Dr. John Fotheringham, a Canadian psychiatrist. These test items have also been selected from various standard psychological tests and assembled in categories such as motor activity, language, and self-help tasks. Test items have been arranged according to the age placement on the reference psychological tests.

Yet another developmental screening test is in the pediatric handbook by Drs. Silver, Kempe and Bruyn. The test was assembled by Dr. Sally Provence who utilized Gesell items and placed them in vertical sequence according to age from birth to  $3\frac{1}{2}$  years. Each item is placed at the age placement used in the parent test. The items are also placed into one of three categories: posture and locomotion; handling of toys; and social and language development. When one administers the test, one draws a profile line connecting the most advanced item passed in each of the sectors and compares the profile line with the child's chronological age.

Dr. Hilda Knobloch, a pediatrician, has abbreviated the Gesell schedule to develop a screening test.

The problem of taking items from various tests is that the psychological tests have different norms for similar test items. For example, the item "sitting steady" is placed at different ages on different tests. Gesell places it at 8.3 months; Bayley at 6.9 months; Griffith at 9 months; and Hetzeswolf at 6.5 months. The item "walking without support" is placed by Gesell at 15 months and by Bayley at 11.4 months. If one utilizes a developmental screening test based on the Bayley exam, one would be concerned about a 14-month old child who is not walking. A screening test based upon the Gesell examination would describe the child as normal. The difference in the age placement of the items is readily explained by differences in standardization techniques and variations in the administration and interpretation of the similar items. One concern of anyone evaluating children with developmental problems is the excessively long duration of time until the developmental problem is first acknowledged and investigated. No doubt one major reason is the failure of physicians providing routine pediatric care to perform systematic developmental assessment of all children at regular intervals. One other reason may be what we consider to be shortcomings of existing developmental screening tests. Shortcomings of existing screening tests are generally a combination of four factors: (1) failure of the screening test to cover the entire preschool-age range, (2) lack of standardization on a large population, (3) failure to show distribution of acquisition



of developmental skills, (4) failure to specify how each item is to be administered and interpreted and how the entire test result should be interpreted.

In view of the need for the early identification of developmental problems, and the shortcomings of existing developmental screening tests, we set about developing a new screening test.

The first step in the development of the Denver Developmental Screening Test (DDST) was a review of existing screening tests for potential test items and the creation of new test items. Two hundred fifty potential test items were administered to 200 children. All but 135 items were eliminated for such reasons as too cumbersome test materials, difficulty in administration and scoring, and irregular distribution curves.

The 135 remaining test items were administered to 1,036 Denver children. An attempt was made to select a sample that would be representative of the racio-ethnic occupational balance in the community. However, the sample was slightly skewed toward the higher occupational categories.

Table 1

DEMOGRAPHIC CHARACTERISTICS OF DENVER AND STANDARDIZATION SAMPLE

Racio	-ethnic group	Denver	Sample
1. 2. 3.	White, excluding Spanish surname Spanish surname Negro	85% 9% 6%	82% 11% 7%
Occup	ation of subjects' fathers	*	
1.	Professional (architects, lawyers, physicians, etc.)	14%	17.5%
2.	Managerial (office managers, business owners, etc.)	14%	17.0%
3.	Salesmen (retail clerks, insurance agents, etc.)	9%	11.4%
4.	Craftsmen, operatives, skilled laborers (bricklayers, carpenters,	1	-6 -4
5•	etc.) Unskilled laborers, service	43%	36.1%
	workers, unemployed (janitors, ware housemen, etc.	20%	18.0%

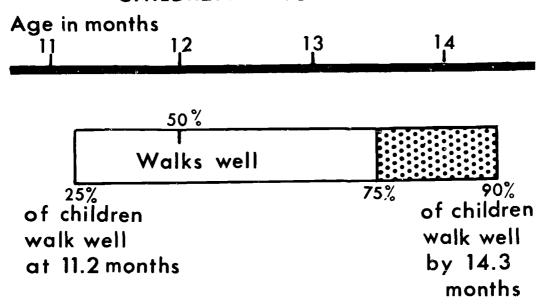


Since the time of the standardization we have tested another 1000 children from Headstart programs and another 1000 from lower social class families. An initial review of the data does not reveal much of a difference between the low social class samples and the cross-section norms containing 18% of its children of low social class families.

One of the medical students working with us had the bright idea of depicting the distribution of acquisition of developmental skills with bars. Each test item bar is located under a horizontal age line so as to show at a glance the age at which the normal sample of Denver children acquired that particular skill. (See Figure 1.)

Figure 1

# DDST FORMAT FOR SHOWING THE AGE AT WHICH VARIOUS PERCENTS OF CHILDREN PASS AN ITEM



The left end of each bar corresponds to the age at which 25% could do that task, the hatch mark corresponds to the age at which 50% of children could do the task, the left end of the shaded area corresponds to the age at which 75% of children do the task and the right end of the bar corresponds to the age at which 90% of children could do the task.



Though the entire test form initially seems to be complex, actually it is quite simple. A horizontal age line across the top and bottom of the test depicts the ages from birth to six years. Each of the test items has been placed into one of four categories. The gross motor includes items of posturing and locomotion. The fine motor-adaptive includes items of nonverbal problem-solving. Language includes items of rearing and verbal production, and personal-social includes items of self care and relating to others. Thus, for each of the 105 test items it is possible to determine the age at which children normally acquire certain skills.

SEAR SOME WITCH! ON LEGS KICKS BALL FORWARD NO HEAD LAD R HEAD UP 450 WALKS HOLDING ON TURNITURE THEOWS BALL OVERHAND HOLS ON 1 1001 BALANCE ON FOOT RAYCHES BOUNCED SITE WITHOUT STANDS ALONE WELL ALM SUPPORT UMPS IN PLACE HEEL TO TOE WALL STANDS HOLDING ON STOOPS & BRCOVERS SIT NEAD PULLS SELF TO STAND PEDALS TRIKE WALKS BACKWARDS POLLS OVER GETS TO SITTING WALKS UP STEP GAASFEELO BITTOOKS SCRIBBLES SPONTANEOUS TO OVENENTS BAGANDS SIVYALES COPIES OF COLIES TOWER OF 2 CURES MIGE A IMITATES ODENONSTEE FOLLOWE ASSI. LOS OF SEED BANGS 2 CURES HELD IN HANDS tower or a custs OF RAISIN TOWER OF & CURES POLLOWS ALLEN ALTAINS MITATES VEST CAL TIME PRAWS MAN 3 PARYS THUMS FINGET GRADE TOGETHER DUMPS RAISIN FROM SOTTLE SPON MAND TO HAND PICKS TOHOUS TIMES 15 PHASE TURE TOWN TOTTLE STMONET TETSPONES NONSPECIFIC S WORDS OTHER THAN MAKE DADA COMPREHENDS COLS. HUNGIT COMBINES 2 DITTERINE WOLDS TURNS TO VOICE PREPOSITIONS POINTS TO I NAMED BPECIFIC LAUGHS RECOONIZES 3 COLORS NAMES LPICTURE EQUEALS FOLLOWS 2 OF 3 DIRECTIONS IMITATES SPEECH SOUNDS GIVES IST & HISTOR STAANGERS IMITATES HOUSEWOOR DONS SHOES NOT 1110 USES TOOM, SPILL NO ITTEL PLATS PAT AUTTONS UP PLATS BALL WITH STAMINES N TA N COUNTY WASHES & DRIES HANDS INDICATES WANTS WITH SUPERVISIO PEEDS SELF CEACET) RESISTS TOY PULL SOT PLATS PEEK A-600 SEPARATES FROM MOTHER FASILY # 902 PASS SUPERVISION REMOVES GARMENT

Figure 2

The first step in administering the test is to determine the child's chronological age and to draw a vertical line through the four sectors at the appropriate location on the horizontal age scale. In each sector one next administers items to the left of the age line until one has a



vertical row of passed items. After establishing a bank of passes, one administers progressively more advanced items until one establishes a bank of failures. Each item passed is scored with a "P"; each item failed, with an "F"; each item refused, with an "R"; and if a child has not had an opportunity to try a task one writes "No" on the item. Each failed item which is completely to the left of the age line represents a delay. Any sector having two or more delays to the left of the age line is interpreted as being abnormal. A sector with one delay and failure of the age line to intersect a passed item constitutes a questionable or borderline performance. Sectors which are not abnormal or questionable are interpreted as being normal. Any child with a questionable or abnormal sector should be retested one week later. If the sector is still questionable or abnormal the child should be referred for a diagnostic evaluation.

One such test profile of a little girl is one who was screened at 17 months of age. Her mother thought she was slow when she did not sit at 12 months. She was, therefore, seen in consultation by an orthopedist who did not discern a reason for her not to be sitting. It was not until she was 17 months of age that her physician noted her to have a general delay in development. On the screening test she had several delays in various sectors indicating an abnormal performance. Further evaluation revealed her to have phenylketonuria. Though she was begun on the specific dietary treatment immediately, she turned out to be retarded and to be too old to benefit from treatment. This case illustrates a common error of assessing only motor development during the first year of life. Had the overall development been assessed, the general delayed development could have been discovered by 6 months of age. If therapy had been instituted at that time, permanent mental retardation might well have been prevented.

The DDST is a screening instrument designed to determine which child ought to be further evaluated by a psychologist or pediatrician who is experienced in developmental evaluation. Since the diagnosis of mental deficiency is generally based upon results of psychological tests, it is important to determine the degree of agreement between interpretation of the DDST and diagnostic psychological tests. To determine the degree of agreement, 236 children varying in age between 1 month and 6 years were evaluated independently by one person administering the DDST and by a psychologist administering one of the following criterion tests: Stanford Binet form L-M, Revised Yale Developmental Schedule, Cattell Infant Intelligence Scale or the Bayley Infant Scale. The DDST was assigned an overall rating of normal, questionable, or abnormal as previously described.

Table 2 shows the average performance on the criterion tests for children in each of the DDST groupings. Actually the degree of agreement is surprising since each test, being constructed differently, measures somewhat different functions. For instance a child might be abnormal on the developmental screening test due to an inability to balance or hop



Table 2

Mean · Standard Deviation for DQ or IQ
on each Criterion Test
on Children Given the Same DDST Rating

1		L	DDST Rating	
Criterion Test	Statistic	Normal	Questionable	Abnormal
Stanford-Binet N=91	N Mean Std. Dev. Range	37 99.57 9.18 84 - 120	20 92.85 13.60 72 - 131	34 67.50 15.72 35 - 111
RYDS (Average) N=64	N Mean Std. Dev. Range	13 97.23 12.27 75 - 116	6 82.67 10.51 75 - 94	45 55.98 21.85 6 - 89
Cattell N=50	N Mean Std. Dev. Range	28 96.14 22.20 60 - 132	12 89.92 15.03 67 - 116	10 50.50 16.96 27 - 86
N. 1. MDI	N Mean Std. Dev. Range	17 80.24 19.52 40 - 120	9 79.00 8.18 62 - 92	5 64.40 19.09 32 - 92
Bayley	Mean Std. Dev. Range	84.82 14.39 56 - 116	88.56 17.41 71 - 124	73.20 12.25 52 - 89
Average	Mean Std. Dev. Range	82.41 16.45 43 - 118	83.56 12.13 68 - 106	68.60 15.46 42 - 90

on one leg. The same child may be able to perform all of the age-appropriate intelligence items on the Stanford Binet. Thus, the same child may be correctly classified as abnormal on the DDST and normal on the Stanford Binet. Though there is a disagreement between the tests, the disagreement may be due more to a variable performance in the child than an error in one of the tests.

DR. MARGE: Are you beginning to find that there are certain factors which have predictive value?

DR. FRANKENBURG: We have undertaken a long-range study to determine this relationship. If one accepts the interactionist theory, one should not attempt to predict later developmental function without also assessing the child's home environment.



Dr. (Bettye) Caldwell considers that the developmental status of preschool-aged children has more value in assessing the child's neurological integrity and past environmental factors than in predicting future intelligence. This interpretation and use of infant tests seems to me to be the most relevant.

The usefulness of a screening test is not only dependent upon its accuracy but also upon the cost. To keep the costs to a minimum, we have arranged with a Canadian and a United States drug company to distribute the test materials free of charge to Canadian and United States physicians, medical students, and nurses. One major obstacle to universal developmental screening is the lack of sufficient time of physicians and nurses to perform the testing. To overcome this problem we are developing a parent self-administered developmental questionnaire which will serve not only as a uniform record of developmental progress but also as a prescreening assessment to determine which child the doctor should further screen with the DDST. Another advantage of the questionnaire is that it can be used to screen children who may have an active illness which may preclude developmental testing at that particular time. Since many children once having completed their basic immunization series are only seen in physician's offices when they are ill, this new form should be very useful. Much to the surprise of many, we have found mothers to report their children's developmental status accurately provided one asks specific questions pertaining to the child's current developmental status.

Another attempt at providing mass preschool screening has been the training of nonprofessionals recruited from poverty areas to serve as screening aides. These women have been trained to screen preschool-aged children for problems in development, articulation, hearing, and eye function. Former trainees have been able to train twice their number to perform the four screening procedures within four weeks. Furthermore, each new technician had 90 to 100% agreement with their professional counterparts for each of the four screening procedures.

By developing self-explanatory training packets, it has been possible for volunteers to almost completely train themselves to administer the four testing procedures. These volunteers are currently working in the pediatric outpatient department of our hospital. The use of nonprofessionals has, therefore, made it possible to provide these screening services at a nominal cost to children who would not have received them if one had to rely upon professionals to provide this service.

DR. STEDMAN: How were you able to train these people in such a short time and still achieve such a high level of performance?

DR. FRANKENBURG: It has been accomplished through detailed planning and the development of standard procedures for selection and training. The work was analyzed to determine the knowledge and skills necessary to



master the job within a reasonable period of time. Selection procedures were then designed to ascertain if job applicants possessed those attributes. On this basis we selected five applicants, two of whom had not completed high school. Teaching manuals providing background information and describing the administration and interpretation of the screening tests were written at the seventh grade reading level. Daily lesson plans were devised to assure optimal utilization of teaching time. Video tapes were also developed to demonstrate the screening techniques and to demonstrate various responses that would be encountered. Procedures for evaluating screening skill were also developed. All five screening aides were trained within four weeks and all are performing very well eight months after they were selected.

To date the aides have screened about 5000 children. In order to evaluate further the accuracy of the screening procedures, 250 children (some with and some without suspected problems) were further evaluated by psychologists, audiologists, speech pathologists, and ophthalmologists. The evaluations revealed many children to have multiple defects. For instance, of the children having speech problems, twice as many had associated IQ scores below 80 as had pure speech problems. A high degree of agreement between the screening findings and the evaluation by the professionals was obtained.

These findings have strong implications on case finding. For instance, it would be advisable to screen the general development of children seen in speech and hearing clinics. The findings also have implications upon methods of diagnostic evaluation as well as possible modes of treatment.

Since children living in poverty areas have a higher incidence of health problems, we recruited women from the same areas to screen these children. It was anticipated that using specially trained nonprofessionals could help to alleviate the manpower shortage and that recruiting women from poverty areas might achieve a communication with the target population. A pilot project of home screening was undertaken to reach the so-called unreached. A Spanish-speaking screening aide was chosen to screen the children in the housing project because a large number of Spanish-speaking people resided in the area. The project was located only three blocks from a neighborhood health center where the same screening service had been provided for over one year.

Prior to initiating the screening service, the aide attended a local tenant council meeting, demonstrated the service, and rallied local support. People attending the meeting requested to have their children screened and referred the aide to neighbors. Thus, it was possible for the aide to gain parental acceptance of screening by 96% of the homes having children under six years of age. One hundred twenty children representing 96% of the preschool-aged children were screened. Only 18 children had previously been screened and most of those children were screened due to their being enrolled in Head Start. Therefore, by home screening it was possible to reach the "unreached."



Not only was the aide able to screen 96% of the preschool-aged children but she also was able to convince 90% of parents of children with suspected problems to take their children to the clinic for follow-up diagnostic and treatment services.

The high percentage of follow-up is very relevant because the parents had not come seeking the screening service. The high percentage of follow-up is also a reflection of the acceptance of the screening program and the acceptance of the aide as a nonprofessional health advisor.

Home screening had a number of important advantages over clinic screening. The children were more relaxed at home and, thus, were better able to cooperate. Many children taken to clinics and physician's offices are fearful because they remember unpleasant clinic experiences such as receiving shots.

The success of this pilot project has prompted us to expand the program to determine its feasibility in other areas of the city.

MR. KRAUSE: How extensively have other areas of the country used the DDST?

DR. FRANKENBURG: I don't know. The test is taught at numerous medical and nursing schools. The nursing division at our medical center has run training sessions for nursing supervisors and for personnel working in physician's offices. The state health departments in Ohio, Wyoming, Colorado, Oklahoma and Tennessee are also using the test in clinics. Many physicians in the private practice of medicine are also using the test. To date, over 11,000 sets of test materials have been given away free. Many agencies not entitled to free distribution have bought the test materials. Despite all of the screening guidelines and legislation that screening be carried out, I know of no large-scale developmental screening project besides our own.

There have been some exciting large-scale, well run programs for vision and hearing screening in Michigan and in Minnesota. These screening programs are generally aimed at four and five-year-olds as well as the school-aged child.

DR. STEDMAN: There are a lot of interesting side implications of this. The notion of a national assessment program is constantly hovering for one thing. I also see this as a potential reply to the argument insurance companies have had for years about providing policies for children with developmental defects—that they cannot do so because they have no actuarial studies. There have been no probabilities, no head-counts of children in this population. This has been due to definitional problems as well as actual "counting" problems.



DR. BELMONT: I am confused because I think there is no sense in screening for a problem that you are not going to treat. I can accept screening for PKU because a treatment program exists, but isn't it putting the cart before the horse to go out and find examples for which (1) the clinical course is not entirely clear, and (2) even if you do know what happens to the people, we don't have the programs to treat them?

DR. FRANKENBURG: Dr. Belmont has raised an important point. As mentioned previously the procedure under discussion is screening. Screening tests do not make diagnoses; rather, they separate children suspected of having a disorder from those who do not. The next step in the process is a diagnostic evaluation. Some people feel we should not screen for slow development until the long waiting lists for diagnostic evaluations have been eliminated. I claim that this is a defeatist approach which will not help children since new approaches and new facilities for evaluating such problems will be hastened with the demonstration of ever increasing needs.

Assuming the child is slow as demonstrated by diagnostic procedures, you ask, "what then?" Slow development is a symptom--similar to fever--of something wrong and, just like fever, may be due to a variety of causes. At the onset of this discussion I discussed the interactionist theory in which intelligence or development develops as a result of intrinsic (genetic) and extrinsic (environmental) factors. One purpose of the diagnostic procedure is to ascertain which extrinsic and intrinsic factors have played a role in producing this delay in development.

Though cures for the intrinsic factors are uncommon, there are certain disease entities which may produce retardation if treatment is delayed too long. Examples of these are congenital cretenism, galactosemia, phenylketonuria, hydrocephalus, etc. In addition, there are intrinsic conditions which though not cured may be ameliorated if diagnosed early. Examples are cerebral palsy, delayed language development secondary to a hearing loss, and a variety of other conditions.

Extrinsic factors which may retard the development of a child are such conditions as maternal deprivation due to absence of the mother or inadequate child care. Both of these conditions, which are very common, can be treated by finding a mother substitute or by helping the mother to provide the child with a more nurturing type of mothering. The high frequency with which children function below their capacity due to emotional disturbances is amazing. Treatment for these factors is certainly available. Frequently children with static neurological problems develop accondary emotional problems due to home conflicts which are due to a lack of parental awareness of the child's handicap. An example of this is the child who fails to respond to parental requests due to lack of comprehension. Such failures to respond are frequently misinterpreted by parents who think the child is lazy or stubborn. Numerous studies have also demonstrated that treatment will be most effective if treatment is not delayed.



In view of the foregoing, one would be negligent if one were to ignore developmental problems in children.

No other area of medicine neglects a malady with the apathetic approach that no cure is available. Leukemia, cystic fibrosis, and diseases such as the Werdnig Hoffmann type do not presently have cures. This state of affairs, however, does not preclude efforts at amelioration and/or cure. The identification and acceptance of a problem is the only way to resolve it.



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## A Review of the Effects of Early Educational Intervention Programs

#### Ira J. Gordon

I want to focus on the effects of intervention programs on early development, with a particular eye on the family as a target rather than just the child as a target, and to talk about programs that are research programs rather than <u>Head Start</u>, or Title I in the Office of Education, or the Parent Child Center programs, or any of the massive service efforts that have little research or evaluation formally built into them.

Listed on Table 1 are 25 factors that have been culled from 30 or 40 different people, who have investigated, in one way or other, the family variables that they think make a difference in the intellectual growth of children.

I have divided them into three categories. I have used the term demographic where Dr. Stedman has used the term ecological factors-things like crowded homes, racial membership, whether there is a father around or not and how he behaves, the type and quality of housing, the level of income, and social class membership. These are large clusters which conceal very often more than they reveal, because to talk about social class difference overlooks the great degree of difference within social class.

Now, the second group is much more specific. It deals with the elements of maternal and paternal behavior that seem to be very closely related, in a number of studies, to actual achievement and behavior of children in school; one example is whether or not the family provides the child with any kind of academic guidance. For instance, I mentioned to Dr. Begab that this is an interesting time to have reenagers. I have two, one whom we are now putting through the hoops of getting into the appropriate college. Obviously, growing up in a professor's family, the expectation from the beginning is that they would go to college. Both my wife and I have been in education all our lives. We know how to talk to teachers and principals and all the ways of playing the game. This is what I mean by academic guidance. It is not simply the kind of guidance received from the counselor in high school--but whether the child is surrounded by an academic climate. He knows his parents are competent and know how to help him work his way through the academic situation.

The second item is the cognitive operational level and the style of the parent. Here I think some of the research that Hess and Shipman did over the years in Chicago, that Eleanor Pavenstadt has done in Boston, and



Table 1

Program Goals in Relation to Changes in Home Characteristics

					Programs			
	Characteristics	Boston	Peabody	Illinois	Howard	Syracuse	NIMH	Florida
Demo	Demographic Factors							
_	Cro.ided homes							
•	Rthni city							
1	Daternal role behavior	×						
7								
2								
٧	Spot 2 1 2 2 2 2							
Par	Parental Cognitive Factors							
7	Academic guidance	100		C C		ت	ن	P.C
ω.	Į.	7,07	اد	26.3				
0	Cultural activities planned		X	×	<u>د</u>			Þ
-	Direct instruction of child		X	×	×			<b>4</b>
	Educational senirations							
1 6	m of months provided	Nurs	Nurs,kg		Nurs	Nurs		
7	Type of resource proveds		X	×	×			×
<u>:</u>	Threilectualtry of marent child	P.C	P, C	P,C	C	O	٥	P,C
÷	FROTTER OF PAR			×		. }		×
	Verbal frequency (eg. ulimer com./							
Par	띪	Þ	>					×
16.	Consistency of mana	<b>⟨</b>	<u> </u>					
17.	Differentiation of Self	4	^					ij
18.								Ъ
19.	Emotional security, self-esteem of par., child	2,4	اد				_	
20	Impulsivity	×	×				\ \ \	×
21:	Internal control	1						×
22.		Ì					<u> </u>	×
23	Trusting attitud	×			<b>\</b>	-	1	*
2/6	ı		×	×			-	*
1 2	Town hobits		X	×				V.
	1							

 $^{\rm l}$  P means parent change sought, C means child

that many of the people in language development have done, is appropriate. How do the parents actually talk to the child? At what level of reasoning do they engage the child? I think one of the best stories is Basil Bernstein's about life in England, as to the difference between working class and middle class behavior. The middle class mother gets on the bus with her four-year-old child and the child stands on the seat. The mother goes through 30 minutes of reasoning with the child about why one should not stand on the bus seat--"You are going to make it dirty for somebody else," and "People are looking at you," and "It's impolite," which may not get the child to sit down at all. She may end up with a more primitive technique for getting the child to sit properly. The working class mother's child stands on the seat and, slap, down he goes. How much learning that there is a reason, other than authority, for doing things is going on in such a home?

One of the key areas in what we know about first-grade vocabulary and first-grade grammar is whether or not there are any efforts in the home to deal with the child at a reasoning, linguistic level beyond the very primitive.

Next, does a family plan cultural activities for the child? "Let's go to the National Zoo or down to the museum."

Whether or not the family engages in direct instruction of a child is where we focus a good part of our attention. There is research not only from the United States but also from Israel, England, Holland, and Switzerland, which indicates that whether the mother (mostly it is the mother) views herself as the teacher of a child; whether she sees this as a functional role she ought to play; whether she thinks there is any connection between learning and development is a critical factor in child learning.

My position is that maturation alone will not take care of intellectual development. The active, direct teaching behavior of the mother in the supermarket, in the street, in the home, wherever she is, has a tremendous payoff in the growth of the child.

The next item is whether or not parents set educational aspirations for the child. Do they expect him to go to college? Do they expect him to stay in high school past age 16? Do they expect him to make good grades? What do they set as goals?

Do they provide resources: books, magazines, toys, games, puzzles? I think one of the interesting things about Head Start, for example, is simply that availability of resources does not mean that the people in the so-called poverty group will necessarily use them.

We have had free public kindergarten in Gainesville (Florida) for a long time. When my children were reaching five, my wife got in the line at midnight, along with some of the neighbors, to make sure the children



got to kindergarten because it was a limited enrollment system. When they got 60 children, that was it. Other places in the community went begging to fill their quotas. The mothers who found out about Head Start, and made sure their children got there, are quite different and the children are different, than those where the social worker had to go out and beat the bushes, dress the child, take him here and there and bring him back home. Whether a family makes use of resources and the type of resources they provide are other factors.

The next three all relate back to language. What is the verbal pattern in the home? Are there lots of opportunities for conversation? What kind of conversation takes place?

Some of Deutsch's research in New York and some other work indicate that this is not purely a social class phenomenon. I am very concerned about graduate students' children, for example, living in campus housing. I am also extremely concerned about suburban and rural children and the lack of opportunity for verbal discourse between parent and child. We should not see this as something that exists only in the urban ghetto. For example, I think that we have a good many disadvantaged children in Montgomery County, Maryland, who have little opportunity to engage in verbal exchange with their parents sitting around at the dinner table.

When we shift from these cognitive items to the emotional, the items are pretty much what you would expect. If a family is consistent in the way it manages the child, both in terms of the mother being inconsistent in her own behavior from day to day and of conflict between the adults as how to rear the child; if the mother is not quite clear as to where she stops and the child begins; if she does not have very much self-esteem; if she is highly impulsive; if she lacks belief in the control of her own destiny; if she does not trust the people around her, obviously, these not only influence the personality of the child, but the intellectual ability of the child as well.

Some of the work of Eleanor Pavenstadt points this out. The Coleman study also used this notion of internal control. We have found this is a very significant factor. If a mother does not feel that anything she does makes a difference, if she feels that she is on some sort of a conveyor belt and the people around her do things on her, to her, for her, and at her and that then she gets turned off at the end of the line, how in the world can she in turn influence or feel she has any influence on the behavior of her own child? Whether the mother sees herself as a potent influence in her own life and then as a potent influence in the life of the child is a significant variable.

What I plan to do now is point up some studies that have selected some of the above items and tried to do something about them. The fact that is most interesting, from the "ecologic" point of Dr. Stedman's, is that none of these university research studies really did anything about what some people consider the most important and fundamental variables such



as income and housing. The only one that even looked at those was Pavenstadt's work in Boston where she examined whether the father was around and what role he played. She did not attempt an intervention study to change the father or to provide any special setting for him.

The <u>Boston study</u> was at the City Hospital Guidance Clinic in the School of Medicine from 1960 to 1965. The goals were defined as a concern for the total personality development of children and the provision of early intervention as a means of helping children toward mental health. Table 2 gives some of the data about these studies.

They believed that cognitive development could not be separated from the total growth of the child, and that any program had to support overall developmental growth in both the personality and the intellectual realm. They had a very small sample of 10 white and 3 Negro families for a total of 45 preschool children. They placed 21 in a special nursery school. These were multi-problem families with long histories of disorganization and failure, and most of them were on welfare sometime during the program.

The initial approach to the parent was to get them to have their children attend the nursery school. This was done by using a family social worker. They included a project party or a home visit or a school visit with the worker. The families were generally not self-motivated because, for them, sending a child to school created a new set of demands rather than freedom. One had to get up at a certain time, had to get the child ready at a certain time. All of this gets in the way of families who are not normally well organized.

Once the child was in school, the teachers were in charge of home contacts. They provided transportation and made home visits, trying to support the parental role where they could. The social worker established a typical case work pattern. There was also a public health nurse in the operation. First, they were trying to get the family involved—simply trying to get them committed to sending the child to school; secondly, to do something in this area of changing the management pattern in the home, changing the disciplinary pattern in the home, moving it from a disorganized family structure to some sort of order; and, third, trying to help the mother move away from being so concerned with her own needs so that she could begin to see the child's needs—this differentiation of self—and then trying to hook the parents up into the larger community, help them find jobs, help them become more self-sustaining.

Basically, it was a program run by professionals in which the social worker, through home techniques, would try to serve as a model for imitation and identification. He would teach the mother such cognitive tasks as naming, identifying and classifying, and although there was no normal curriculum for parent education, he was concerned with improving the language structure in the home.



Table 2

Design Characteristics of University Program

#### Location Boston Peabody Illinois Howard Syracuse Florida Characteristics NIMH College Univ. Univ. Univ. Univ. Univ. Sample Families 3 43 30 38 20 30 145 Negro 10 0 0 39 0 30 White Locus of Program Home Х Х X Center Roles of Parents Parent Educator X Develop materials Х Volunteer Х X X X Teach own child X X Observer, recipient X Data Sources Tests Child Cognitive X Х X Х Х Child Affective Parent Cognitive Parent Affective Other Systematic Observation Х Parent interview X Anecdotes



There was a split between teacher role and the social worker role. The teacher was concerned with the child and the social worker with the parent. That is a very brief capsule, but that is all I can give on each of these projects. We can go into detail later.

The second project is the <u>Peabody project</u>. This project has been going on for a long period of time. It originally began in 1961 under the supervision of Dr. Susan W. Gray and has received probably the most attention of any of the early training projects. The families were all Negro and lived in a town of about 25,000. There were 61 children of whom 43 were in experimental groups. They were trying to intervene in oeder to influence cognitive development and motivation, which they felt might affect later school performance.

They felt that they had to do something about the restricted language code in the home, the general pattern of adult-child interaction, the disorganization of perceptual stimuli, the necessity for the mother to live on a day-to-day basis, the lack of a time and space orientation in the home, and the use of physical rather than verbal means of control.

They had a two-phase program: the summer phase, which was a group program in nursery school and later in kindergarten, and a winter phase of home visitation.

The home visitors were professional, certified teachers. During the ten-week summer program, they served as liaison between home and school. The home visitor arranged for the parents to visit the school, explained the activities to them, emphasized the importance of home follow-up, and arranged for physical examinations for the children.

During the winter, she went once a week to each home at the convenience of the family. The first goal, the one that I mentioned in the previous table, was to have the mother see herself as a teacher and involve herself as an active participant. They supplied the mothers with Ebony magazine. They made them aware of other activities such as adult education, employment, and housing. They used operant conditioning techniques, using positive reinforcement for any behavior of the parent showing concern for the child.

They taught the mothers how to behave in operant fashions with the children. They asked the parents to plan time for training the children. They used role playing to help the parents. They used books with children. They assisted in food preparation. They made trips to the library.

In the third year, when the children were in regular school, the home visitor arranged biweekly contacts and moved into a liaison role, so they had a long-term commitment to these families. (The Pavenstadt program was a short-term commitment.) They began with families in nursery school and carried them through three years of summer and winter programs in which there was a link all along the line.



The essential features were cognitive orientation; preschool program and follow-up in regular school; and a systematic home visitor program using professionals to help the mother, first, supplement the child's educational experience and, second, try to learn to cope with her own environment.

The third program was the <u>Illinois University program</u> of Karnes. The Illinois project was specifically designed to study the effects of short-term intervention. They used parent training and instruction to see what effect teaching a parent about cognitive operations would have on the intellectual and language development of the child.

The training program was only for parents. They didn't work with the children at all. There was no preschool or nursery school. The basic hypothesis was that training the parent would yield gains in measured intelligence and linguistic skills. There were 13 Negro parents in a matched control group. They attended 11 weekly, two-hour sessions and they were paid three dollars a session. Three experienced teachers instructed them. At each meeting the mothers made educational materials themselves from inexpensive materials or from items found in the home, and time was spent assisting them to find ways to utilize the material.

This was then followed up by a biweekly visit if the mother had been present at the meeting. If she had been absent, the teacher made a weekly visit. The language development program was based on the Illinois Test of Psycholinguistic Ability. The parents were taught how to read to their children and how to formulate questions relating to language. They were also taught art work with crayons, finger painting, puppet play--all of the variety of so-called "creative playthings" activity. They were also given some help in Piaget-type classification and number. This was a very short-run program.

The <u>Howard University</u> project here in Washington was "designed to help children and parents participate in and contribute to their children's enlarged experience and to widen their own interests and knowledge so they might make use of the facilities and opportunities available in their neighborhoods and in their larger communities."

The participants were all Negro families from a low-income neighbor-hood. Teachers visited the homes and conducted interviews with the parents; each of the children visited the school with the parents and got an exam; and the children were bussed to school.

Although they said their aim was involvement of parents, they really were not too successful in achieving that goal. They essentially ran a good traditional preschool program. They also found, as did the Boston and Peabody people, that even making contact with these families, even getting them to get the child to come to this school, was not an easy matter. Life situations built up over a long period of time, along with very negative attitudes toward school, had to be overcome.



They had group meetings of the parents at school or in the neighborhood and talked about child care in the usual "What do I do when my child does such and such?" fashion, and they answered questions that parents had about child rearing.

In the second year of their program, they tried to involve parents in making trips with the children, reading to the children, taking them on walks and so forth. There was no organized curriculum for the parents as compared with the Illinois and Peabody programs, and they dealt with problems ad hoc in the committee meetings. Whatever the parents brought up became the agenda.

The <u>Syracuse project</u> is the one that Don Stedman mentioned when he referred to Bettye Caldwell. Here we have a different project from all of the others that I have mentioned before. This was not aimed at the family. This was a longitudinal intervention, research and development program primarily to see what would happen when you provided day care for very young children beginning at six months of age.

The aim was to provide comprehensive care: a health program, an educational program, a welfare program. Another distinctive element of the Syracuse model was that while all of the Boston, Peabody, and Illinois children were so-called poverty children-ghetto children, disadvantaged children-the Syracuse University children were a mixed group, both in racial and socioeconomic background. They attended all day long. There was no attempt at home visitation, or having mothers read to children, or involving them in any other fashion than being supportive and attending something similar to PTA meetings.

The educational program was highly cognitive--education based on the work of J. McV. Hunt and Pinget, but using reinforcement procedures. The first phase of the work was finished in June 1969; I will report on Caldwell's latest findings.

All of the programs up to this point have had either a mix of group care and family concern or, in Caldwell's case, just group care.

The next two programs had no school setting at all. This is the work of Marl Schaefer here in Washington (the NIMH program), and the work that we are doing at the University of Florida. Schaefer selected a group of people from the worst census tract in the city of Cushington and paid the mothers to allow a middle-class, college-educated tutor to come in and work directly with her child.

The tuto, worked an hour a day, five days a week, and emphasized verbal stimulation. They started with youngsters about the age of 15 months and carried them up to 3 years. There was no set curriculum. The tutors did whatever they felt they could or should or whatever the spirit moved them, but they kept rather elaborate diary records. Schaefer is,



after the fact, seeing what were the things that were done, and I am sure, since he is an extremely careful and capable man, he will be able to tell us relationships between some particular techniques that were used and the achievement of the children.

The other home visit program is the Florida model, which is quite different from Schaefer's. This was a program designed to teach the mother a set of very specific sequential tasks to use with her infant beginning at 3 months of age and carrying through 2 years.

The basic orientation of the program emphasized that the earliest years of life are critical. The program had three goals: first, the development of a career program for disadvantaged women who would serve as parent educators and child development workers; second, the education of mothers in specific techniques for cognitive and verbal stimulation accompanying an interpersonal relationship; and, third, the provision for infants of an environment to provide a basis for effective growth.

This, like the Peabody model, was essentially a Piagetian orientation, coupled with some of Bernstein's notions about language. It presented the mother, as part of the learning task for the child, with a model of a more elaborate language code than they might otherwise use.

First, there was the development of specific tasks or activities; second, the training of a group of disadvantaged women to be the trainers of other women (a basic difference from the five programs presented above, all of which used professionals); and third, a field program of a once-a-week home visit for approximately an hour a week in which the parent educator used role playing and demonstration to try and teach the mother something to do with the child. The parent educator also served as a data gatherer.

If you look at Table 2, you will notice that four of the programs have home elements in them: Peabody, Illinois, NIMH (Schaefer's program), and the University of Florida. Four of them are center or institution based, and only in the case of Peabody do you have a combination of home visit and center program for the children.

You can look at roles of parents at varying levels of involvement from simply being the receiver of aid at the observer-recipient level, to being involved in teaching her own child, to being used as a volunteer, to being somebody who would develop the materials she, herself, would use, on up to being an employed person in a university job. You can see the variety of ways in which people in these various projects saw the parents.

Of particular concern and interest to me is the fact that all the projects attempted to measure the c'ild on some sort of cognitive measure. All of them paid lip service to changing the parent, but there was



practically no measurement of change in parents. The Florida program used tests to measure parents and several projects attempted some measurement of parents through systematic observation, or parent interview, or anecdotes. The systematic measurement, however, is of the child and, unfortunately, by means of some sort of standard intelligence test. I assume that some of you share my biases about using the standard intelligence tests as the ultimate measure for this kind of work, particularly as a measure of the very early years when they are not very reliable and we have not very good data as to their validity.

We have a mix in these studies from direct intervention into the home, to virtually no attention to the home. Programs began with 3-month olds in Florida, 6-month olds in Syracuse, and 15-month olds in Washington, and with children as old as 3 or 4 years in some of the other projects. Programs varied from focusing on the cognitive to attempts to mix cognitive and affective variables. To some degree, I would suggest that this represents the state of where we are; these are probably the key studies.

There are other studies going on: Weikart's work in Ypsilanti, Michigan, and the program at North Carolina are examples. Generally these are mixtures of intervention, research and development in the field, not nice, clear, clean laboratory studies. They are all somewhat "messy." That does not bother me because I think they have to be somewhat messy at this point. They are all exploring. They are all pioneering, but they are certainly not definitive in any sense of the word.

Let's try and look at some of the data that has come out of them.

If you will look at Table 3, you will note that the Binet, WISC, the ITPA, the PPVT all fall into the category of cognitive measures. They are all attempting to assess the "intellectual" ability of the child-reasoning, thinking, language development, the way in which the child deals with his world. It is clear that how the child performs on even such a thing as the Wechsler Scale relates to his level of reflection and impulsivity, to his self-esteem, to his sense of trust, and to how well he thinks the examiner is treating him as a human being. Part of the problem in the field is that even though most other developmentalists recognize that attitudes, values, self-esteem, and motivation are very important attributes that influence behavior, by and large programs are being assessed by measures that are not looking at these attributes. They are being assessed by measures such as the Stanford-Binet and the Bayley Scales. This is one of the real problems in the field. We do not have adequate assessment techniques for the affective domain. I think this is going to be one of the main contributions that Earl Schaefer is going to make, because he is getting at some of these things.

All of the results show that the children involved in the programs do better than the children who are not involved. I don't think this is a great, earthshaking surprise but I feel that I have to say it.



Table 3

Summary of Measurement of Children

Project	Measure	Exp. N	Cont. N	Findings
Boston U	Unspecified			Mental age growth
Peabody	Stanford Binet WISC	38	42	Experimental better than control, most exposed group best  Experimental better than control  Experimental better than control
	PPVT Reading Readiness Stanford Ach. Tests Kagan Reflect-Impulse Piers & Harris Self-Concept			better than control better than control better than control more reflective, few
Illinois	Stanford-Binet ITPA	13	13	Experimental gained more than control  Experimental gained over control in visual decoding, auditory-vocal association & sequencing  Experimental gained over own pretests
Howard	Stanford-Binet	38	69	Mean gain over two-year period higher for experimental
Syracuse	Cattell or Binet	22	16	Enrichment group shows longitudinal gains, control shows decline
NIMH	Bayley	30	30	At 27 months, experimental group superior to control
Florida	Griffiths	85	61	Experimental better than control on overall hearing and speech, eye and hand and personal-social; no difference on perfor-
	Series materials (tasks taught to mothers)	71	99	mance and locomoter sub-scales Higher proportion of experimental able to do more tasks than control



Gray and Klaus have issued a seven-year report on the Peabody project that began in 1961. At the fourth-grade level they say "our answer to whether such retardation can be offset is one of cautious optimism."

"The effects of our intervention programs are clearly evidenced through the second year of public schooling, one year after intervention ceased. This is still in effect and most apparent in the Binet after two more years of non-intervention. Still it is clear from our data that with a parallel decline across the four groups-these are groups that started at four points, and the control group in the second through fourth grade--that an intervention program before school entrance such as ours cannot carry the entire burden of off-setting progressive retardation. There are no significant differences at the fourth-grade level left between experimental and control group children."

I think there are good and cogent reasons why this is what they have found. If we look at the Howard report, which just came out, we find that the nursery-group children made significant gains on the Stanford-Binet, but the scores on the two subtests of the Illinois Test of Psycholinguistics, the Auditory-Association and the Auditory-Automatic indicated that by the end of the two years, these children were still over a year below their age norm in associative language ability and grammar, and in understanding the meaning of words. This is after two years of effort in their nursery-school program. This corroborates the impression of their teaching and research staff that the children still had a long way to go before catching up with their middle-class peers in expressive language skills.

I mentioned that Schaefer is perhaps going to be one of the most critical researchers in this area, because he is moving from simply the descriptive "the-experimental-do-better-than-controls" statement into correlational studies-careful correlational studies between measures of the mother based upon his tutor's observations of them and child performance in the testing situation. These are to some degree anecdotal, but at least written down and codified. His scale, for example, shows that there is a high relationship between the behavior of the mother observed by the tutor, in terms of hostility, amount of detachment and involvement, level of interest, and verbal expressiveness and the hostility, belligerence, irritability, and negativism of the child in the test situation. The higher the hostility of the mother, particularly when she is a hostile, uninvolved mother, the lower the child's performance on the Stanford-Binet at 36 months of age.

Here you have a very clear relationship between the affective behavior of the mother studied over a period of time daily in the home and the intellectual performance of the child in a test situation.

We need a good deal more of this type of data. Schaefer shows relationships between hostile mother, hostile child, and low performance.



It may very well be that the low performance is really another indication of the hostility rather than what the child might do if he didn't feel like kicking the examiner in the shins at that particular moment.

These correlations are respectable. They are in the 60's and 50's. If you remember that the correlation between intelligence test scores and reading in schools runs in the high 60's, and that the correlation between graduate record exams and performance in graduate school is near zero, then I think these look very respectable!

We have, then, a relationship between the affective behavior of the mother and the cognitive, as well as the affective, behavior of the child.

Weikart, in his infant study, which began later than those reported here, has learned from all of these. He is using ahome-teaching model in which his teachers are public school teachers. He has divided "his" mothers into four categories: the good intuitive mother, the mother who wants to do the right thing but does not know what the right thing is, the noninvolved mother (which to some degree relates to Schaefer's low involvement), and the detrimental mother, which is probably Schaefer's hostile, low-involved mother.

Weikart has not produced data at this point, but he is trying to see whether home teaching by a public school teacher, compared to home visiting by a college volunteer, compared to no teaching, makes any difference when dealing with these different types of mothers.

Other studies have been reported in <u>Children</u> magazine in March, 1969. Palmer's work in Harlem, the work at Yale, and the work at the Children's Hospital in Washington, D. C. are briefly described.

Palmer has produced some data which indicate that, for two-year-olds in Marlem, individualized direct instruction is the key. The key is not in the curriculum. The key is in the length of time during which the youngster has one person paying attention to him and to him alone. What the adult does is probably not as significant, from Palmer's point of view, as the focusing of time and attention.

All these studies stress interpersonal relationships. All of them, except Caldwell's, stress home factors. All of them are concerned about the mother's mental health--whether or not they are measuring it. Pavenstadt said, for example, that disorganized families, initial distrust and surpicion; concrete action instead of words; egocentric, impulsive behavior; isolated and poorly defined self of the mother represent the kind of family they were dealing with.

Where does this leave us? First, I think that these studies, along with the Westinghouse report, seem to indicate that whenever you stop, things are going to slide back. If I can quote from Earl Schaefer: "Programs have to be early and continuous."



If we really adopt an ecological frame of reference, we cannot look at the child as an entity that resembles a savings and loan account in which if you invest a hundred dollars, interest is going to grow. It does not work that way. The nature of the life situation carries such weight that we simply cannot build up, in the early years, a sufficient bulwark to overcome what the child is going to meet later in the school, in the street, and in the home.

Therefore, we have to move into more comprehensive approaches. The studies reported here were focusing on very narrow areas. If we want to have a program that is going to make an impact, it seems to me it has to be imbedded in a comprehensive system of social change.

We found, for example in Florida, that many of our mothers, even though they fell into Weikart's "wanting" category were unable to avail themselves of the learning opportunity because of life circumstance.

It is going to require adequate housing, adequate food, adequate medical services, adequate income, adequate power--they are all intertwined in a single ecological system with adequate parent education.

We have had families who needed commodity foods but legally could not get them and ones who needed medical or legal service. Some families lived so far out that they walked two miles to a creek to get water. We had femilies with no electricity, with no screens, no floors even--dirt floors. We had families who were deeply in debt, including some of our parent educators. The saving difference was that our parent educators were on an annual wage. They were hired as employees of the University. That meant sick leave, use of the credit union, and all of the benefits that go along with being a university employee. But the mothers who dropped out had no resources for overcoming these barriers. One of the changes we noted was the change in our parent educators. As a result of a steady income and a steady job that held some prestige in their community, they had opportunities to learn about management of credit. They learned about social agencies. They got involved in Governor Kirk's program, "Operation Concern." One of the reasons I feel so strongly about the importance of using nonprofessionals is that such a change takes place. My plea, then, is that we adopt a wide spectrum orientation.

The issue of whether to intervene in the home or in a center is really a matter of judgement at this time. I don't think that we have any hard data that say that good institutional day care is harmful to very young children. As a matter of fact, Caldwell says it may even be good for children to be moved into centers very early—at six months of age. This is going to mean a change in the legal structure of day care, but it is going to mean that some quality person is going to have to be involved in what these institutions are. It will not do simply to place children into any kind of program. My concern now is with the whole process of curriculum and instruction. We need to take a closer look at what Schaefer's tutors actually did, what our parent educators actually did, and what materials seemed to matter.



In our project, the curriculum was confined to specific concrete exercises. Basically, this was sound and successful. As our parent educators gained in experience and self-confidence, they were able to make a number of suggestions for relating what we were doing in the curriculum more closely to the cultural norms than those of us who pulled them out of Piaget were able to do. Our basic curriculum development model now, as we work with two- to three-year-olds, is to develop some sort of goal, then meet with our parent educators and staff, and think of all of the possible types of specific ways in which we might meet that particular goal using something very simple.

Right now we are dealing with cutting with scissors, of all things. We don't simply want children to cut with the scissors. There is no point in just teaching a two and a half year old to cut with scissors. He will learn it by six anyhow. But he now sees cutting as tool-using. The scissors is a tool that extends him. We have come up with all kinds of things--making montages, making daisy chairs, making hats--you name it, and somebody is doing it.

We are also accompanying this act with a good deal of "language envelope" in which the parent educator is teaching the mother to talk about what the child is doing while he is doing it. "Oh, look, that is an interesting thing. You have these things chained together." We introduce this kind of language pattern, which is not always natural in these homes.

I think that a curriculum such as the one we used in our infant study may have been too narrow because it was too focused on specific cognitive tasks. We need to devise a curriculum which stresses and utilizes curiosity, openness, and exploration far more than we did in our pilot work. This creates a variety of problems, both in training parent educators and teachers and in the teaching of mothers. The primary technique that we found in the home was an ordering, forbidding approach with little joy expressed at success and little opportunity for simple repetition of activities the child could already do.

Although the parent educators did well with the materials provided them, very often teaching looked like testing. You told the child what to do and he did it; you made a check mark in your record and on to the next item.

This, to me, is extremely important. We need to design materials and instructions so that the child's horizons are expanded and so that the mother comes to enjoy and value this new scope rather than restricting him. We need to develop and provide for parallel tasks as well as sequential ones.

For example, come back to scissors cutting. As homey as that is, this came from one of our parent educators. She wanted to teach the children to cut with scissors. We got her the very blunt ones. For



some of our workers, cutting itself was the beginning and the end of the operation. You took a long strip of paper and the child cut it. They took this activity into the home and the mother got a long strip of paper and the child cut it. The adults were ready to go on to something else. We wanted them to find ways of continuing to let the child fool with the scissors, fool with the paper, and produce new things. So now we are thinking of a bulletin board in each home. The child will make things in the home learning center, take some of these home to display. The mother will work with the child to make something at home and he will bring it back into the group setting to display. In this way we hope to work on the affective-celf-confidence, esteem, creativity, dimension which removes "cutting with scissors" from simply a motor skill.

Believe me, it may sound easy to say here, but it is one awful task in the field. We are concerned that our families are organized in a somewhat rote memory fashion. We need to learn far more than we know about general home conditions. We find radios and television sets on in the home, but nobody watching. There is noise in the background.

Our data suggest that there are relationships between the amount of verbal expression in the home and performance at age one, and at age two, on standard tests.

We believe that language development needs the interpersonal setting. I am aware of the Children's Television Workshop, but I am not at all convinced that the mothers that I work with will take advantage of this program, particularly if it interferes with soap operas. It will just not be turned on in the first place. If it is turned on, there is no pattern in these homes of attending to the set. If I had four-year-olds, my wife and I would sit them down and say, "Let's watch the television workshop." That is not about to happen in these homes, unless we work hard for it.

So the problem we have is encouraging ways for parents to communicate with their children and to realize that what they say, how they say it, and when they say it makes a difference.

Further, we find that these parents are not prone to let their children make mistakes. Parent and parent educators overly assist the child to perform a task in the right fashion and do not let him learn through any semblance of a discovery approach. I think that one of the reasons we may not get continuing improvement or maintenance is that we have not really found ways to change this character of the home, so that these kinds of activities go on. We have approached it to some degree in our program, but by no means have we got the think licked.

When the child moves into a somewhat traditional school, he is right back into the rote memory operation. I have seen, in a number of schools, every child on the same page, every child reciting the same work, every child making the same phonetic sound. You then have



to develop an intervention program that tries to "free up" the climate, deal with intellectual discovery, possible cognitive ways of learning, that won't lose its effectiveness because <u>both</u> the school and the home move it back into traditional ways.

I think we have to change both institutions, not simply one. What are the issues then? <u>First</u>, how do we change both home and school?

Second, the use of professionals versus the use of nonprofessionals. Who are better at what activities? What kind of tasks are appropriate?

Third, should we still concern ourselves with the mother, or should we, as some people have suggested, forget the mother, and concern ourselves only with the infant and provide for infant and early child care?

Fourth, and I think we have not looked closely enough at this, sex differences in learning. One of our most interesting findings is that most of our gains were made by the girls. In some respect, we may have retarded locomotor development in the boys in the first year of life. They look worse than control boys do. Just why this should be I don't claim to know, but I think we must take some leads from Ragan and investigate the way mothers deal with their boys versus the way mothers deal with their girls. What role do biological factors play in sex differences? I think we have a whole lot to learn about this area.

Fifth, the whole idea of a middle-class language versus a dialect is of importance. The Howard study, the Peabody study, our study, Schaefer's study--all of them indicate a language deficit. We are faced, however, with people who tell us it is not language deficit, it is a different language. I am convinced it is a different language, but it functions as a language deficit for operating in the schools and general culture as it now exists. I think to try and shift to a notion that all language is relative is self-defeating for the people who are taking that position. Let me remind you these are class and not racial differences. We have to examine in intervention programs, particularly, as we move into new kinds of social relationships, this whole issue of deficit versus dialect.

Sixth, we need to examine, in the area of curriculum, operant conditioning approaches versus open exploration approaches and how they get used in combination. My biases are known. I am in favor of the open exploration approach. I think that operant conditioning approaches, however, may be seen by the parent and by the teacher as very efficient and very useful because they fit very neatly into what they have always done. It just makes them more efficient at the kind of orientation they already employ. We need to raise the question: "How do you help children expand, grow, be creative, if you use operant techniques to reinforce creativity?" I do not know whether you can, but that is a whole area of investigation for school and home.



Seventh, the amount of structure which is desirable varies. We relied very heavily on a controlled curriculum. Other people have used a very loose one. I do not know whether we really know which is better or why.

Eighth is the question of timing. Some of Caldwell's work reported at APA (Sept., 1969) shows that it did not matter if the child entered the day care center before he was three or after he was three. Our study shows that the children who entered at 12 months looked no different at 24 months from the other 24-month-old children who had started at three months. Is this critical period really a critical period? Do we have to get in early or is often more important than early? There is the whole question of pacing and timing.

Ninth, there is the question that Jensen has reopened for us concerning genetic factors. I think everything that I have done in this particular project and just generally working where I have been working for 20 years, suggests to me that people like Jensen ought to get retrained in cultural anthropology, that they are assuming genetic factors because they do not understand the culture.

The children we deal with, as I said, are living in an ordering-forbidding world, in a rote-memory world. They have an addring-forbidding rote-memory teacher an ordering-forbidding rote-memory mother, an ordering-forbidding rote-memory minister. This, I think, is the reason for the difference--not ethnic, genetic, or overall social-class factors.

But this raises the problem for us. How do we break up a pattern which we think in the long run in a technological society is detrimental to these children? How in the world do you break a culture pattern firmly entrenched in home and school? I would suggest that you at least go back and read something written in 1946 by Kort Lewin in a book called Resolving Social Conflicts. In it he described how to convert Germany into a democracy. The problem is somewhat the same: how do we change an authoritarian school teacher or an authoritarian parent into a more open, more "learning" kind of person? Further, have we the right?

Another major question is, "Who will control whatever intervention programs may be allowed to flourish?" Is the consumer to control it? Is the researcher to control it? Can we learn how to find a mix in which both have something to say? I don't really know how that is going to turn out, but we are facing this issue in the parent-child center, the Head Start, follow-through, and other programs.

We have a whole host of research issues. There is the problem of measurement. We have virtually no adequate measurement techniques for the early childhood years. This is deplorable. My testers' experiences with the Bayley Scale, which is probably the best American instrument, lead them to believe that it is not an effective measuring technique in the normal testing situation. When there are racial and social-class



differences between the examiner and child, or when the examination takes place in an institutional framework, we lack effective measures. Even if we say that self-concept originates in the first three years of life and that how one views himself is a critical variable in all that happens to him afterwards, we have not the vaguest notion of how to measure this variable in the first three years.

We are beginning in some of our work with the two-year-olds to try and move toward an observational technique. We watch a child as he is busy with a toy. Another child who is a little bigger and a little stronger comes over and takes it away from him and the child we are observing kicks him, screams, hollers, yells, and beats on him. How, what is that? Is that good or bad self-concept? Or he may look and see that his child is not about to surrender it and is bigger than he, so he runs over and gets the adult. Is this good or bad self-concept?

We do not have the theoretical notions well-defined. We do not have empirical measures. We had thought we were going to lick this. We planned to observe these behaviors and study the relationship between the observed behavior and a self-concept scale. So we used a nonverbal scale, developed at Delaware by Long, Henderson, and Ziller. However, our three-year-olds cannot deal with it at all. We are stuck because the scale we were going to use as a baseline does not work. We need a good deal of work here.

What has happened on many of these studies is that we fall back on the Stanford-Binet or the Bayley Scales in desperation rather than because we find them useful.

Some massive efforts, it seems to me, must be made in instrument development. Now, look at the money and look at the time that a bench researcher may spend, learning how to develop and use an electron microscope or learning how to slice tissue. While it is routine and dull work, the investment of time and money is fantastic. There is no comparable investment in time and money in the behavioral area, and until there is, we are really going to be faced with sun dials instead of chronometers.

We need longitudinal studies using various patterns. Those who subscribe to a transactional view know that children are affecting the mothers just as much as mothers are affecting the children. How do you disentagle it? One of the things Caldwell said about a year ago was that some of the children, according to the parents, were turning into absolute monsters because they had so much attention and tender, loving care in the day care center. They were so used to commanding adult attention and getting reinforced for seeking attention, they would go home and make life miserable for the mother, because the mother was not able to pay the same kind of attention to them that was being paid in the day care center. We see similar events. We have youngsters starting to make demands on parents for many things. A mother with



nine children has to drop out. She has not the time or the patience to spend with this child in the way he wants.

We need to look at the basic effect of what the programs are doing to the parents. Schaefer reports that, although his children are growing, his families are getting more divorces. Mothers are beginning to move away as they watch his tutors. They are going on for more schooling. They are getting steamed up and they are breaking out of the mold to some degree. It is showing up more in his experimental than in his control group. I could raise the question as to whether the divorce is good or bad. Anyway, it is happening.

It may be that those who are acquiring the values of the technological society in his experimental group are also acquiring the value of divorce as a spin-off of a technological society. It reminds me of our early attempts in public housing. We did not know all of the side effects. I think here is where the word "ecological" has to come in. We need to look into the whole system to see that what we are doing might be accomplishing something, but also has effects that we did not predict, expect, or know about at all.

We also need to get researchers to use the same sort of measuring tools so we can get some crost validation. I do not need to remind this group, I guess, of the difficulty of field research, the problems of attrition, the problems of the Rosenthal effect, the whole problem of maintaining a population in a technical study.

Yet, I am firmly convinced we cannot shift these studies into laboratories. I think we need a lot of basic laboratory work, but we need to continually test in <u>field</u> settings. We perhaps also need to change some of our notions of what an experiment is. To me, some of the main values are not the experimental versus control findings. They are in going back and carefully examining within the experimental group the variables that might have made some of these children or some of these parents flourish when others did not. Along with that, field studies should use a program modification approach in which you are continually assessing.

If you look at industry, for example, you see quality control all along the assembly line. We need this kind of testing. It should also have built into it the freedom to shift the procedure as you get some indication from the quality control, rather than the usual static laboratory experimental design in which you are boxed in and say, "This is what I set out to do, and even though it is going all wrong, I don't dare not do it because then I am contaminating the experiment."

We have to forget about contamination and become a good deal more heuristic, a good deal more exploratory, a good deal more open to deal with our project as we get feedback from it as to things that go and things that don't go. This requires the kind of operations research



in which we keep extremely careful records of where we switched, why we switched, and what we then moved toward.

We need to fund a good many comprehensive programs and build inside of the comprehensive umbrella a lot of small scale studies rather than funding a lot of individual entrepreneural research that doesn't tie together in any kind of a package.

We need to find ways to deal with high-school youth as interveners in early childhood education. In effect, we are still not "off the pad." We need a tremendous amount of developmental research to investigate the varieties of issues that I have tried to sketch out for you, to allow these extremely capable people like Schaefer, Caldwell, Weikart, and Karnes to stay with what they are doing, to study it longitudinally. "Opefully, we will find data from which we can say: for this kind of population and this kind of setting, and under these conditions, procedures A, B, C seem to work most effectively while under these conditions, procedures D, E, and F seem to work. I prefer this to looking for the one magic approach that is going to solve everything across the board.

I don't think we can hold off on providing services until we have more definitive answers from research. In fact, I think the way you get the definitive answers is by the kind of field study which is a good mix of service and research in and of itself.

I know, as a teacher of teachers, that teachers say, "Tell us what the research says and then we will know what to do." As a researcher, when I walk out of that into my other office in effect, I get panic-stricken that the educational process and the service programs are outrunning the research. I wish it were true as has been said, that research is 20 years ahead of service. I don't think it is at all because the earliest project I talked about was 1961. If you are talking about basic research, I have tramendous respect for somebody like Lew Lipsitt at Brown University who investigates infant learning. But for the life of me, I cannot go from the operant conditioning of the sucking reflex to service. I cannot get there.

So to me, if you are going to wait for results from that kind of research, you are going to wait forever. I think in education we have learned virtually nothing from the psychology of learning for 69 years. The gap is just too big.

MR. LYNCH: The work of Lew Lipsitt stemmed from our inability to test hearing defects in children. He is using operant techniques because they happen to be the only ones that work with a pre-verbal child. As a matter of fact, it is through techniques like his that others are discovering very interesting facts about the day-old infant's hearing ability. This has "demolished" the myth of the inert, passive stimulus receiver--and it got very immediate practical applications but not a program of service.



MR. SMITH: One thing must be said: most of the intervention research that has been undertaken is <u>teaching</u> oriented, even when it involves a parent. It is an effort to make the parents teachers, and the approach is cognitive-development oriented. How can we make this child a brighter child? One of the observations which has been made is that it does not seem to matter too much how early you start.

DR. GORDON: I have tried to indicate that I do not see cognitive growth as the only outcome of intervention programs. I am concerned about youngsters feeling good about themselves, feeling adequate, feeling comfortable. I think I stressed something about the mother feeling competent, feeling that she is accomplishing what she is trying to do for herself.

I think the quality of life is an extremely important aspect of it. If there is anything that I have learned (and I am not really always sure what I have learned in the last three years), it is that I reject the notion of the "culture of poverty" as a label. We have families living side by side who on some external measurement are very much alike, who have obviously, when you visit in the home, tremendous qualitative and quantitative ways in which they are different from one another.

MR. KRAUSE: It may very well be that most of the people who grow up in poverty areas do not get identified as the subject matter of our present concern; namely, mental retardation. However, I am told by good sources that poor people represent more than 75% of our mental retardates. Here we have a source of the vast majority of our mental retardates and I think the kind of work here is going to have some influence on the frequency of mental retardation in this country.

DR. GORDON: This review should not be taken pessimistically. It was designed to present you with the state of the art, to indicate to you that although there is a set of unanswered programmatic theoretical and methodological questions, the field is also engaged in exciting discoveries from a variety of viewpoints. Although I have highlighted the issues and played down the fact that experimental groups have always done better than controls at the original termination of projects, these studies and the laboratory work of people like Lipsitt have indicated that infants and very young children are quite ready and competent to learn, that parents can be actively involved in children's learning, that paraprofessionals can function in educational roles in early childhood, and that group care is not the anathema we once thought it was. These studies have all highlighted and emphasized that there is such a thing as education for very young children. As we develop day-care programs, they will profit from this pioneer work by including educational components which will perhaps allow us to curther investigate the role of planted educational programs in the intellectual and personality development of children.



#### New Directions in Reformulation Efforts of Teacher Education

#### Nicholas J. Anastasiow

American education has been characterized repeatedly by slogans. In fact, education might be described as having moved forward slogan by slogan: progressive education, team teaching, ungraded schools, prescriptive teaching, computer assisted instruction. There is a major problem with slogans: slogans are perceived as offering panaceas or universal cures for the wrongs that are found in the schools. Schools are panacea-bound, that is, looking for all-inclusive right answers for their problems. Once a new innovative technique is ad pted the schools become bound to it as the way to channel personnel energies and support.

But changes have been occurring very rapidly in our country and our schools reflect the pressing need to modify the repressive nature of the school classroom.

It is recognized that there have been major breakthroughs in the knowledge of how learning takes place. Secondly, development in communication and information theory has indicated major techniques for knowing how to facilitate and understand the multiplicity of environments for learning. Thirdly, it is recognized that what is selected as the content and process of education is a planued choice in deciding what kind of a world is desired by those who do the training. It is clear that the current social system demands that man respond to the system rather than the system respond to the fulfillment of man. It is recognized by many that the success of the current system is at the expense of man, the environment in which he lives, and perhaps the world itself.

It is also recognized that the children in our culture will live in a world in which they are a minority. Unless changes in values and moral orientations are made, the majority of men, particularly in the developing nations, will be unwilling to accept and participate in a hierarchical social-political system within which they will not be rewarded.

It would appear that the inconsistencies of our value systems and man's misuse of man, of the environment of the earth, have led to the alienation of significant populations of youth who are profoundly disturbed at the failure of societies to reach humanistic goals. Yet these same students seem to lack the skills and capacities to create viable solutions. It then follows that efforts in teacher-reformulation must be to draw upon the existing knowledge base to assist children in developing the capacities to create an open society, built on a moral base, that is concerned with systems that fulfill the needs of man.



It is recognized that the experience of the student in today's world is of a significantly different nature than that of the student in the past. This does not mean to imply that the usefulness of knowledge is in question but rather that current modes and strategies of training may no longer work.

It is not so much that current education has failed. Rather it is abundantly clear that the society that has been constructed, including its educational process, is ro longer a viable means for ensuring man's existence. Our society has accomplished certain successes but many of these successes have been at the expense of significant segments of this world's population.

It is now recognized that the price for the kinds of success formerly desired is so great that man no longer adheres to the old goals because the moral and ethical values of the society are endangered. It is man who points to the need to redirect our efforts not because of our failures, but because the product of education must be of a different nature in tomorrow's world.

This paper is concerned with only one section of the problem, that is the reformulation of teacher education. For a more comprehensive and thoroughly literate discussion of the total problem the reader is referred to Charles Silberman's <u>Crisis in the Classroom</u> (Random House, New York, 1970).

The schools have appeared to change in the following six ways:

- Updating subject matter
- 2. Introducing new courses
- 3. Reorganization of old courses (new math)
- 4. Using newer technological aides
- 5. Emphasizing underlying processes of knowledge
- 6. Renewed emphasis on how children learn

It appears that an attempt to provide for individualized learning underlies most of these six areas of change. It is assumed that the best learning environment places the learner-infant, young child, or adult-near the level of his current functioning. The learner is seen to bring a series of past competencies to a new situation; he acts upon these competencies with the new information presented.

This kind of assumption seems to be implicit in team teaching as a reorganization of personnel to enable teachers to provide more adequate instruction nearer the child's level of achievement. Computer-assisted instruction allows the child to progress at his own rate and assess his skills and abilities.

"Prescriptive teaching" does much the same, and "ungraded" instruction is essentially ungrading the teacher's expectations of an individual child



from arbitrary norms of age or grade to individualized learning. Each of these innovations appears to be an attempt to individualize the instruction for the child by basing the teacher's expectations of what a child will do on accurate assessment of the child's level of academic and emotional-social (affective) achievement.

Teaching then becomes the accurate interpretation, diagnosis, or evaluation of the student's performance, capabilities, and achievement. Planning instructional activities attempts to maximize student progress. Once the instructional procedures have been initiated, evaluation becomes a continuous and integral part of the teaching-learning process. The teacher's critical task is determining in what way a child will learn, not why he hasn't learned. When a teacher sees a bit of a child's classroom behavior, the key for his planning the next instructional situation is interpretation. If the interpretation he brings to it is diagnosis only, and labeling, he will find out more about why a child hasn't learned, than how a child will learn. In this sense, the teacher can bring in audiovisual materials; he can plan a different kind of lesson; he can change the instructional situation based on his interpretation of the child's behavior. Teaching is perceived as a means of maximizing the probability that a child will become cognitively involved in what is being presented.

All learning is viewed here as the result of the <u>individual's</u> transactions with the environment. This notion perceives individuals of all ages as acting in any setting as a learner of new information and the possessor of previously acquired skills and competencies. That is, each individual brings to a new situation past experiences and competencies upon which he may develop new skills or knowledge. Necessary to learning is the prior acquisition of prerequisite capabilities, what Gagne refers to as "specific readiness."

Each teacher must be a "student" who learns about his pupils, recognizing that he and his pupils will construct their own knowledge based on each pupil's current set of competencies. Whether they are children, teachers in training, or college faculties who train teachers, learners have this common characteristic. Thus any undergraduate, graduate, or public school training program must develop models that allow for individualized learning.

This point of view, then, proposes that there are no such things as age, grade or norm expectations; that the expectation of what is the appropriate learning situation for a child is the set of competencies that he brings to the situation, and the teacher's assessment of what are the needed competencies for him to be able to perform that which has been determined by the school or the culture or the teacher as the next step.

If we accept this point of view about learning, then these assumptions hold true for undergraduate teacher education. The set of competencies that undergraduate teachers in training possess must be assessed and interpreted. Having diagnosed these prospective teachers, an instructor would



have to evaluate and plan clinical situations, enabling the group for whose training he was responsible to perform certain required tasks. This has not been the method of undergraduate education in the past, however.

It would appear that college professors have assumed that undergraduate students meet the prerequisites for their course and possess the skills necessary for successful completion of the course. Freshman undergraduates have graduated from high school and have been admitted to a college; having taken prescribed courses, sophomores are passed on to higher level courses and so forth. In addition, it was assumed that all students were ready for the next step because they had taken the first step. It is assumed that learning can take place by didactic lecturing in courses. Training of teachers has been modeled in the liberal arts tradition, which in this paper is seen as a very inaccurate model for the training of teachers to perform certain tasks in the classroom. Teacher Educator Programs probably have both been violating the notion of assessing prerequisite skills of prospective teachers and, further, have used a lecture method which is inadequate for training in interpretative, evaluative and diagnostic skills.

Today in education—in undergraduate education and education in general—we face quite a different situation than has been ever faced before: the teacher shortage, demanding nearly 220,000 teachers a year, is lessening. The number of children entering schools has reached a plateau. Education (including Special Education) has an opportunity to begin looking at the quality of its training programs, as Clark suggests, rather than at quantity.

During the Second World War, one of the people at Stanford used to say that, if there were not a doctor in the town, the patient would die: a druggist, a nurse, or anybody else could not perform the doctor's functions. However, if there were no teacher, anybody could perform the role in the classroom. It seems that society has looked on the teacher's role in just that way--a non-technical role that anyone in the community willing to do so could fill.

Clark believes this attitude toward teaching must change and will with quality as the hallmark of teaching in the 70's. Miller, however, says of preposals for change submitted so far: "Although they are better than ever, they are weefully inadequate to move ahead with the future." Though different in some respects from Gerry Smith's "omnicompetent" teacher, Miller would require of teachers in his ideal program:

- 1. Two years of broad, non-professional education;
- 2. Multi-media introduction to teaching in the junior year;
- 3. A semester abroad;
- 4. A pre-service program with a strong inquiry bias;
- 5. Competence in research methodology and design;



- 6. Experience with innovations and the process of change;
- 7. Continuous pupil progress and team teaching;
- 8. Independent study;
- 9. Student-planned courses
- Carefully supervised, extensive, realistic pre-service programs.

Miller lists ten requirements in addition to those mentioned above.

Many authors are suggesting today just such an omnicompetent teacher, a "man for all seasons." Unless it is possible to have tutorial programs taught by Leonardo da Vinci, this idea of the omnicompetent teacher seems to be unrealistic. It seems difficult, for instance, to justify requiring competence in research methodology and design. Therefore, programs must be examined to be sure that only behaviors that teachers need to perform are included. In addition, programs must be examined to insure that the training procedures included are bringing teachers to criterion performance.

"Performance criteria" and "systems approach" are familiar terms in today's teacher education programs. The disconcerting problem with these programs, however, is the proliferation of performance criteria based on what exists, rather than on what might be. They assume that education should be an objective pursuit. William James long ago warned that education must, by its very nature, be an ethical, human, and "very non-objective kind of enterprise."

David Glieseman seriously questions the value of psychology in teaching. He suggests that a vast amount of information currently taught is not useful in teaching and may even get in the way. He feels we must be much more selective and explicit, careful not to present every behavior men are capable of. Moreover, he suggests that many psychological concepts currently taught have not been subjected to validation in the complex reality of the classroom.

In his films, "Critical Moments in Teaching," Gliessman attempts to present a protocol of classroom reality, exploring honestly and explicitly what teachers will deal with. Prospective teachers and trainers of teachers can view a situation together for a common basis of discussion.

Gliessman suggests a large number of psychological concepts are not useful in forming hypotheses to interpret (or diagnose) in the classroom. For example, of what use to a teacher is the concept of retroactive inhibition? Gliessman suggests that the stress should be on functional learning, i.e., learning to interpret and understand from observation of real teacher-pupil behavior. (Videotape or film provides a method of freezing the dynamic, changing classroom for leisurely examination.) A trainer of teachers must then view the student's behavior and interpret and diagnose in response. Mesearch evidence indicates that repeated viewing and interpretation of particular classroom behaviors result in cumulative improvement of the student's ability to interpret.



Other models include the Spring 1970 <u>Journal of Research and Development in Education</u> description of nine redesigned elementary teacher-training programs. In general, they are behaviorally oriented, stressing the need to formulate objectives in terms of behaviors the trainer wishes the teacher to perform.

Most new teacher training programs stress multi-media use. Multi-media presentation increases the probability that a student's attention will be drawn to the relevant dimensions of what is to be learned, while allowing for a wide range of individual differences. It is a means of relating the undergraduate's past competencies to present task performance requirements.

It is not always clear that performance criteria programs are aware of the need to follow Gagne's advice that:

In the most general sense instruction becomes not primarily a matter of communicating something that is to be stored. Instead it is a matter of stimulating the use of capabilities the learner already has at his disposal and making sure he has the requisite capabilities for the present learning task, as well as for many more to come.

In addition, McIntosh's suggestion that personnel in these "newer" programs might well tend to use the language of everyday speech for technical communication needs to be given serious attention. Medical researchers, for instance, use a highly specific, esoteric language. On the other hand, the language of education is the language of daily use. When a language cannot precisely describe a phenomenon, McIntosh argues, discussions must occur in the context of the phenomenon. Only then can the trainer of teachers identify an event or problem for his trainees and be reasonably sure that he has established a common basis of understanding. Largely because of our language's lack of specificity, it seems important that discussions about educational variables, children, and children's behaviors occur in a real or simulated classroom context.

The major reformer, B. O. Smith, has in his book, <u>Teachers for Tomorrow's World</u>, presented an even stronger need for radical reform in teacher education. He suggests that there has to be a focus on specific training of teachers in real classroom settings. Undergraduate programs would have to be redesigned in Smith's view so that training becomes the central element. It would appear that Smith would not accept films and other audio-visual materials alone as Gliessman would: he would want prospective teachers to have real contact very early in their experience under highly specified training conditions, preferably in the sophomore year.

Smith points out an additional advantage to identifying prospective teachers early for placement in real classroom situations. Education still draws on the upper-lower class for teachers, who, if their contact with



children comes in the fifth year, can not afford to change professions. Putting students into the classroom environment early gives them an opportunity to change careers earlier if they find the situation not to their liking.

Smith sees current undergraduate teacher education largely as a failure, outmoded, inadequately designed, and staffed by personnel unable to perform the tasks required. He stresses the need to focus on teacher training, not teacher education. The only contact with the real world prospective teachers have is in student teaching, a program Smith says fails in what it purports to do.

Smith suggests that theory's real place in future teachers' education is as a source of concepts on which a teacher will base hypotheses. These concepts the teacher holds probably affect his attitude toward children; for example, a teacher who accepts frustration as a potential source of aggression will respond differently than one who sees aggression as a product of a "bad boy."

To Smith, concepts derived from theory provide the teacher with training in interpretative and replicative uses of knowledge. Thus, the teacher is required constantly to interpret and diagnose a child's behavior, deciding the next step in the instructional process. Interpretation guided by theory leads to action and a new step in the instruction of individual children.

To Smith, the trainers of Teachers, therefore, must not pattern their courses after the liberal arts. They should use the more practical organization of law and medicine, where case study and clinical work are emphasized. Educational pedagogy then needs to identify concepts such as motivation, feedback, and explanation which can be used to interpret situations teachers most frequently encounter.

Interpretation in Smith's model is the key construct, since the teacher is seen as responding to the meaning of what he observes, rather than to the event itself only. This notion implies that the initial phases of training must contain real behavioral situations, providing planned interpretative sessions in which concepts are presented to be learned and used in subsequent teaching. The model thus allows for past competencies of the student in training, a means whereby the professor and student view the same event, the student interprets the pupil's behavior and the professor interprets the student's behavior.

In addition, Smith says situational models should be provided in extraclassroom, as well as classroom situations. Protocol audio-visual material must be developed to cover instructional, managerial, and control situations. Teachers are not only in classrooms with students; they are also members of professional organizations; they work with parents; they have to respond to the principal; they have to respond to other teachers. Teachers are not



being trained in the different kinds of communication patterns they would encounter in these various roles.

Smith lists ten minimal abilities which a program of teacher education should develop:

- Performing stimulant operations (questioning, structuring, probing);
- 2. Manipulating the different kinds of knowledge;
- 3. Performing reinforcement operations;
- 4. Negotiating interpersonal relations;
- 5. Diagnosing student needs and learning difficulties;
- Communicating and empathizing with students, parents, and others;
- 7. Performing in and with small and large groups;
- 8. Utilizing technological equipment;
- 9. Evaluating student achievement;
- 10. Judging appropriateness of instructional materials.

The training process would include the following:

- -- Establishment of the practice situation
- -- Specification of the behavior
- -- Performance of the specified behavior
- -- Feedback of information about the performance
- -- Modification of the performance in the light of the feedback
- Performance-feedback-correction-practice schedule continued until desirable skillfulness is achieved

This is an expansion of the "micro-teaching" model. Stressed throughout the program is the notion of feedback and assisting the teacher and the child to focus on relevant behavior.

Smith adds to this model a training program that would deal directly with the teacher's interpsychic and interpersonal needs. He focuses on personality as a complex of factors modifiable by instruction:

An internal frame of reference consisting of self-evaluations, feeling and attitudes, regarding one's adequacy and worth and a defense system together with the constitutional style of behavior.

The trainer of teachers, Smith feels, has the responsibility of dealing directly with the future teacher's personality dimensions:

- 1. Feelings about one's own limitations;
- The need to be liked and to be approved of by pupils and peers;



- 3. Feelings of inferiority;
- 4. Feelings of insecurity;
- 5. Paranoid tendencies;
- 6. Suspicion and fear of pupils.

It would appear that in teacher training programs prospective teacher's attitudes, biases, and personal ideosyncracies which might interfere with his performance in the classroom must be confronted and be a part of the training program. This point will be discussed more fully at the end of the paper.

Trainers of teachers must also deal with future teachers' attitudes toward children:

- -- Dislikes and preferences for particular children
- -- Dislikes for particular ethnic groups
- -- Favorable disposition toward docile children
- -- Inclination toward accepting complaint and withdrawn behavior, rather than toward aggressive and blatant behavior
- -- Low expectations of some (particularly poor) students

Teacher's expectations will definitely influence what and how well his pupils do. There is perhaps no attitude of a teacher that debilitates a pupil more than low expectations.

Training must focus, Smith says, on helping the trainee become aware of his attitudes and providing situations that will cause reflection and change. He suggests that attitudes are based on feeling and cognition:

- A feeling attitude can be changed through counselling procedures including behavior modification;
- A heavily cognitive attitude can be changed through examination of its content, reasons, and evidence, as well as through group discussions.

A plan for changing attitudes should be part of every teacher training program. If a teacher, for example, finds himself instructing a curriculum emphasizing inquiry, process of orientation, and creativity, he may be working against the program's goals if he tends to reinforce and reward docile children. Smith feels that success in changing the schools will be achieved when an influential mass of well trained teachers exists who will not give in to less competent teachers.

Though more highly developed, Guba's model of a professional center and Smith's concept of a training center are similar. The professional center concept is new, joining the university and the school district to work on common and separate problems. It places undergraduate students in schools much earlier (sophomore or junior year) to provide a longer,



continuous experience in the classroom. It gives the student a chance to observe several models of teachers and the opportunity to change professions if he finds he is not suited to teaching. Moreover, Guba feels that the professional center provides evaluation of future teachers much better than Smith's training center does.

The professional center has four components: teaching team, resource team, clinical team, and developmental unit. The instructional unit is six classrooms; four teachers are maintained for instruction, and four students in training are added to the unit. The two extra teachers are released to serve on the resource team. The teaching team--six teachers-would function in ungraded classes; although in Guba's model, team teaching, individualized instruction, or any other methodologies could be employed.

In addition to teachers released from teaching teams, the resource team would be composed of university personnel: student interns or graduates with Master of Arts degrees. The resource team functions as an auxiliary to the teaching team, finding material, supervising classes, and demonstrating classroom concepts. They function to channel to the development team problems identified by teachers.

The development unit would be composed of evaluators, substantive area specialists who would design, structure, and field test new instructional materials. They would spend a great deal of time evaluating curriculum materials and designing new materials in the school context, rather than in the collection of hard research data. This unit would probably include the school reading and curriculum specialists; both these school personnel would work with subject matter specialists from the university and those who teach particular specialties in the school of education.

Guba would have the clinical team responsible for in-service training in:

- 1. Role differentiation;
- 2. Training resource teams;
- 3. Service as the university's change agent.

Guba hopes that mutual interaction between the school district and the university will result in mutual change in both. Guba's model is method-free. Other than designing a way to unite the university and school, it does not prescribe how or for what they should train.

To summarize briefly, it seems that most new models of teacher training assume that we have to train teachers to perform specific activities. Second, training programs must include both the cognitive dimension and interpersonal or attitudinal dimension of the teacher in training. Third, learning occurs on a variety of levels based on ideosyncratic backgrounds



and past competencies: professors, graduate students, undergraduate students, and children in school all learn in basically the same way.

Another proposed model for training teachers is Orme's. Orme presents a model of teacher training in terms of the construction with the system for cultural and instructional expectations, learner objectives and motivation, instructional content, and instructional procedures, with parallel requirements for teacher competence at each level. The instructional process, like Smith's model, divides into four levels: motivation, presentation, practice, and feedback.

The large Orme model can be discussed in terms of the teacher's expectations, demands, values, and biases, and in terms of the learner's objectives, motivation, abilities, prior history of learning, and role expectation. Orme applies knowledge, comprehension, application, analysis, synthesis, and evaluation to operations and instructional goals; however, this discussion will treat only one area, the instructional process. Of Orme's presentation modes for teaching, how to probe in a modified microteaching situation will be the only part of his system discussed here.

Probing is the kind of questions teachers ask. Typical questions in readers and textbooks are answered "yes" or "no." Questions in elementary school readers about, for example, <u>Tom Sawyer</u> or <u>Huckleberry Finn</u> might be:

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"What was the name of the boy?"
"What was the name of his friend?"
"What was the name of the river?"
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Though these are simply informational questions, more sophisticated questions might request:

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"What do you know about the life and times in the book Huckleberry Finn?"
"What kinds of occupations do you think they had?"
"What was the family pattern like if the father had that kind of education?"
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These latter questions approach a sort of critical awareness.

Rarely do questions require an evaluative level of reading: "What is the basic theme of <u>Huckleberry Finn?"</u> The basic theme of <u>Huckleberry Finn</u> might be interpreted as several; for instance, it probably is Huck's Quandry between good, personified by Aunt Sally, and evil, personified by Huck's father. Children can discover through reading and discussion that individuals are both good and evil.

Orme is one of a number of investigators who are presently trying to break down the whole process of teaching teachers to ask more sophisticated questions. How do we teach teachers to go beyond the informational level?



How do we get teachers to respond to what a child does in the classroom by taking the child to a deeper awareness level or getting at the content of what they want to teach? Orme proposes the following steps: teacher's questions, pupil's response, teacher's decision to probe or not to probe. If the teacher probes, what kind of probe does he make? Is it clarification, critical awareness, prompting, or redirection? What are the consequences of initial probing? What does the teacher do next?

Orme experimented with four training procedures. His controls had a pre-test with no consistent training, and they had a trial. The second group was composed of teachers in training rating other teachers on a prepared form. The third group were observers only; they did not rate anyone. The fourth group had direct practice, going through the entire sequence of decisions and probings.

Orme observed the time each of the four groups required to learn the sequence and found the following:

- -- Group 1 (controls) experienced very little change;
- -- Group 2 (raters) experienced very little change;
- -- Group 3 (observers) experienced an important, more dramatic change;
- -- Group 4 (direct practitioners) experienced the most dramatic change.

More dramatic changes resulted from expanding the original test groups by three: (1) parallen practice; (2) vicarious practice; and (3) use of an observational model with peer supervision. In 1969 Orme was able to train about 300 teachers in this one aspect of the probing technique.

Orme's model is an example of an attempt to devise a training procedure to enable students to perform a desired behavior. It is a modification of the micro-teaching technique, which employs videotaped feedback to a student who has just taught a five-minute prepared lesson. The micro-teaching situation handles 20 teachers in training well; Orme's technique, on the other hand, might turn out larger numbers.

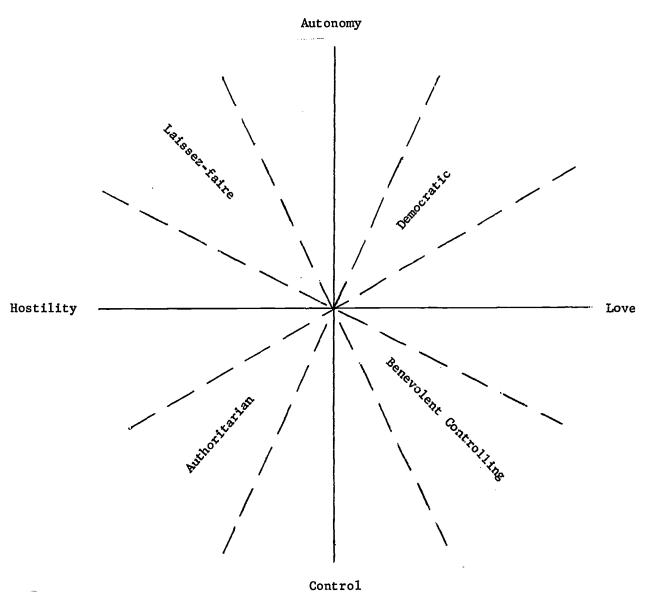
One of education's problems stems from the wide variety of disciplines—anthropology, sociology, and psychology—it draws from. Teacher education has tried to expose its trainees to all these areas. It has failed to examine each of these relevant fields for applications and solutions for problems teachers encounter in their classrooms and has attempted to give total exposure instead. This, in turn, has resulted from our failure to specify the tasks teachers must perform in classrooms.

Our culture can no longer afford not to define performance criteria. Techniques like Orme's appear to be able to train large numbers of people in specific tasks. But the problem of identifying these specific behaviors remains unsolved. This is where research must be done.



A balance of autonomy and love would be what I describe as a democratic person. A process-oriented curriculum needs just this sort of teacher, since process-oriented education focuses on the child's attaining underlying understandings and other less rigid types of information. This teacher would have to be fairly autonomous and accepting in his responses to children. This is the quadrant of the Schaefer twodimensional model characterized by high autonomy and warmth.

Figure 1 (Expanded after Schaefer)





Theory's place for the teacher seems to be the same as for the clinical psychologist. Theory doesn't cure the patient. It does, however, provide the therapist (and teacher) with a hypothesis of how to respond to the behavior that is before him.

The ultimate object of teacher training must be to involve students cognitively. The content of training curriculum must be limited and only expanded to reflect this goal. It would appear that direct work by prospective teachers in schools should begin at the junior, or preferably sophomore year to train not an omnicompetent teacher, but to train prospective teachers competent at different roles.

In this sense, attention must be paid to the personality dimension of prospective teachers. Evidence has suggested that warmth or liking for children is an important aspect of a child's learning. Studies have demonstrated the effect of teachers' warmth on children's achievement; however, other studies have not been able to show an effect.

Some of the earlier teacher-child studies by Sears, Soars, and Spaulding have shown that students can operate on self-reinforcement schedules. In addition, Spaulding was also able to show that teachers might achieve academic goals, even though they might not have been warm. That is, teachers who were hostile toward children, using very punitive techniques, had academic success; however, when concepts like creativity and self-concept were measured, children in these classrooms did not gain in the socio-emotional areas. These data suggest that a warmth-achievement relationship was too simplistic a model. Achievement as a result of punishment, for instance, might very well show negative self-concepts and decreased creativity.

It may be useful to examine the results of parent attitudes in the child's development for guidelines of what to expect of teacher-child transaction. In general, research (see Anastasiow, 1963) has indicated parental warmth, setting of achievement standards, and parents' use of reasoning as the three variables associated with a child's school success.

The author used Schaefer's model to study sex role and parent attitudes; the model included two dimensions of "autonomy-control" and "hostility-love." Schaefer later expanded his model into a three-dimensional, spherical scheme and others have used the model.

In this earlier research, statistical clusters were found containing such variables as "democratic procedures," "rewarding independence," and "high self-esteem." These parental qualities seemed to be associated with those qualities which are judged as very favorable attainments by a child. In a pilot study I expanded the application of the model to examine teachers rather than parents (Anastasiow, 1968). In essence, the position was that these teachers' preferred personality style interacts with the methodology used in the classroom.



The second quadrant, benevolent control, describes a warm teacher relatively high in control. This would appear to be the cultural stereotype of the teacher. This teacher is perceived to be motivated out of liking children; he wants the children to learn; and he frequently uses control techniques to insure that children will learn. There are hypothesized to be large numbers of teachers who are benevolent controllers.

Another kind of hypothesized teacher is the authoritarian. He is perceived as having very tight control of the classroom, using punitive disciplinary and negative reinforcement techniques. This teacher would be amenable to process-oriented teaching although he might adopt the curriculum presented in his school district and implement it in his own way.

The fourth type of teacher is the <u>laissez-faire</u> teacher, who presents some problems in interpreting. He may be motivated by hostility toward the children in his class and thereby exercise little control. On the other hand, the <u>laissez-faire</u> teacher may be submissive to control by principal, supervisor, or peers. I suspect that it is submissiveness to control of the authority figure that defines the <u>laissez-faire</u> teacher.

Our original work with these four types of teacher personalities began when it became apparent that teachers in an innovative program were reacting quite differently to communications about teaching techniques. Some teachers rationalized away the innovations as unimportant; others appeared to assimilate the communication as identical with existing practices; still others investigated the new techniques in some detail and attempted to put them into practice.

These different reactions may be understood in terms of psychophysical research on judging weights. In these studies when subjects were given a set of cups filled with varying amounts of water and asked to order the weights, the subjects did discover the relative weights of all the cups and ordered them, but each subject ordered them idiosyncratically. When several cups varied slightly in weight, the subject tended to judge them of equal weight: that is, he perceived an average or "anchoring" weight around which he assimilated cups of similar weight. Cups that varied from the anchor weight were judged much heavier or lighter than they really were; they were contrasted away from the anchor.

Communication about a fairly democratic process-oriented curriculum, for example, is hypothesized as contrasted away or assimilated by an authoritarian teacher. "That is what I have wanted to do. That is what I want to do in the classroom. Those are the goals that I have been working toward," he might claim. Or he might say he had been doing the same thing for some time.

Since the communication was much nearer the democratic teacher's anchoring point, he is hypothesized as asking more questions about the



proposed technique. The underlying goals of the innovation seemed to be more similar to the democratic teacher's than those of the other types.

Originally it was thought that the <u>laissez-faire</u> teacher would not put the new techniques into practice. He was hypothesized as wanting to allow his class more autonomy. However, our experiences indicated that <u>laissez-faire</u> teachers appeared not to be able to understand the intent of the program. <u>Laissez-faire</u> teachers insisted on being given daily lessons rather than making their own classroom curriculum decisions.

Since attempts at communicating the new techniques were apparently not succeeding, the personality types of 15 teachers involved in an experimental primary and nursery school program were investigated to see if they fell into one of Schaefer's four categories. The experimental program's director and independent observers rated teachers individually and as members of two-man teaching teams for successful accomplishment of the process-oriented program goals.

Teachers' personalities were ascertained using Schutz's FIRO-B, modified to reflect dimensions of warmth and control in situations teachers encounter in and out of the classroom. The FIRO-B had three scales concerned with the following questions:

- -- How much warmth do I want other people (or my students) to express to me?
- -- How much warmth do I want to express to other people?
- -- How much control do I like other people to have over me?
- -- How much control do I like to have over me by other people?

There was also a scale measuring "inclusion" which was not used when factor and cluster analyses revealed that the six scales could be reduced to two factors, that of warmth and control.

In addition, data of behavior of students in the classrooms was gathered using Spaulding's Coping Analysis Schedule for Settings. The scale is a time sampling technique that measures appropriate and inappropriate pupil behavior on 13 dimensions. A minimum of 7 hours were spent in each classroom observing rest, free play, snack, reading, and a variety of other behaviors.

Support for the 4-type personality model was gained even from this small sample of 15 teachers' self ratings. Most were <u>laissez-faire</u> teachers. The 2 teachers typed democratic were rated as the most successful by the curriculum director and the 2 project directors.

This sort of information in advance is perceived as critical in teaching teachers in the field or in teacher training. <u>Laissez-faire</u> teachers or prospective teachers would need more direction and assistance than would



democratic teachers. Highly programmed or computer-assisted curricula might be used with the <u>laissez-faire</u> teacher at the onset of the program. Greater freedom to select material should be expected of the democratic teacher. Whether the authoritarian teacher can meet the performance criteria of the newer inquiry innovation programs is questionable. One of the authoritarian teachers observed in the study referred to above spanked two-year-olds when they had an accident in bowel training. When she was instructed not to spank children, she then withheld snacks. The program director was unable to modify her punitive behavior. It is interesting that most of the authoritarian teachers left the project. It can only be inferred that the pressure to achieve goals inconsistent with their values may have led to their decisions to leave.

In this study democratic teachers experienced less inappropriate behavior by students than did <u>laissez-faire</u> teachers. Moreover, the analysis of the Spaulding-scale observations generally suggests more behavioral classroom problems in the <u>laissez-faire</u> and authoritarian class.

Data from this and other studies indicate that the democratic teacher may be able to produce independent, creative youngsters, while the benevolent controller (high control, high warmth) will have well organized and contained classes who are less individually assertive. If a program's goals call for goals other than the development of independence and creativity, perhaps a teacher other than a democratic one is called for.

These findings may give the innovator a clue as to why the achievement of students has not always served as an adequate criterion of teacher behavior. Students can and have accomplished academic goals under a variety of teacher types.

In addition, the larger problem of assisting teachers in being able to perform according to an immovator's criterion indicates that not all teachers may be able to achieve these goals under typical supervisor-teacher conferences, staff meetings or in-service programs or in teacher training.

These results support the notion that to be effective in implementing a desired curriculum program, the trainer must define his criterion performance in terms of behaviors specifically required of the teacher. He then must develop means to change the behavior of the teacher in the direction indicated by the new technique based on the teacher's current status which include his personality, cognitive competencies, and skills brought to the current situation.

It would be simplest, of course, to train only those prospective teachers who already meet the standards required, but few trainers have this luxury. Perhaps it is well that they do not, since such selectivity would let the trainer avoid the responsibility of acting as an effective change agent.



The implications for teacher training are marked. If those who train teachers desire certain outcomes, attention must be given to modifying teacher training based on the personalities and competencies of prospective teachers.



Rubella, Developmental Problems and Family Health Services

## Louis Z. Cooper

I believe it is important to give you some idea of why we have devoted so much time, effort and money to the study of rubella--this mild virus disease.

The disease itself is a sufficiently large personal and public health problem to justify a great amount of study for its own sake. What makes it even more exciting to me is that it is the kind of a problem which serves as a valid model for the development of programs for all children. These programs could be total programs, covering health and education in the broadest sense and could have an important impact on all segments of a community.

I'm going to divide my presentation into several parts. One will be a "show and tell" about rubella. What's it all about? I think it's important for us to share a common background of information before we move into the next area: current concepts of immunization and prevention. This is another exciting facet of the rubella problem.

As far as I know, rubella is among the first of the common causes of mental retardation that we are now in a position to prevent. When we talk about immunization, I'm not going to give any simple "party line." I'm not going to tell you that there are no problems or that rubella will soon be a disease of only historic interest. You are entitled to know that the prevention of rubella is a very complex issue and still an unsolved problem.

In order for you to understand these complexities you must understand something about the natural history of rubella.

Finally, since the focus of our concern is mental retardation, I will talk about some results of studies by our research teams at New York University. These studies are concerned with the behavioral and intellectual consequences of rubella.

Rubella has been an especially productive area of research since 1961 when the rubella virus was first isolated in tissue culture by investigators at Walter Reed and Harvard. This progress has been the subject of two international conferences held within the past year.

I will talk, however, primarily from personal experience at New York University Medical Center because I'm more familiar with it. Since this experience has been similar to experiences in other major medical centers



where people are concerned with rubella, I will not attempt to give credit to all the individual contributions of the many investigators throughout the world.

At New York University and Bellevue Hospital rubella research has been guided, since 1948, by Dr. Saul Krugman who is now Professor and Chairman of the Department of Pediatrics. Current work on the rubella problem involves several dozen people in a truly multidisciplinary effort. Dr. Stella Chess, a child psychiatrist, is responsible for the psychiatric and psychological aspects of the program. Her work is supported by a grant from the Children's Bureau. Our major sources of funds are the National Institute of Allergy and Infectious Diseases, the National Foundation, and the Health Research Council of the City of New York. Many other agencies and groups have helped in the past by providing important support.

How common is rubella and how big a problem is it? In epidemic years, like 1964, more than one percent of all live births were rubella damaged, which means more than 30,000 children in one year. In the interepidemic years the figure is much smaller, perhaps one-tenth to one-hundredth of that figure. This is still a sizable number. However, it is the epidemic years that totally overwhelm community service programs.

Rubella epidemics have two fists. The first is the springtime illness in children and young adults. Then eight to nine months later there is a second epidemic--the birth of babies with birth defects because of maternal infection the previous spring.

The problem is compounded by the epidemic nature of rubella and the severe involvement which the children may have. Needs for service are great, and are made more complex because they come in waves. You can't spread them out so that there are 20 a year. There are 200 in 1 year and then there are only a handful for the next 4 or 5 years, so it's very hard to plan services.

Which segments of the community are hit hardest by rubella? In 1964, a cross section of our communities was involved. Since that time, however, rubella in pregnancy has been a special problem for the blacks and poor people. Members of the white middle class, faced with rubella in pregnancy, find abortions in one way or another. But in 1964 the availability of abortion was not so well-recognized and the real hazards of rubella were frequently underestimated by physicians. So, many mothers completed their pregnancies. Therefore, as in most other aspects of health care, the problem exists everywhere, but is especially acute among the poor.

As you know, rubella is a <u>mild</u> viral illness, characterized most typically by a three-day rash. There may be no rash at all, and this is one of the real hazards; you can have this illness with no clinical signs or symptoms. In a typical case you see a blotchy rash. The rash is the



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same in the adult. The child has a few swollen glands. He may or may not have a runny nose or fever, and usually is not particularly sick. Unfortunately, clinical rubella is indistinguishable from a number of other illnesses caused by viruses. But rubella causes birth defects. The others don't seem to.

Much of the confusion in the past few years about the magnitude of the risk in rubella in pregnancy is related to the fact that <u>no</u> physician is able to make an unequivocable diagnosis of rubella on clinical grounds. You have to use the virus laboratory and it wasn't until 1961 that viral diagnostic tools became available even on a research basis.

In order to understand the subtle features of a rubella vaccine program, you must understand the virus excretion and antibody response patterns in natural rubella. Rubella virus is present in pharyngeal secretions for up to one week before the onset of the rash, and virus may persist there for several weeks. Thus, the period of contagion begins before the patient feels sick. Obviously, quarantine cannot effectively control the spread of this type of disease.

With regard to rubella in pregnancy, what is important is that the virus is present in the blood stream (what we call viremia) also for a week before signs of clinical illness.

Before onset of the rash there is no rubella antibody in the blood. Promptly with appearance of the rash, the antibody becomes detectible in the blood and persists for weeks and months. In fact, in most instances it persists for life. What is important about the presence or absence of rubella antibody is this. If a patient does not have rubella antibody, this indicates that she has not had rubella infection in the past, and she must be considered <u>susceptible</u> to rubella and all its consequences. In contrast, the person who has detectible antibody at the time of exposure has had this infection sometime in the past and is now immune. She will not get the disease again.

We used to think--that is, until 1969--that you probably could not become infected again. We now know that you may. But from the point of view of the pregnant woman, if she has any antibody and she is exposed, though she may get infected, she probably doesn't have viremia. The virus doesn't go through her blood stream to the placenta, doesn't infect the child, and doesn't cause birth defects.

Of course, what we all hope for from immunization programs are two things. The first is to prevent the disease in the community so that the likelihood of women being exposed is decreased. Secondly, if women are exposed, we hope they will have protective immunity from a previous vaccination that will prevent infection of the fetu. These concepts are fundamental to our subsequent discussions of vaccination.



Some children have congenital rubella, and the sharp contrast between these children and others is obvious. Such a child at 11 months of age may present the following picture. He weighs 9 pounds, can't hold up his head and has the full pattern of severe congenital rubella: severe brain damage, deafness, bilateral cataracts, congenital heart disease, and a huge liver and spleen. He is still heavily infected with disease and is still contagious to people around him. This is a condition that we must eliminate.

The pattern of virus excretion and antibody response in congenital rubella also contrasts sharply with that seen in postnatal rubella. When a fetus is infected in utero, usually in the first trimester of pregnancy, instead of being infected for only one or two weeks, the fetus remains infected throughout pregnancy and frequently for months thereafter. Fortunately, the infection seems to cease in almost all by the end of the second year of life. The brain is one of the areas of most persistent infection. As you know, much brain development takes place during infancy. Persistent rubella infection, encephalitis, interferes with this brain development. Most, if not all, of this brain damage is irreversible.

In 1964, rubella viral diagnostic tools had just become available. As the epidemic began, fetal specimens obtained at therapeutic abortion for maternal rubella were sent to our laboratories. Virologic studies revealed that the placenta and virtually every fetal organ could be infected with rubella virus. There was a predilection for certain target organs such as the eyes, the brain, the heart, but you could get virus out of the whole fetus. So it wasn't really surprising that the children born from mothers whose pregnancies weren't interrupted had evidence of disease in virtually every organ.

Congenital rubella causes severe intrauterine growth retardation. Birth weights are low even when you correct for prematurity. This is important not only for survival, but the low birth weight correlates highly with the degree of intellectual impairment. Infants with low birth weight are usually the ones who turn out to be severely retarded.

There is a wide range of conditions which are transient among surviving infants. They represent acute medical problems but are not of permanent consequence. In the fall of 1964, many babies were born with neonatal thrombocytopenic purpura. This means a newborn baby with a decreased number of platelets in the blood, resulting in bleeding into the skin. There are often a wide variety of blood abnormalities and changes in the bones. Rubella pneumonia and rubella-induced hepatitis are common transient problems also.

Certain other effects of rubella, however, are permanent. Rubella causes a patent ductus arteriosus, an opening between the pulmonary artery and the aorta which does not close as it normally should at birth. Narrowing of the pulmonary arteries is another cardiovascular abnormality.



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This is of medical importance but, fortunately, in contrast to some of the other defects, techniques are available for cure of these lesions.

Cardiac anomalies may not represent a problem to the special educator or to the general community; several eye defects do. One serious problem is rubella cataracts. Roughly one-half of children with rubella cataracts have disease in both eyes. Good surgery can yield useful vision. Poor surgery leaves a blind child. The timing of surgery is of importance and it is an issue relevant to people concerned with education of children. Ideally, as soon as these cataracts are recognized, frequently in the first month or two of life, they should be removed so that an infant can see. These children frequently are deaf as well, so they are deprived of sensory input (sight and sound) at a crucial time. We'd like to get rid of the cataracts immediately; in practical terms, surgery for rubella cataract in the young infant is very difficult because the eyes are so small. In our own program, we believe the best solution is to wait until the children are approximately one year old. At that time, in skilled hands, excellent surgical results can be obtained.

In the meantime, the special educator has to be aware of the fact that he has a blind child--or a child who has a pair of opaque lenses between the world and his retina--and this is a problem with regard to education.

Glaucoma is another rubella-caused eye defect. It is much less common than the cataract, but it also leads to blindness unless surgery is prompt and proper.

One of the big problems for all of us concerned with delivery of health services is that there are apparently very few eye surgeons in America who know how to handle these eye lesions properly to get the best results. There is a problem also in seeing that referral is always made to such surgeons rather than to the casual operators. What a difference there is between the blind child and the child who has some useful vision! We have not solved the logistical, economic and moral problems of providing each child with these defects the best chance of living with useful vision rather than darkness.

Severe myopia, nearsightedness, is an eye condition frequently over-looked in congenital rubella. Since these children too are frequently deaf, diagnosis and correction with proper glasses is very important.

Rubella causes speckling of the retina that you see as dark and light splotches. This sometimes has a "salt and pepper" appearance. Usually these retinal changes don't interfere with vision. They are, however, a very useful diagnostic sign, especially if you have a child who is retarded for no apparent reason or deaf for no apparent reason. If you see those eye lesions you should think of rubella, and you can do appropriate laboratory tests to prove the diagnosis.



The frequency of specific defects among 376 children following maternal rubella is outlined in one of my studies: no defect in 70 children, deafness in 252 children, heart disease in 182, cataracts in 108, glaucoma in 12, retinopathy in 147, psychomotor retardation in 170, and purpura in 85 children. Sixty-one children have died. The psychomotor retardation was mild in 84, moderate in 40, and severe in 46 children. (Of these 170, 30 are now in public facilities for the mentally retarded.) Forty-six children had "cerebral palsy."

What is the risk of some rubella damage when a mother has rubella in pregnancy? This has been highly debated ever since 1941. Until the new viral diagnostic techniques were developed, no one could be sure when a woman had rubella. The ridiculously low figure of 10% damage probably represented diagnostic errors and the 95% estimate may have resulted from the bias of retrospective studies. Our own studies have been predominantly retrospective with regard to pregnancy. Current data indicate that when rubella occurs during the first 8 weeks of pregnancy the risk of damage is well in excess of 50%. The risk drops off sharply in the third and fourth months and then, for practical purposes, is nil thereafter. The important point is that we consider the odds to be very unfavorable when rubella occurs in early pregnancy.

With regard to any individual pregnancy, though, it's impossible to predict the outcome. The case of the twins, Carole Ann and Joanne, high-lights that fact. Carole Ann is much smaller than her sister. She is deaf, and she has congenital heart disease. Joanne is normal in all respects. Our laboratory tests showed that Carole Ann was infected with rubella virus while her twin sister, living in the same uterus, was not infected. If you can't predict the outcome in any one uterus, you can see the impossibility of predicting for other individual pregnancies.

It is of great importance to correlate the specific defects with the time of the maternal infection. Neonatal thrombocytopenic purpura, congenital heart disease, cataracts and glaucoma follow rubella during the first eight weeks of pregnancy. The other major manifestations, hearing loss and psychomotor retardation, can result from rubella any time during the first four months of life. These findings make sense because the brain is still developing throughout fetal life and you can still interfere with it; whereas, organogenesis, including formation of the eye and the heart, is complete by eight weeks.

You might wonder if it is possible to detect an infected fetus by the same techniques that have been used with suspect mongoloid births. Dr. Henry Nadler thought once that it was, but he is a cytogeneticist, not a virologist. He and I are concerned about that particular one. No one else has found rubella virus in ammiotic fluid. We continue to try to grow rubella virus from ammiotic fluid cells, but even if we occasionally find virus, this is no answer to the problem, and I'll tell you why.



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Rubella virus infection is a particulate infection. The virus only infects a small minority of the cells, anywhere from one cell in ten thousand fetal cells to one in a quarter of a million. Out of the amniotic fluids you get just a handful of cells and the virus is fairly hard to grow, and so your sampling problem is great. If you found the virus in the cells, wonderful; you'd know this was a positive one. But failure to detect virus would never provide reassurance.

Amniocytosis can never be done without some risk to the fetus, but the risk becomes minimal as early as the third month. If you could use this method or some other to determine whether the fetus were infected, this would allow some people to make a more rational decision concerning interrupted pregnancy or give them more reassurance in continuing the pregnancy. However, there are no techniques that I see on the horizon that will do this.

How does the rubella virus do its work? We now know (on a cellular level) that it interferes with cell division. Infected cells don't divide as often as uninfected ones so children have an abnormally low number of cells in certain target organs. The virus also causes inflammation just like many other viruses and bacteria. It is this combination, the interference with cell division and cell growth and the ability to create inflammation, that does the damage. I think we soon may obtain specific molecular clues as to the effect of rubella virus on cells. This information may have significant implications with regard to other biologic phenomena, such as aging.

What concerned us after we had roughly four or five hundred of these children and most of them had survived the first rocky years? We and the parents realized that the children were not going to die and the parents came to us and said, "Now, what are we going to do with them?" We quickly saturated all the traditional facilities for the hearing impaired and the visually impaired. Our data showed that most of our children (over half) were multihandicapped.

There just weren't facilities for these children. They were totally disruptive for their families and a real problem for the rest of the community. We observed desertion, abandonment, divorce, sibling difficulties, and even parental suicide. The impact of one of these difficult children on a household can be beyond belief.

It's clear to me that for some children there is probably nothing you can do except provide humane care. The traditional residential facility for the mentally retarded is perhaps an acceptable solution for such a child because of the extensive and irreversible damage to the brain. But what distresses me terribly is that there are lots of other children now in public residential facilities for the retarded who perhaps with proper early intervention wouldn't have to be in that public facility. This is why we began to experiment with early intervention programs. It was clear



to us that the teachers of the deaf could not handle these kids, nor could teachers of the blind or the brain-injured. With the help of the New York City Board of Education, we decided to try to use a team approach to handling these children. A teacher of the deaf, a teacher of the blind, and a teacher of the brain-injured were brought together in one old ward at Bellevue Hospital. Under the umbrella of our rubella medical staff team, which was there primarily for moral support, the teachers began to take in multihandicapped children who couldn't get in any other facility. All were victims of the 1964 rubella epidemic and were just three years old when the program opened in the fall of 1967.

During the past two years, some of the children have been able to improve and fit into other existing facilities. Their parents are now better prepared for this and so are the children themselves. We too have learned some lessons from this experience. Now we are picking up infants and getting them into programs. Whether this approach works or not we have no idea, but it certainly is helping to take away the feeling of hopelessness and helplessness that many of the families have.

The program at St. Joseph's School for the Deaf has a definite family orientation. The mothers of multihandicapped small infants get together, compare notes, and are given some help in how to manage their children. Parent counseling must also be given on an individual basis. We want to avoid what our Spanish and Black families are prone to call their "good" babies. The children remain forever on their backs with a bottle in their mouths, not eating any solid food and bothering no one. We know good and well that eventually the situation reaches a point where there's nothing that can be done except to arrange for transfer of the child to Willowbrook where we have more than 25 children now.

The "pipelines" for entrance to our program are quite variable and unstructured. The inefficient nature of that pipeline is one of the potential lessons to be learned from rubella epidemics. Our children have been referred by private physicians, hospital clinics, agencies and other parents. In early 1965 we wrote letters to all the pediatric chiefs around saying we were interested in rubella children. Since we had the only rubella lab in metropolitan New York, it wasn't too hard to obtain referrals. Our surveys indicate that we service approximately 25% of the rubella children in metropolitan New York. We have been impressed that children who have families with resources, both intellectual and financial, have been able to get some service. But you can imagine what kind of services our children from the inner-city have gotten.

What we are shooting for is a suitable structure for early identification of the infant with congenital rubella. This structure should include a mechanism for delivery of longitudinally programmed, coordinated comprehensive service to the children and their families. The availability of reliable epidemiological data generated from a program of early pickup and sophisticated evaluation would help to prevent the periodic crises such



as have existed in the 5 years since the 1964 epidemic--if these data were made available on a routine basis to those agencies which are charged to educate and habilitate the congenitally impaired. The lack of coordination between the Departments of Health, Education, Mental Hygiene and Social Service is appalling and unacceptable. That the rubella kids from 1964 are five years old and all of a sudden the sc'ool systems all over the country are waking up to the fact that they have hundreds of deaf children and no place for them is ridiculous. This situation reflects a refusal to accept responsibility for children at too many levels in too many bureaus and departments.

Since rubella is a contagious disease, and a vaccine has recently been licensed, this disease may serve as a useful model for bringing the health, habilitation, and education establishments together in a meaningful way. The National Communicable Disease Center (NCDC) is charged with assessing the effectiveness of rubella vaccines. The only true measure of effectiveness is "does rubella vaccine prevent the birth of infants with congenital rubella?" NCDC will have to set up a Congenital Rubella Registry to obtain these data.

The U.S. Office of Education is now encouraging experimental programs of early education for the handicapped. Early education requires early identification. This is especially important for the deaf or blind child. I believe you can see how rubella provides a meeting ground of mutual interest and responsibility for agencies which should be involved in coordinated programming. We have some thoughts on how this can be done and will attempt to test these ideas in New York City during the coming year.

The effects of our current services, which involve too little service arriving too late, are well documented in our records for the 1964 crop of rubella babies. Of those with bilateral cataracts one-third are now dead, a third are already in institutions, and the other third are sort of barely making it in some of the helter-skelter programs that have been put together in metropolitan New York.

That was a quick summary of what's going on in our rubella units, trying to characterize the natural history of the disease, the impact on the community, the impact on facilities, and some of the very unsophisticated but goodhearted attempts of our special educators and social service staff to try to do better with our new crop of rubella babies than we did with our 1964 rubella babies. That new crop consists of about 50 babies from the 1968 year, which was not an epidemic year.

Well, what about how often these epidemics occur and possible prevention programs?

Rubella occurs every year but it occurs at irregular intervals in major epidemics which dump large numbers of severely handicapped children



into the community. The pattern is too irregular for anyone to predict when the next epidemic of rubella will be. All you can say is that there is a major epidemic every 5 to 15 years. Since it has been 6 years since the last major epidemic of rubella, there is an ever increasing percentage of our population who are rubella susceptible. What it takes to have an epidemic is enough susceptible people in the community and enough virus in the community to start the sort of chain reaction that results in epidemic spread. Understanding of the dynamics of that chain reaction is beyond our epidemiologic competence at this time. The people who are trying to get \$9.6 million from Congress for the immunization program this year (1969) are talking about trying to prevent the epidemic in 1970-71. It may or may not occur during that year. Nevertheless, with each passing year we become at greater risk for another epidemic.

How can you prevent this? The Advisory Committee on Immunization Practices of the Public Health Service has set forth some fairly straightforward guidelines. Let me show you why they have established the guidelines as they did and then let me show you the hazards in these guidelines.

A cumulative percentage of reported cases of rubella by age groups shows that the curve is steepest during the early school years, the age 4 through 8 school years. Rubella spreads most rapidly among children in their first group experience: nursery school, kindergarten, first and second grade. Rubella doesn't seem to be as highly contagious as smallpox or even measles, so there is little rubella before there is contact with a lot of other children. What is distressing is that not enough children do get rubella, so roughly 20% of women of child-bearing age in most of our cities still haven't had rubella. There's where the risk is--in this 20%. In Puerto Rico at the moment, 60% of the women of child-bearing age have never had rubella and in Hawaii the figure is about 50%, so they have real problems.

The Committee on Immunization Practices decided that this country would approach immunization in the traditional fashion for our country; that is to say, we would try to create herd immunity. It has always been much easier to immunize children in our country than to immunize adults and the people who make immunization policies are, by and large, pediatricians and/or public health people. Therefore, they recommended that first priority for immunization would be for children in the first grades of school, grades K through 3. The idea was to create herd immunity: have so many children immune to rubella by vaccination that we will be safe from epidemic spread.

There's another reason for staying away from the primary target group. The rubella virus vaccines are all live vaccines, which means that when you're vaccinated you have a small infection. You probably have some viremia, although it must be a low-grade one with only small



amounts of virus in the blood stream. We don't know if these virus vaccines, if administered to a woman in early pregnancy, would infect the fetus and cause the same kind of birth defects as the natural infection. Since we can't do the kind of experiment which would let us know, we have to assume there is too much risk involved and rule out immunization of any woman who is pregnant or likely to become pregnant during the subsequent two months. This greatly complicates trying to immunize the primary target group.

This approach may work, but nobody really can be sure whether it will work or not for two reasons. Number one, we don't know what percentage of the population we have to immunize to create herd immunity to prevent epidemic spread. With polio it was said that you required about 80%. With polio virus vaccine it was easy to do because it's an oral vaccine and, in addition, vaccinees shed it in their stool, so you might immunize two or three persons with one dose of vaccine. When the baby's diapers got changed the mother got vaccinated.

One of the vital features of rubella vaccine is that it doesn't spread. You can vaccinate the child and he can ride in the elevator with a pregnant lady and he won't infect her. But that makes it harder to get massive herd immunity. It may take 85% or 95% immunization. This is the first problem in terms of preventing epidemics by vaccinating this group.

The second problem is whether rubella virus vaccination prevents reinfection and spread. Since the vaccines have only been available three years, we don't know how long immunity is going to last. We know it lasts three years, but there are some disquieting early reports concerning the type of immunity.

You will recall that there is a rise in antibodies promptly after onset of rash and that if you have any antibody you can't get the disease again when you're exposed. Well, the vaccines don't produce so high a rise in antibody. We now are concerned that if you heavily expose a vaccinated person he can be reinfected. Though he doesn't get sick, he may shed some virus in his pharynx and may have the capacity to infect someone else. So that's another thing that's disquieting about the concept of herd immunity.

The Europeans, particularly in England, Switzerland, the Netherlands, and Belgium, have decided to take a different approach. They are not going to try to create herd immunity at this point. They are going to immunize girls who are 13 years old. They have a captive group because in Europe the girls are still all in school and pregnancy is uncommon. They hope to protect girls before they reach child-bearing age. With this approach, even though there's rubella in the community, maternal immunity should protect the fetus.

I don't know who's right. No one knows for sure. In practical terms, since the Committee on Immunization Practices after much discussion has



decided this is the route we will go, this is the route we have to go. Throughout the country efforts are being made by state health officials and by some of the voluntary agencies to gear up for programs of this kind. In New York City, Mayor Lindsay is a wise man and he was sold the concept of buying 250,000 doses of rubella vaccine. We are going to vaccinate our children in grades K through 2 this year and those in Headstart and child care centers.

Another approach involves vaccination of women in the immediate postpartum period. The one time you're sure a woman isn't pregnant is two hours after she has delivered. In New York we are gearing up to do blood tests on every woman who is pregnant to see if she has rubella antibody. If she is susceptible we watch her carefully and get her through pregnancy, hopefully, without rubella. Then we can vaccinate her immediately after she delivers.

As you know, in every state, you have to get a premarital serology for syphilis and you also have routine syphilis serologies when you're pregnant. It would involve little additional paperwork and no additional blood drawing to have a rubella antibody test accomplished on the same blood specimen. In fact, we are trying to convince laboratories throughout the country to do a triple test, a test which includes a syphilis serology, a rubella antibody test, and an Rh blood type test. As you know, there are now programs for prevention of erythroblastosis, Rh sensitization in pregnant women, which is another cause of brain-injured children. Thus by increasing our laboratory competence just a little bit, we could make a direct attack on three causes of birth defects and mental retardation: syphilis, rubella, and Rh disease, now all preventable. The costs would be quite small and the payback great.

The antibody test is a simple test in its cost, much less than a dollar. It's really in the pennies in terms of reagent and time. A qualified technician can do four or five hundred of them a day with ease and the test takes one day to complete. There are problems of standardization of the tests and of lack of reliability in inexperienced hands or with casual operators.

What has happened as these tests have become available, is that they have been viewed as a great profit-making deal for small laboratories. They charge \$10 and \$15 a test and still do a poor job. So our National Communicable Disease Center for the past year has been working with a small committee to try to standardize this test and to get the small operators off the street.

I have been a part of that committee and I think we are making progress toward a simple standardized test that every city laboratory and every state laboratory should be able to do with no trouble. It's a political issue and it is a financial issue. But this is the direction I think we must move in and the only way I know to be sure we move in this direction



is to let the people know that this test can be available if they make their wants known to the public health officials.

As I say, New York is gearing up to do this on all premarital syphilis serologies that come into the Board of Health, 75,000 a year, and this should be done everywhere.

When are we going to be able to eliminate rubella as a cause of birth defects? Nobody has the slightest idea. It took 5 years to reduce the frequency of measles somewhat over 90%, at least if you go by the available figures. Measles was a much easier virus vaccine to give than rubella, so I would suspect that it will take at least that long to achieve the same results with rubella.

In the meantime, we are going to continue to have lots of rubella damaged babies, but I do think that within 10 years the rubella baby should be a rarity. It would be distressing to me if it were not.

It might be of interest to consider the comparative effects of measles--traditional measles--and rubella. In a child, measles is usually a moderately severe illness characterized by high fever, cough, symptoms of a cold, and the child's feeling crummy for upwards of a week. Measles is associated with many complications, the most common being pneumonia and infections of the middle ear. The most distressing, and one which is a cause of retardation, is encephalitis. When adults have measles, they frequently are quite sick. When a pregnant woman gets measles, she frequently is so sick that she may have a spontaneous abortion.

Until measles immunization became widespread, we had roughly 400 or 500 deaths a year from complications of measles in this country, and there must have been an average of 4,000,000 cases of measles a year in this country. Only 400,000 were reported, but there had to be 3,000,000 to 4,000,000 because no one gets to be 20--or less than 1% of the population gets to be 20--without having had measles. In underdeveloped countries, measles is the cause of thousands of deaths each year. Measles immunization has been very important in such places also.

Rubella is traditionally a very mild illness. Adults may be sick, and occasionally someone may be so sick with rubella that you think he has measles, but that's very uncommon. With adults you frequently see arthritis or arthralgia. This can be quite severe but fortunately goes away in a few days or, rarely, in a few months. Our vaccines cause this same kind of joint symptoms, although they don't cause rash or fever. Adult women who receive rubella vaccine may develop joint swelling and pain lasting from a few hours or days to a few months.

There is another important point that concerns us and makes us worry about the concept of herd immunity. In 1969 in urban centers throughout the United States, especially in poverty areas, there were



mild epidemics of measles: this, despite almost six years of measles immunization programs.

One of the most distressing outbreaks and one of the best studied by the National Communicable Disease Center was an outbreak on Governors Island in New York. As you know, Governors Island is where a military population lives. What was distressing was that there was an outbreak among children on the island despite the fact that there was 85% immunity on the island due to immunization. The vaccine itself worked well. It protected the children who had been immunized. The attack rate was only about 2% among vaccinated children versus 40% in the unimmunized children. So that's great. If you can get a vaccine that's really that protective, that's wonderful. What was distressing is the fact that the epidemic spread in a community that was so highly immunized. Those who want to look on the good side of this say that this was an unusual circumstance. New York City proper fed that epidemic on Governors Island since there's free interchange with the New York City school systems. On the other side are those who are unhappy that measles spread in a community with 85% immunization. However, we must be cautious in extrapolating too far from one disease to another since each has its own peculiarities. In addition, the Governors Island study, though a good descriptive study, was not a controlled experiment.

The rubella virus does give us a break in that it, differing from such as the influenza virus, appears to be what we call antigenetically stable. There is no evidence that the rubella virus of 1941 is any different from the one in 1969, and protection by infection in 1941 should protect you in 1970.

The formal testing of the behavioral and intellectual functions of the rubella-damaged child is extremely difficult, yet some steps have been taken in that direction. Dr. Janet Hardy, in the Department of Pediatrics at Johns Hopkins, has been responsible for their contribution to the Collaborative Project of NINDS over many years. When rubella 1964 came along she quite wisely began to pick up rubella children who were not part of the Collaborative Project sample and began a set of longitudinal evaluations similar to those received by children in the Collaborative Project.

Dr. Hardy now has available the data on I.Q. testing at 4 years of age of 102 rubella children, all of whom had communication problems. Fifteen of the children were "above average." There were no "superiors," although you would expect some in a normal population. There were a large number of children, 40, in the borderline or clearly defective range. One thing of interest was that although small head size, microcephaly, has always been associated with mental retardation, that isn't always the case in rubella. Rubella children can have small heads and still be bright.



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Dr. Hardy pointed out to me that she thought some of the figures might be a little bit inflated because of the way in which the test used (the Merrill-Palmer) was scored: the non-verbal children were automatically given credit for all the portions of the test that required verbal skills. Nevertheless, these data show that in her group there were many more defective children and fewer above-average children than would be expected normally.

In rubella children with normal hearing, the same thing obtains. The whole curve is just shifted sizably and significantly downward.

Dr. Stella Chess has done a series of studies (the New York Longitudinal Studies) which are concerned with the behavioral and intellectual development of middle class and Puerto Rican "normal" children in New York. When we collected our group of rubella babies, we went to her and asked if she would put our rubella children into the same kind of testing program she had used with normal children. The Children's Bureau funded her for a three-year study which she is completing this year (1969). We hope that she will be able to follow up with more observations of these children in a few years. It might be worthwhile to mention a few items from her progress report of February, 1969. Her sample is larger now, and there's a somewhat more detailed analysis of data, but I think the important features are relatively unchanged. Remember, her study was an attempt to determine the special behavioral and intellectual sequelae of fetal rubella.

All of these children were seen by a psychiatrist on an individual visit; by a psychiatric social worker on an individual visit, frequently to the home; by a psychologist; and by specially trained observers who visited the homes and scored the children on their behavioral and temperamental characteristics. What was of interest to me was the psychiatrist's diagnosis of a representative sample of 121 of the 300 children. The psychiatrist called 35 of them normal and all the rest went by a long list of diagnoses, including mental retardation, mental retardation with autism, chronic brain syndrome, chronic brain syndrome with autistic features, chronic brain syndrome with situational maladjustment, or reactive behavioral disorder. It's obvious he couldn't make up his mind what to label these children. They are a difficult group in whom retardation and behavioral disturbances play a prominent feature.

With regard to levels of temperament, the scoring so far is of some interest. The children had higher scores in reactions to stress and frustration than did normal children in the New York Longitudinal Study. There was a higher proportion of irregular biological functioning. Adaptive ability scores showed that these children were relatively non-adaptable to daily routines. Threshold scores showed increased sensitivity. There was an increased proportion of high intensity scores; that is, such things as more and more prolonged temper tantrums. In the mood



category, there was a disproportionate number of negative mood responses. Thus, these children's behavioral patterns are different from normal children.

With regard to the psychometric testing, of the first 67 children that Dr. Fernandez tested, 7 were severely retarded, 8 were retarded, 11 were called low average, 22 were average, and 8 were bright normal. No children scored in the superior range. So, in New York as in Baltimore (Dr. Hardy's study), there was a significant downward shifting of the curve.

Another item that I thought of interest: Dr. Chess' team spent a good deal of time studying parental attitudes. One of the questions they concerned themselves with was the parents' evaluation of the child's intelligence, including his memory. I think this has importance with regard to explaining how it sometimes is difficult to get the children into the right place at the right time. What they found was that even though mothers would tell long tales illustrating how retarded the children were in terms of their functional capacities, they then would go on to say that the child had normal intelligence. The parents would explain their judgment of the child's normal intelligence by saying such things as, "What a remarkable memory he has. He remembered the doctor's office and he hadn't been there in a year." or, "He remembered a tear in the slipcover on the sofa for months and months, even though we covered the sofa with a pillow." What I think is probably obvious on just an observational basis is the fact that these parents grasped for any kind of straw they could interpret as indicating that their children were functioning at a higher intellectual level than they really were.

We are waiting to see what happens to these children as they get into more challenging learning situations. They all are approaching or at traditional school age. Obviously, it's our suspicion that some of the children who appear to be normal in terms of all our available tests will probably crop up with problems in learning that reflect the fact that their brains have been infected and that neurons have been destroyed. We will look for evidence of this.

Dr. Rolf Lundstrom in Sweden recently completed a study of his rubella children from the 1951 epidemic. They have just finished their traditional Swedish schooling and are 16 or 17 years old. Most of these children did very well in school. I want to remind you that Dr. Lundstrom's study, which was a very important study, was all accomplished in the days prior to laboratory diagnoses for rubella. His cases are tainted by the potential for inclusion of non-rubella children, so I wouldn't rely too heavily on the fact that his children did all right in school.

Why is our experience with rubella children important? It is because they aren't different from other children with brain injury, hearing deficits, or visual impairment. Therefore, they should represent a model



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for development of new and better approaches. We would not be doing organ transplants or even considering organ transplants if we had not learned a great deal about immunology in the past 15 years. We have learned about immunology by studying what have been called "experiments of nature," that is, children with altered immune states. These children have been the tools by which we have been able to learn about normal immune mechanisms. The payback to these children was development of new treatment methods which have allowed many to live normal lives. The spin off to others has been enormous with organ transplantation and prevention of Rh disease (erythroblastosis) as examples well-known to each of you. It now seems quite simple to treat the child who has an immune deficiency with a gamma globulin produced in the laboratory. It is important to remember that this has become available because physician-researchers took unfortunate experiments of nature and used them as tools to learn about normal physiology and biochemistry.

It is time that the educators wake up! Instead of looking at these special children as a problem to be endured, passed off to the special educator and forgotten, these children should be marvelous examples for learning about learning, and about human development, and about life.

I have been appalled in the last five years to learn that many educators separate themselves into service people, teacher trainers, or research people. This concept of separating service. teaching and research is absurd and I'm sure has hampered progress in education to an enormous extent.

The other thing that's appalled me is how little doctors know about what educators do and how little educators know about the advances in medicine. The fact that it took five years for educators to learn about a rubella epidemic, as I said at the beginning, is totally inconceivable.

I would hope that from this experience permanent structures for communication would be built which will serve the community in good stead from now on. We don't know what the next thalidomide will be or the next virus infection or what the consequences of some new advance in medicine or some air pollutant are going to be on child development. There is no reason, with the current state of hardware in terms of information handling and the current state of knowledge in medicine and education, that we can't create programs that are able to detect, define, and quantify programs of this kind so that we can do something about them quickly.

I would hope that this may be the most important lesson that we can learn from the rubella experience, which we hope will be our last such experience with this particular virus.

