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ABSTRACT

Presented are four papers from a conference on mental retardation and families (1971). In the first paper, research is cited to show that current educational programs do not adequately exploit children's potential, and that child centered programs which ignore family/community influence do not significantly influence children's adjustment and achievement. Recommended among supports for families is establishment of a National Institute on the Family, which might compile research, foster advocacy groups, or lobby for family agencies and programs. Described next is a language research/demonstration training program, in which training of 40 retarded children, 16- to 36-months-old, begins with primitive and moves in stages to complex language use, and parents are taught to train their children. In the third paper, the author uses the Pennsylvania and other court cases to describe use of litigation for achieving access to education for all retarded children, for creating new forums, for raising new questions for public discourse, and for redressing grievances. Considered in the last paper are needs of incapacitated older adults, and of older retarded adults who are about to lose a parental figure or parental support. Suggested for serving the older population are a monitoring system to begin with younger handicapped persons and continue with lifelong followup, and a comprehensive protective service program in the community mental health center. (MC)

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U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
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The mentally retarded and their families:
a conference on a family-centered approach to
providing services to the mentally retarded.

BELMONT CONFERENCE CENTER

Elkridge, Maryland

September 1971

Edited by Donald J. Stedman

Office of Mental Retardation Coordination
U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
December 1972

The 1971 Staff Development Conference of The Office of Mental Retardation Coordination

INTRODUCTION

The problems of mental retardation affect families. Because this is so little appreciated and understood, the Office of Mental Retardation Coordination (formerly the Secretary's Committee on Mental Retardation), USDHEW, Washington, D.C., sponsored a special conference on "Mental Retardation and Families" at Belmont Conference Center in Elkridge, Maryland on September 21-22, 1971.

The purpose of the conference was to consider, in depth, with the help of some outstanding leaders in the field, a few of the areas where families are involved in or affected by the mentally retarded child or adult in their midst. The family being the major point of service of DHEW, it seemed important to sharpen our current perceptions and actions in the area.

Leadership chosen included: *Thomas K. Gilhool,* Attorney at Law from Philadelphia and a principal legal counsel for the Pennsylvania Association for Retarded Children in their suit against the Commonwealth of Pennsylvania; *Earl Schaefer,* a developmental psychologist and long time research scientist at the National Institute of Mental Health, now Professor of Maternal and Child Health and Research Scientist at the Frank Porter Graham Child Development Center at the University of North Carolina, Chapel Hill; *William Bricker,* psychologist and special educator, Kennedy Professor of Psychology at George Peabody College and Director of Research Training in the JFK Center in Nashville, Tennessee; and *Leroy H. Jones,* social worker and Executive Director of The Bensenville Home Society in Bensenville, Illinois.

Presentations and discussions ranged across ages and severity of mental retardation, from basic research to current practice, and from education to biomedical factors involved.

Participants were key federal agency, special interest group, and administrative-program development personnel. The group, in addition to the above, included:

Wallace K. Babington, Director, Office of Mental Retardation Coordination, DHEW

Mrs. Beverly Bell, Social Science Analyst, Division of Research and Demonstrations, Social and Rehabilitation Service, DHEW

Edgar A. Bering, Jr., M.D., Special Assistant to the Director, Office of Special Programs, National Institute of Neurological Diseases and Stroke, National Institutes of Health, DHEW

John Courie, formerly Chief of Legislative Affairs, National Association for Retarded Children

Robert Gettings, Executive Director, National Association of Coordinators of State Programs for the Mentally Retarded

Martin Gula, Specialist on Residential Group Care, Office of Child Development, DHEW

Elsie D. Helsel, Ph.D., United Cerebral Palsy Associations, Inc.

Rudolf P. Hormuth, Special Consultant on Mental Retardation, Maternal and Child Health Service, DHEW

Thomas Irvin, Division of Educational Services, Bureau of Education for the Handicapped, DHEW

Herman Kaplow, Community Services Administration, Social and Rehabilitation Service, DHEW

Fred J. Krause, now Acting Executive Director, President's Committee on Mental Retardation, DHEW

Richard A. Lippke, formerly Deputy Director, Office of Mental Retardation Coordination, DHEW

Francis X. Lynch, Director, Division of Developmental Disabilities, Social and Rehabilitation Service, DHEW

Dr. Robert Palk, formerly of the Division of Training Programs, Bureau of Education for the Handicapped. DHEW

Dr. Robert Quinn, Social Problems Specialist, Mental Health Services Development Branch, National Institute of Mental Health, Health Services and Mental Health Administration. DHEW

George Soloyanis, Ph.D., Executive Director, American Association on Mental Deficiency

Dr. Theodore Tjossem, Director, Mental Retardation Branch, National Institute of Child Health and Human Development, National Institutes of Health, DHEW

The results included the edited presentations in this document and a significant advance in perspective in the general problem area.

Special thanks are due Wallace K. Babington, Director of the Office of Mental Retardation Coordination, his staff, the Belmont Conference Center staff, and to all the participants for their lively interest and investment of time and energy.

Donald J. Stedman[1]
Conference Coordinator
Chapel Hill, North Carolina

CONTENTS

THE FAMILY AND THE EDUCATIONAL PROCESS[3]

Earl S. Schaefer

My goal is to inform, to persuade, and to move each of you to accept personal responsibility for social change in programs that relate to families and children. I would like to tell you of an anecdote of an event that increased my awareness of personal responsibility to apply knowledge to promote human welfare. I had developed spherical conceptual models for parent behavior and child behavior (Schaefer, 1971) and told Dr. Babska, a Polish psychologist, of my dream of studying the relationships of the two models to one another. She looked at me and said, "If you really understood these things, you would go out and try to change them." That is my challenge and the challenge of the conference to you. If you really understand the importance of the family, you will go out and try to develop an effective support system for family care and education of children.

An interpretation of research on early education and the role of the family in child development suggests the need for family-centered child care and education programs. My work on early education has evolved through several stages since 1964, at which time I began to realize the need for education during the period of early development of relationships and language. That insight led to the development of the infant education project, a tutoring program in the home during the second and third years of life. However, when the tutoring ended at three years of age, the children's I.Q. began to drop, suggesting the need for continuing education. The need for early education and for continuing education suggested that the family is an important educational institution from birth to maturity, in fact, that the family is the major educational institution of society. However, just as the child cannot function effectively as an isolated monad, the nuclear family cannot function effectively as an isolated unit. Therefore, we must develop the community as a support system for families and we must integrate the child care and education professions into a support system for family care and education of children.

Going beyond our current professions and institutions, we must ask, "Where are the agencies in society that are promoting the cause of the family?" We have major health agencies and education agencies, but where are the major family agencies? Very few exist, at national, state, or local levels. Therefore, we need to develop family agencies and what is more, we need to develop a national family lobby or family union. Recently, the education professions have been successful in their legislative programs by organizing an educational lobby. The health professions have been successful in many of their legislative goals by organizing a health coalition. The development of family agencies and of a family lobby may be necessary to develop programs that support families in their major role in child care and education.

The definition of education in Webster's Unabridged Dictionary as "the act or process of rearing or bringing up" suggests the major educational role of the family. A second definition—"the process of providing with knowledge, skill, competence or usually desirable qualities of behavior and education"—also applies to the family. However, the definitions of an educator "one skilled in teaching" and "a student of the theory-practice of education" are applied almost exclusively to professional educators. Yet, if parents are engaged in education, then they should truly be educators, should be skilled in teaching, and should be students of the theory and practice of education. This analysis suggests the need to emphasize the role of the family in the educational process.

A common sense analysis of major characteristics of family care and education will support the importance of the family. Ten characteristics of families that suggest the great cumulative impact of the family upon child development are listed in Table 1 (Schaefer, In Press).

The cumulative effect of these different characteristics and family care of children is the basis of the primary importance of the family in the educational process.

Although one would expect these characteristics of family interaction to influence the child's development, the degree of that apparent influence in one recent study was startling. Alex Rode (1971) had children report their parents' behavior toward them and had them report their own alienation on Keniston's alienation inventory and found that 79 per cent of the variation in the child's report of his own alienation was related to his descriptions of his parents' behavior. Alienated high school students described their fathers as neglecting, ignoring, detached, distant and hostile and their mothers as rejecting, hostile, and over-involved—controlling through withdrawal of relationship, through instilling persistent anxiety, and through guilt. The somewhat different patterns for mothers and fathers increase the credibility of the finding that children's perceptions of their parents behavior is highly related to the degree of alienation.

Another study suggests that studies of parent-child relationships alone are insufficient in considering family influence on child behavior. Danjczek (1971) had principals and teachers nominate well adjusted and maladjusted children from intact families in their classrooms and then asked the fathers to describe their wives' behavior and the mothers to describe their husbands' behavior. With small samples of intact families of adjusted and maladjusted children, she found highly significant differences in marital adjustment related to the child's functioning in the classroom. This study suggests that parent-child interaction alone is not an adequate measure of family interaction. Apparently, the husband-wife interaction and perhaps the whole network of family relationships also influence the child's development.

Merill Roff (1950) in a review of intra-family resemblances, reported that the child's character development—moral attitudes and opinions—are highly related to those of his parents. He also reviewed studies that the child's attitudes toward the church, war, communism, and his political loyalties correlated with those of his parents.

A recent study by Smart and Fejer (1970) suggests that even drug use by adolescents may be highly related to their experience in the family. It fascinated me that if the child reported his mother used tranquilizers almost every day, as contrasted to reporting that his mother never used them, the child was eight times as likely to report that he used tranquilizers. But the similiarity in drug use did not

TABLE 1

1. **Priority**	The family influences the early development of relationships, and interests and language.
2. **Duration**	The family maintains contact with the child from birth to maturity.
3. **Continuity**	Prolonged separations of parents and children are rare. Separations are often investigated under the concept of maternal deprivation.
4. **Amount**	The total amount of interaction of children with parents tends to be greater than with any other adults.
5. **Extensity**	Parents and children interact in many different situations and share many different experiences.
6. **Intensity**	The degree of involvement of the child with the parent tends to be more intense than with other adults.
7. **Pervasiveness**	The parent influences the child's contact with other persons and institutions and controls the child's access to society and society's access to the child.
8. **Consistency**	The parent's behavior with the child tends to be consistent over time.
9. **Responsibility**	Both parents and society recognize the parent's primary responsibility for the child's welfare and development.
10. **Variability**	The extreme variability of family care and education, from extremes of acceptance, involvement, and stimulation to extremes of neglect, abuse, and physical deprivation, is related to variability in child development.

stop with tranquilizers; if the mother frequently used tranquilizers the child was also more likely to report use of barbituates, marijuana, LSD, and other drugs. The child's report of his father's drug use was also related to his report of his own drug use. Smart and Fejer concluded that parents are models for the drug use of their children. The other studies reviewed above suggest that their generalization is also true of many other behaviors.

Since intelligence test scores are highly related to educational achievement, a review of studies of parent influence on intellectual development will provide further evidence of the importance of the family in the education process. My interest in early education was aroused by the fact that major differences between socio-economic groups in mental test scores emerge during the second and third years of life, i.e., the period of early language development. The mean mental test scores of different social groups stabilize before school entrance. The schools typically do not change levels of intellectual functioning, they merely educate at the level established prior to school entrance. The family initially establishes the child's level of intellectual functioning, maintains it, and the schools have been relatively powerless to change it. These data again indicate that the family is the major educational institution, both in priority and in amount of influence on the child's intellectual functioning.

Among the many studies that show that mental test scores of different social groups develop during the first three years is the original standardization of the Stanford-Binet by Terman and Merill (1937). They reported that differences among children from different occupational groups were approximately as great for children between two and a half and five years as for any subsequent age period. A number of studies show that the difference can be shown by standard mental tests at the end of the second year of life, during the period of early language development. Since early language measures are the best predictors of later IQ, and vocabulary scores correlate highly with total mental test scores (Schaefer, 1970), it is not surprising that several studies find that language development that is influenced by the child's early experience in the family is the best predictor of the child's academic achievement. Perhaps learning the language during the second and third year of life is the most important learning of the child, and the family is influencing that early learning. The family not only influences early language development, but also much of the child's subsequent informal language learning during the school years.

Research data on early intellectual development motivated the design of the infant education project, a home tutoring project during the second and third year of life. Data on family influence on intellectual development should have motivated an attempt to work with the family on the child's intellectual development. However, at that time I had too little faith in the ability of families to support the development of their children, or too little faith in our ability to work with parents on the child's intellectual stimulation. Therefore, we decided to go into the homes and to tutor the infants to foster their intellectual development. We made several major errors in that project, from which we have learned a great deal about early education programs. Because the errors we made are frequently made by child care and education professions and institutions, I would like to describe them.

The infant education project began home tutoring a group of poor black infants at fifteen months (Schaefer and Aaronson, In press). We discovered that fifteen months is a rather late period to begin an educational program because some of the children were very withdrawn, apathetic, and unable to relate to the tutor because of their early experiences. For some children, it took months to develop a relationship that would allow the tutor to provide appropriate educational experiences to the child. Thus the first major error of our project was that we began too late. We tutored the children for approximately four hours a week until they were three years of age and then stopped, as we had planned in our research design. That was the second major error of our program—we stopped too early. However, at the time we stopped tutoring, the mental test scores suggested that the project had been a success for the tutored infants had a mean IQ of 106 and the control group a mean IQ of 89, and the 17 point difference between groups was highly statistically significant and apparently socially significant. However, three years after we stopped tutoring the experimental group, there is only a small, insignificant difference between the infants who had the early child-centered tutoring and the control group. Thus, the data confirm the thesis—the need for early education—and suggests the antithesis—the need for continuing education.

An analysis of the relationships between data on the maternal behavior of the mothers of the tutored children and their children's intellectual development, found that the hostile, rejecting, detached, neglecting mothers who did not provide verbal stimulation and were not interested and involved in their educational experiences tended to have children with low IQ's. Both tutoring and the quality of maternal care had influenced the child's intellectual development during the second and third years of life.

The tutoring could be interpreted as supplementary maternal care, for the tutors' activities of developing a positive relationship with the child, providing enriched experience and language stimulation were similar to the pattern of maternal care that fosters the child's development. These data, as well as other studies to be reviewed below, suggested that we had made a third major error–we had intended to supplement but implicitly had supplanted maternal care of the infant. Our actions had implicitly said, "We (the tutors) are the experts, we will take responsibility for the education of your infant." In the long term evaluation, this policy has been unsuccessful, for the results of the early intervention did not result in significant differences three years after the tutoring ended. I now believe we should have focused upon working with the parents and our actions should have said, "You have the primary responsibility for your child, you can develop the skills needed to educate your child. We will help you with methods and materials to do the job yourself." From the experience of the infant education project, we confirmed the thesis–the need for early education, we developed the antithesis–the need for continuing education, and we began to grasp the synthesis–the need to develop the family as an educational institution from birth to maturity.

Additional evidence of the importance of the family in the education of the child is provided by a study of the development of children in an orphanage as contrasted to children in families. Skeels et al. (1938) reported that the language scores of children in an orphanage were only one-fourth to one-half those of children reared in families. The authors interpreted their findings as revealing the effectiveness of family care and suggested as an explanation of their finding: "*. . .the orphanage situation was characteristically deficient in the factors known to be associated with good language development–such factors as adult-child ratio, parent goals for child achievement, standard of acceptability of verbal expression, number of hours being read to and being told stories, breadth of experiences, and extensions of environment.*"

Other Iowa studies show that genetics influence the intellectual development of the child but that differences in environment may influence the degree of development of the child's potential. Skeels and Harms (1948) found that children of mentally retarded mothers and laborer fathers, when placed in good adoptive homes, achieved a mean IQ of 104, and Skodak and Skeels (1949) reported that children whose natural mothers had a mean IQ of 89 achieved a mean IQ of approximately 110 in good adoptive homes. These data suggest that a radical change in environment may produce a radical change in intellectual functioning between generations. Jensen (1969), in emphasizing the genetic influence in intellectual development, quoted data from Skodak and Skeels (1949) that showed the correlation between the IQs of the adopted children and those of their natural parents but did not cite the differences in intellectual functioning between parents and children that are probably related to differences in environment.

A study of parent behavior and child development by Rupp (1969) quantified cultural pedagogical milieu, which was related to parent educational levels. Among a group of children from the lowest educational level, variations in the cultural-pedagogical milieu of the home were significantly related to reading achievement in the first grade. Kent and Davis (1957) studied parents of delinquents, of normal school children, and of children referred to psychiatric out-patient clinics. Parents of delinquents tended to be unconcerned, neglecting, and ignoring. Parents of normals tended to have normal affection and discipline in the home. Children referred to psychiatric treatment had parents who were seen as more demanding and overanxious. Within the school sample, parents of children with high IQs tended to be more demanding and parents of children with low IQs tended to be unconcerned. Apparently, the variables that are related to emotional development and intellectual development differ to some extent. Werner, Bierman, and French (1971) quantified educational stimulation and emotional support and found educational stimulation more related to academic achievements and emotional support more related to absence of emotional problems. Thus, different patterns of parent behavior may develop different strengths and skills in children.

Data from several major longitudinal studies also support the conclusion that parent behavior influences the intellectual development of children. A study of a national sample of approximately 5000 children from England, Scotland, and Wales by Douglas (1964) quantified the quality of the schools the children attended and the degree of parent involvement in the child's education as shown by mother's visits to the teacher and principal and father's visits to the school. The degree of parental involvement in the child's education explained approximately four times as much of the variance in the child's mental test and achievement test scores at age eleven as did the quality of the schools. After controlling for socio-economic status of the parents, variations in parental involvement were still related to variations in child test scores. The quality of family care of the child also tended to be related to socio-economic status of the family.

A study by Milner (1951) had similar findings on socio-economic status, child care and education, and child achievement. Children with low test scores came from homes with very few books, were read to infrequently, and were given harsh physical punishment. Milner also reported that the child's test scores and parent behavior were both related to socio-economic status of the family. Perhaps different socio-economic levels lead to different styles of life, different types of child-rearing, and different achievement levels of children. This suggests that responsibility for rearing children does not rest in the family alone but also in a society that assigns a given role and style of life to families and either supports or does not support family care and education of children.

A study of Moore (1968) in England showed that early observations of parent behavior can predict the child's later intelligence and reading skills. From home visits at the child's age of two and a half years, Moore qualified the quality and quantity of verbal stimulation; the toys, books, and experiences provided, and the quality of the parent-child interaction. These early ratings were significant related to the child's I.Q. at three years but more highly related to the child's I.Q. at eight years, perhaps showing the early and continuing impact of parent behavior. Significant correlations were found with the child's reading at seven years. Even after controlling for socio-economic status of the parents, sizeable correlations were found between early ratings of parent behavior and the child's development. Since the home tends to be a relatively stable, consistent educational environment, parents who educate early probably educate later also. The longitudinal studies, which find sizeable relationships between early parent behaviors and child development even after controlling for socio-economic status, can be interpreted as revealing the cumulative impact of parent behavior.

Perhaps even more convincing is the intervention research on family education of children. Levenstein (1970) directed a fascinating study in which she conceptualized books and toys as verbal interaction stimulus material. Social workers took books and toys into homes, demonstrated their use to the mothers, had the mothers use them with their preschool children, and left the materials there. With approximately thirty-two visits over a seven month period, during which they left approximately a dozen books and a dozen toys, the children gained approximately seventeen points in I.Q. With fewer visits the next year, they were able to maintain the even increase the child's level of intellectual functioning. Levenstein's program is almost a feasible social program for supporting family education. It is of interest to me to contrast Levensteins' program with my own child-centered infant education program in which we saw children approximately 300 times over a twenty-one month period. Both my child-centered program and Levenstein's parent-centered produced approximately the same gains in intellectual functioning, but her program was less costly and probably will have much greater long-term effect. Therefore, I try to persuade others not to do my child-centered program but to adopt a parent-centered program such as Levenstein's, Karnes', or Gray's.

In Karnes', et al (1970) program, small groups of mothers were brought into a center and taught skills in early education by working with them on the development of materials and methods and also by visits to their homes at least once a month to support the group work in the center. With mothers who were not working, the group program in the center was very effective, producing approximately a seventeen point I.Q. gain in the children of the mothers who remained in the program. The finding that working mothers were less motivated to participate suggests that parents should be trained very early in child development skills, perhaps before and during pregnancy, in order to insure that they will have the motivation and skills required to effectively participate in the care and education of their children.

Both Weikart (1968) and Gray (1970) have used home programs that teach mothers skills in early education to supplement preschool programs. These programs have been relatively effective; in fact, Weikart (1968) has reported approximately a thirty point gain in low IQ children in a one year home and school program. However, in these early education programs that show very promising immediate results, long-term follow-up shows that year by year, after the special intervention program has ended, the differences between the experimental and control group decline. Perhaps we need not only continuing education for children, but also continuing education for parents on the skills needed to support the continuing education of their children. The skills needed to teach a one-year-old are quite different than those needed for a three-, six-, nine-, or twelve-year-old. For that reason, plans should be made to work with parents on the child's education from birth to maturity.

Gray (1970) recently reported contrasting a child-centered preschool program with a parent-centered weekly visit in the home. The two programs had equal short term effectiveness, but working with the mother had greater long-term effectiveness. Gray reported vertical diffusion of the effects to younger children in the family and horizontal diffusion in the neighborhood and also stated that working with the mother cost one-fifth as much as the preschool program. Gray's report suggested that a program might work with the mother from birth through five years for the cost of a year of pre-school. Thus, parent-centered programs might be far less costly and far less expensive than our current child-centered early education programs.

The experience of the parent-centered early education programs that the children's IQs drop after termination of the program is also true, perhaps even more true, of child-centered programs. Just as the infant education project found that differences decreased year-by-year, Caldwell and Smith (1968) reported results of the follow-up of a good university day care program that had resulted in relatively high levels of intellectual function. A year after the children left the day care center their mean IQ dropped approximately eight points. Thus, they also found the need to follow through and to provide for continuing stimulation. Apparently, brief child-centered programs may have minimal long term effect. That conclusion may also be true of children at older ages in school, because it is not the intensive, brief program that produces the child's cumulative development, but the continuing effect of his total social environment—family, community, mass media and the school—that shapes the child. The evidence of the major role of the family should influence child care and education institutions, professions, and programs.

Results of these cross-sectional, longitudinal, and intervention researches clearly demonstrate that children have far more potential than is being developed by the current educational programs. I interpret the research as indicating the need for a major objective of increasing the effectiveness of family education of children. I am concerned with that objective from the point of view of equality of opportunity. If we have equal education in the schools, but unequal education in the home and community, many children will not develop their potential and will not be able to compete effectively with children from more favorable home environments. Studies by Moore, Rupp, Douglas, Milner and others show that early and continuing parent behavior influences heavily the child's mental test scores and reading scores during the school years. Thus, if we neglect the family as an educational institution, we are not going to achieve our educational objective of equal opportunity for all.

The studies I have cited and other studies suggest that the quality of the early and continuing maternal and paternal care in the family influences the child's adjustment, alienation, character development, drug addiction, delinquency, task-oriented behaviors, language development, mental test scores, reading scores and academic achievement. These studies suggest that child-centered programs alone, that ignore the influence of the family and community, in the long run are not going to be effective in significantly influencing the child's adjustment and achievement.

The evidence is clear that the child's education should begin prior to his enrollment in school or preschool; in fact, the child's education should begin prior to his development of early relationships and early language, at birth. In order to call attention to the need for development of this area of early education in the family, I have proposed a new concept of *Ur-education*—basic, primitive early education (Schaefer, 1970). I developed this new concept because if I said "early education" people would assume I meant preschool education, and I don't. The first stage of Ur-education is the development of a positive, loving attachment to the child by the parent. The child responds to the parent's positive attachment by developing a positive attachment to the parent during the first year of life. In the context of their positive relationship, the parent and child share activities and experiences that educate the child. An example of Ur-education would be a parent looking at a picture book with a child. During the shared activity, the positive relationship is reinforced; the child developed the ability to listen, attend, concentrate and persist at a task; as well as interests and language skills. Since successful Ur-education may be a necessary basis for subsequent academic education, to solve our current educational problems we must focus upon improving the process of Ur-education—basic, primitive early education in the family.

We must develop education as a process that begins at birth and ends at death, not at school graduation or maturity (Schaefer, 1971). We must recognize the family as the major educational institution. Although we now have an Office of Education, I see the present Office of Education as the office of schooling, operating on a restricted model of education which focuses on the school age child in the classroom with a professional educator learning the academic subjects through formal instruction in order to earn academic credentials. That may be schooling, but it isn't all of education. Schools may be necessary, but they aren't sufficient to foster the child's education as defined by Webster's Unabridged Dictionary. In fact, learning goes on in the family and in the community and through the mass media, and our educational professions and institutions have largely neglected and ignored that learning, almost denied the existence and desirability of that learning.

As a result of our current definitions of education, we teach children they are merely students until they graduate from high school, college, or graduate school. Yet children can be teachers also, apparently very effective teachers. Therefore, we should be motivating and training children to teach one another and we should be teaching them the skills they will need as future parent educators. If we would teach them to participate as both teachers and students throughout their life span, they might become parents who would have the motivation and skills they will need to educate their children. The schools should develop an objective of not only developing future citizens and workers, but also future parent educators as part of the curriculum from kindergarten through school graduation. The skills and attitudes that would be useful to future parent educators would also be useful to future workers and citizens; for education, teaching and learning in their varied forms, is a major component of our entire life experience.

The research on family influence on the child's development suggests the need to extend the current classroom perspective on education into a lifetime and lifespace or ecological perspective that recognizes that education begins at birth and ends at death, that everyone is a student and everyone a teacher, and that recognizes the family as the major educational institution (Schaefer, 1971). I am also concerned with the effectiveness of the mass media in this educational process. Shramm, Parker, and Lyle (1961) reported that the average child spends more time with television during the first sixteen years of life than in the school, that the child spends approximately thirty hours a week with the mass media, with approximately 60 per cent of that time with television. Yet we haven't planned use of the mass media as education, haven't attempted to influence the educational value of the mass media, and haven't taught parents and children how to use it effectively. The mass media could be an efficient and effective force for lifetime and lifespace education. Yet little attention has been given to training parents and children how to use the mass media as an educational resource.

What can be done to influence the effectiveness of family care and education of children? Perhaps an examination of four major influences on family effectiveness would contribute an answer. An obvious variable is parental *skills* in child care and education. Some parents, through their experiences and training, have many skills in child care and education, a knowledge of methods and materials and how to utilize them effectively with children of different age levels. Many of the interventions programs in early childhood education have had success in developing such skills, at least for the period of the project. Perhaps an equally important goal would be to develop parents who are constantly attempting to learn new skills, parents who are students of better child care and education methods.

Another variable that is related to effectiveness of parental care is parental *strengths*, which might include parental education, qualities of personality and character, financial resources, etc. Perhaps building strengths in families is the long term goal of many health, education, and welfare programs but the goal of increasing family strength and ability to cope with problems might be made more explicit and be given higher priority in society.

Increasing awareness is developing of the extent to which major *stresses* influence the quality of family care and education of children. Studies of samples of the general population and studies of families that abuse and neglect their children find that poor health, financial distress, marital conflict, many closely-spaced births, crowding and other stresses influence the quality of parent-child relationships, maternal care, and the child's development. Thus, a major approach to increasing the effectiveness of family care would be to reduce the stresses on families.

The last of the major influences on the quality of family care and education that should be stressed is the amount of *support*, social and emotional, as well as financial and material support. In the past, this support was largely provided by the informal support system of relatives, friends, neighbors, and neighborhood social groups. Within our mobile society, this informal support system is, to some extent, breaking down. We now must ask "How can we develop again an informal support system for family care and education? How can the child care and education professions and institutions develop a formal support system that will strengthen and complement the informal support system? How can we reduce the isolation of nuclear families by building the community? How can we develop communities and a society that will provide for the needs of parents so they, in turn, can provide for the needs of their children?"

The studies of neglected and abused children are very impressive in the demonstration of the lack of *Strengths* and *Skills*, of the presence of many *Stresses* and of the absence of *Supports* in their families. The importance of the family in child care and education and the degree of importance of these major influences suggests we need to provide for the needs of parents as well as the needs of children.

In view of the apparent success of the parent-centered intervention projects, the question must be asked, "Who is training children and young adults for their roles as parents?" Do we still assume that training is provided by the nuclear or extended family or by the community? If so, that assumption in a mobile society with isolated nuclear families, increasing age segregation, and unstable and fragmented neighborhoods is probably often false. Many children of all social groups are not well prepared for their roles as parents. Both the training and experience that would develop skills in child care and education they will need as parents are presently lacking. Theretore, we need to build a system for training parents and future parents in the care of children.

Parents often need training, guidance, consultation, and support during pregnancy and during the first weeks and months of the child's life. Some research suggests that the mother-child relationship may stabilize during the first weeks of life. Broussard found that television instruction in child care and development on obstetrical wards significantly improved a mother's perception of her infant, as contrasted to the average infant at approximately four weeks of age. Later Broussard and Hartner (1969) found that the mother's description of her child at four weeks was related to a judgment that the child needed psychiatric care at four and a half years of age. The period of pregnancy, delivery, and first weeks of life may be a critical period for the development of the parent-child relationship. Perhaps this is a most important period to provide training and support for parents to facilitate the development of a positive attachment to the child.

Hopefully, the evidence of the importance of family care and education and the evidence that family care can be influenced will provide the *motivation* for the development of a comprehensive support system for family care and education. That *motivation* will provide the impetus for the development of the *manpower*, the *money*, the *methods*, the *materials*, and *models* that will contribute to a support system for family care and education of children.

Setting standards for family care and education might increase our motivation to work with families. If we can set standards for day care, can we also set standards for family care of children? If a concensus were developed about standards of family care, we might then develop the training needed by the personnel in the family care system, the kind of support system needed, the resources, methods and material needed to meet the standards. We might recognize that the isolated nuclear family cannot achieve the goals set by the standards without an informal and formal support system.

The need for standards of family care is illustrated by some of our current attempts to solve social problems. In some ways the school lunch program is rather ridiculous. Should we only worry about feeding the child while he is in school? During the first two years, during which most of the development of the brain is completed, the child's need for adequate nutrition is clear. If we feed children in the school lunch program during the school year, what about week-ends, holidays, and vacation periods? Just as the child's need for education extends from birth to maturity, the child's need for adequate nutrition extends from the prenatal period through maturity. Therefore, we should be concerned with an adequate standard of nutrition and education in the home, not merely in the school lunchroom and classroom.

Clearly, adequate nutrition in the home is essential, but we should go beyond nutrition to provide for the other basic needs of children. If the child's early education is important and if we believe in equality of educational opportunity, should society provide the necessary educational materials in the home as well as in the school? Doesn't the child need books—picture books, nursery rhyme books, storybooks, books of all kinds—to foster his early language learning, to develop the interests, skills, and behaviors necessary to master reading? Perhaps this is the type of thinking we would do if we made a commitment to help families to achieve minimal standards of child care and education.

However, my perception of child care and education professions and institutions is that they are largely child-centered in their focus. Although their explicit goal is usually to supplement family care and education, the implicit effect is often to supplant it. I heard a teacher say to a group of parents, "Please don't teach your child how to read, write, or do arithmetic. Your methods may be different than mine. Just send me a happy child and I will educate him." That is not supplementing family education, that is supplanting it. I fear that is what most of our child care and education institutions, professions, and programs do. Implicitly, they communicate to parents, "We are the experts and we will take responsibility for the development of your children." But the professions and institutions haven't been able to care for and educate children without the help of families. They haven't done it and they can't do it. Therefore, our professions and institutions must change their major focus to strengthening and supporting family care and education of children. If the professions and institutions would do the job that Levenstein, Gray, Karnes, and Weikart have shown can be done, they might be far more effective at lower cost than the current child-centered programs.

When we realize the importance of programs that strengthen and support family care and education, we will find many specific ways of achieving that goal. I have spoken of the need to view the child as a future parent and of providing training and supervised experience in child care. One way in which this might be done is through a four generation approach to child care in which an older, experienced mother might work with a young mother with her first infant and include as part of this unit one or more school age–high school or even elementary school–children. Each of the four generations could contribute and profit from working together on child care. The older mother would have an opportunity to utilize her knowledge and experience in a constructive way, the young mother would be trained and supported during the critical period of learning how to care for her infant, the infant would be receiving additional care and stimulation, and the school age children would be trained for their future roles as parents.

Although professionals often speak of parents, typically both the speaker and the audience interpret parents as mothers. Yet, the research evidence suggests we should also train males for their roles as fathers. The study on alienated high school students who perceived their fathers as neglecting, ignoring, distant, and detached suggests that fathers should have a greater role in child care and education; the fact that alienated children described their mothers as hostile and overinvolved suggests that mothers should also have other interests apart from childrearing. In families in which women also work outside the home, it is unjust that the total responsibility for child care and education be assigned to the mother. If fathers were to become more involved with children and mothers were to develop more interests outside the home, both fathers and mothers might be teaching their children and might be learning to become more effective educators. Perhaps children would be more adjusted and competent, women would be happier, and men might learn to be more concerned with human needs and human relationships.

As well as preparing children for their future roles as mothers and fathers, perhaps it would be equally as important to prepare them for their future roles as husbands and wives. The study by Danjczek (1971) which suggests that the husband-wife relationship may correlate with the child's adjustment and competence in the schools as much as the parent-child relationship suggests that we must analyze the problem of man-woman relationships as much as adult-child relationships. Perhaps we might find answers to the questions, "How can a man support a woman in child care? How can a woman support a man in his role as father?" When we have found ways of training for family living and of strengthening and supporting families, the current emphasis on marriage and the family as a source of social problems and psychopathology may be replaced by an emphasis on marriage and the family as a positive force for human development.

What is the response to the increasing recognition of the need to support families? As might be expected from our fragmented and specialized services, a fragmented approach to provision of family services seems to be developing. Current programs are sending into homes family planning aides, nutrition aides, health aides, education aides, social workers, and public health nurses. How many different persons can be sent into homes? Currently, parents are expected to be generalists with skills in health, nutrition, child care, education, recreation and the entire range of skills required to rear a child. Yet our current course is to fragment the supportive services to families. Perhaps we need a more integrated approach of a generalist, a family child care and education consultant, who could provide most of the help needed by families to rear children. The family generalist might provide training and support, might be a resource person who might assist the family in obtaining more specialized assistance, and might be an advocate for family needs. Since these generalists would have a very personal knowledge of family needs, for housing, food, clothing, books, toys, and experiences, I think they would become advocates for family needs.

In order to provide for family needs, we need to develop family agencies at all levels of government. I believe we need a National Institute on the Family much more than we need a National Institute on Alcoholism or a National Institute on Schizophrenia. Why should we focus our efforts only on remedial treatment after problems develop instead of attempting to prevent problems? Perhaps an emphasis on human ecology, on the healthy positive forces of family and community, might prevent many of our social problems. We need family agencies to be advocates and organizers. We need family research to find more effective ways of strengthening families. We need to develop a national family policy that includes but goes beyond family planning. I have been told that in France the national family union is represented at the cabinet level on social policy decisions. We need family programs and family training for a wide variety of people, both for the public and for professional personnel.

To develop political support for family agencies and family programs, we need a family lobby. Apparently organized political power is necessary to obtain legislation, funds, and programs. Labor unions have political power because they are organized. The health professions have influenced legislation through organization and the education professions are able to influence legislation by lobbying. Who is presenting the needs of families; who is organizing an effective voice for family programs? Clearly, we need a coalition of organizations that are interested in family welfare to support family legislation, programs, and agencies.

In order to mobilize latent support for family programs, a group of people have developed an informal organization at the University of North Carolina to discuss family needs and possible ways of meeting these needs. The interest and enthusiasm expressed at the initial meetings suggests that many other people might be interested in such groups. If such groups would organize at universities, in communities, in the states, and at the national level, I think that effective support would be developed for that most neglected, but most important institution—the family.

We are at a critical period of choice for our child care and education institutions and professions. Are we going to continue to neglect and ignore the role of the family? Are we going to continue to supplement and implicitly supplant families? Are we going to develop preschool programs that ignore families? Are we going to develop day care centers that neglect families? Or are we going to use all of our child care and education programs to strengthen and support families and to develop a support system for family and community? The choice of supplementing and supplanting or of strengthening and supporting families will be a critical choice for the future of American families, communities, institutions, and professions. What the choice will be is uncertain, but the choice should not be made blindly but after careful consideration of both alternatives. Clearly I believe that we need to make major changes in our current child-centered approaches to child care and education, that our major effects should be devoted to integrating our professions and institutions into an effective support system for family and community.

In order to mobilize the potential energy of families and communities, we must recognize that all members of society are involved in helping relationships and teaching relationships, that everyone can be a helper and everyone can be a teacher. Fostering the child's health, welfare, and education is not merely the role of the professional but of all family and community members. We must recognize the need for a comprehensive integrated system of child care and education that integrates the work of the professions and institutions with the contributions of family and communities. Therefore, I repeat my initial challenge to you, "If you understand the importance of the family, and the need to develop a support system for the family, why don't you go out and change our professions and institutions?"

RESEARCH AND DEMONSTRATION WITH TODDLERS AND THEIR PARENTS

William A. Bricker

The Toddler Project is a research and demonstration project funded primarily by the National Institute of Child Health and Human Development (NICHD). I would like to recount the history that has led to the formation of the Toddler Project because I think it will help you to understand how the structure of the project has evolved. In 1958, Diane Bricker and I started as a team working with retarded children at the Columbus State Institute which was then called the Columbus State School. Dr. Dorothy Sievers, then Director of Research at the Institute, had received a grant from the U.S. Office of Education to investigate the effects of language stimulation on retarded children in the community and in the institution. Diane, who was trained as a speech therapist, was hired as one of the language teachers in the program and I was hired as the project's statistician. During our association with this project we became interested in language and developing training procedures for teaching language to retarded children. This intervention project followed Osgood's model and used traditional teaching procedures in the classroom. Because minimal gains were made by the experimental children in this project we began searching for alternative methods for teaching language skills to low-functioning children. Our search led to the possibility of using operant principles to teach language. A move to the University of Oregon and subsequent association with a group of noninstitutionalized autistic children solidified our involvement in language and the use of the operant approach to teach this complex form of behavior to alingual or severely language deficient children.

In the program at Oregon, we worked with a child for an hour each day, five days a week, while the mother watched. As the mother became familiar with the procedures being used, she would be substituted as one of the data collectors in the "laboratory situation." Then as the mother became even more skilled, we let her do the training while we sat and watched.

So we had a parent program going in 1963. We never collected any data on it at that time. Our data collection process had to do with three phases of the children's learning: (1) imitation, (2) discrimination, and (3) motor development.

DR. SOLOYANIS: Did you plan for the mother to get that involved, or is it something that just happened?

DR. BRICKER: Well, they were sitting there everyday watching through a one-way mirror. And we thought, "Why not use this valuable resource who spends more time and is more involved with the child than anyone else?"

We acquired a substantial amount of information about autistic children. We noticed that some of the deficits that seemed to be affecting the autistic children were fairly specific. I don't want to talk about it to any great extent, but the deficits often seemed to be in the acquisition of word meaning, something having to do with cross model transfer. We have been checking that hypothesis for the last eight years; however, we haven't found enough autistic children to evaluate our hunches. Since we needed more children to test our emerging language training program than were available in Eugene, Oregon, I decided to apply for a Kennedy visiting professorship at George Peabody College for Teachers. I was accepted as a Kennedy Professor and moved to George Peabody College in 1965 and started to work at Clover Bottom Hospital and School.

Clover Bottom had 1,400 residents with approximately 120 in the severe to profound range. These children seemed to be similar to autistic children, but there were a lot more of them. We fully expected at that time that we would find over 100 children who were autistic. This didn't prove to be the case. We only found two out of the entire population that had the characteristics that Kahner, Rimland and others have defined as autism. That was a disappointment, but we went to work on developing a longitudinal language training program for severely retarded children.

Figure 1 presents a lattice of the language training program we developed during the next several years. The language program is composed of six basic components: (1) reinforcement control, (2) audiometric evaluation, (3) receptive vocabulary (comprehension), (4) imitation, (5) productive vocabulary (expression) and (6) sentence production (syntax). The lattice shows each of the program steps and their interrelationships on a time and order basis. The lattice starts at the left with initial behavior control and then proceeds to the right. Boxes that are approximately equidistant from the left are assumed to be essentially independent and could be begun as simultaneous training activities. Boxes connected by a line are related and the content in a box on the left of any other connected box represents training activities that should be completed before activities described in the next box to the right are begun. The boxes above the ascending diagonal represent the sequence of terminal behavior states that are established as a consequence of the training programs underlying them. Training starts with a very primitive form of behavior and moves through successive stages until one reaches complex social uses of language. Essentially, our experimental work has consisted of taking each program box and attempting to develop the most efficient means for training that specific language component.

During my involvement with various institutions over a five-year span I reached the conclusion that it is relatively futile to try to develop and apply training programs within institutions given their current conditions. We decided a more appropriate goal would be to keep children out of institutions.

At that time Dr. Don Stedman set up an infant evaluation clinic at the John F. Kennedy Center at George Peabody College. The basic idea of the clinic was to train public health nurses to administer the Denver Developmental Screening Instrument and, in some cases, the Bayley Scales. The public health nurses and other well-baby clinics then referred to the Kennedy Center those children whose development was apparently delayed. These children were brought in for more thorough evaluation at the infant evaluation clinic. Through this process, the clinic staff developed a list of about 40 young retarded children for whom there was no existing referral agency. As a result the Toddler Research and Intervention Project (Toddler Project) was initiated.

The Toddler Project is what I want to discuss today. The children enrolled in this project range in age from 16 to 36 months. Half of the children are developmentally normal while the other half are definitely retarded (e.g., Down's Syndrome, hydrocephalis, known brain trauma) with developmental quotients around 50.

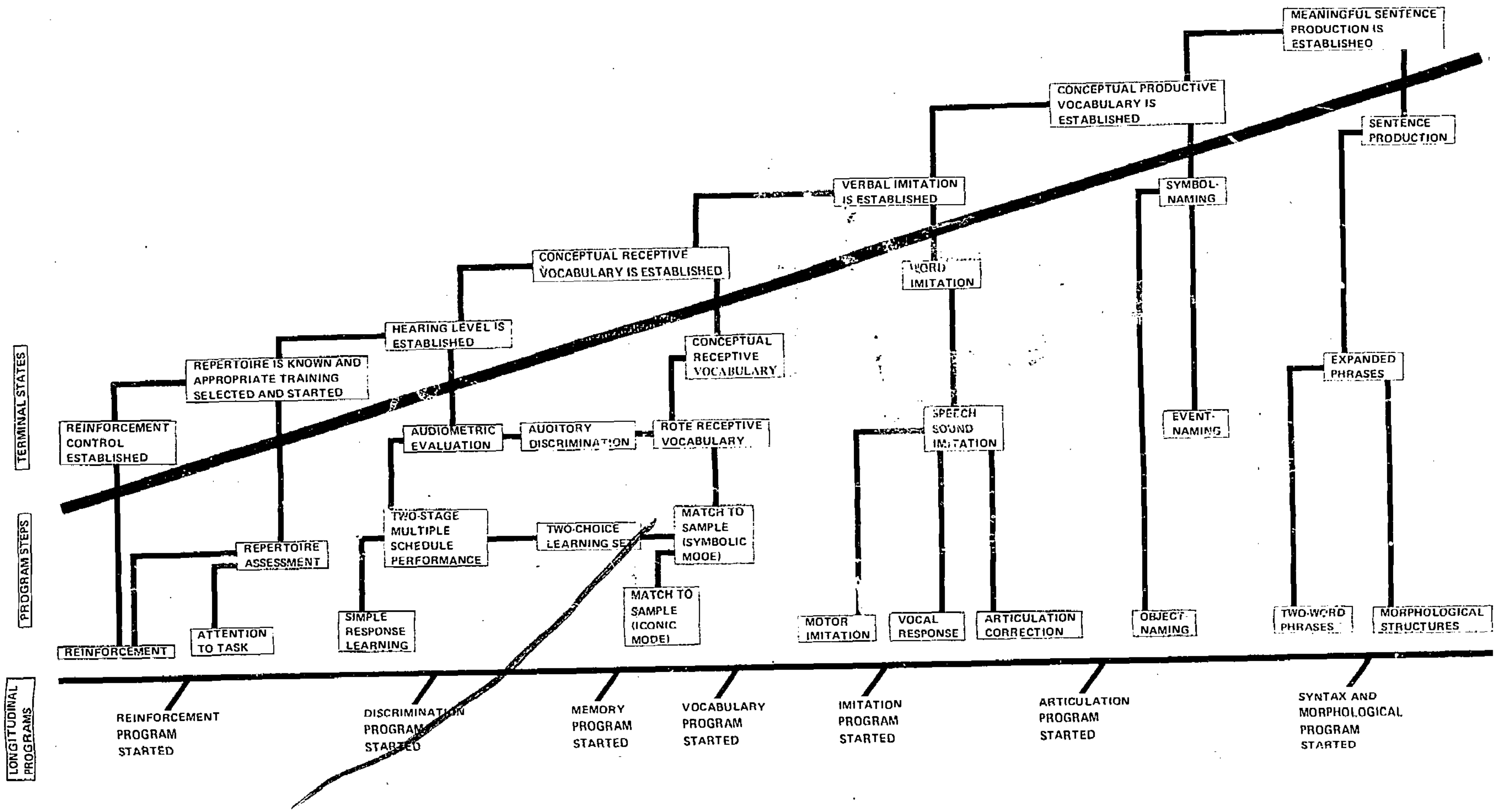
During the past year we operated a morning and afternoon class with ten children in each group. However, this summer we had only a morning group composed entirely of delayed children. We have had very little trouble getting our normal children into the program. Parents are very willing to bring their children who are one to two years of age into a three-hour program. Many of them would like to have a day care program.

There have been several important outcomes from using the nondelayed children. One is that we can use the children as models of behavior at that age. We can pick up and be sensitive to how children are behaving "normally" and pick up some of our training ideas from just watching how these children interact with their world. Secondly, the normal children operate as models for the delayed youngsters, and they are engaging in some advanced forms of behavior that the delayed child, if left to his own devices, wouldn't emit. Third is that we have a group of very energetic graduate students who are learning behavior modification techniques among other skills, and they can sometimes become a little overzealous in the application of the knowledge and be shooting for forms of behavior that are atypical even for normal children. So we try to keep them in bounds by having them work with both normal and delayed children.

The classroom activities are structured and follow as much as possible the format outlined below:

Parent-child Training Sessions
Opening Group
Activity Time
Outdoor Play or Music
Juice
Art
Closing Group

During group time the children are required to sit in chairs placed in a semi-circle. The teacher faces the children and then gives directions that each child is to follow, such as touch your nose or clap your hands. Other teachers, assistants, or mothers sit behind the children and prompt the response physically if the child does not emit it spontaneously or responds


TERMINAL STATES
PROGRAM STEPS
LONGITUDINAL PROGRAMS
REINFORCEMENT CONTROL ESTABLISHED
REPERTOIRE IS KNOWN AND APPROPRIATE TRAINING SELECTED AND STARTED
HEARING LEVEL IS ESTABLISHED
CONCEPTUAL RECEPTIVE VOCABULARY IS ESTABLISHED
VERBAL IMITATION IS ESTABLISHED
CONCEPTUAL PRODUCTIVE VOCABULARY IS ESTABLISHED
MEANINGFUL SENTENCE PRODUCTION IS ESTABLISHED
REINFORCEMENT
REPERTOIRE ASSESSMENT
ATTENTION TO TASK
AUDIOMETRIC EVALUATION
AUDITORY DISCRIMINATION
TWO-STAGE MULTIPLE SCHEDULE PERFORMANCE
SIMPLE RESPONSE LEARNING
TWO-CHOICE LEARNING SET
MATCH TO SAMPLE (SYMBOLIC MODE)
MATCH TO SAMPLE (ICONIC MODE)
ROTE RECEPTIVE VOCABULARY
CONCEPTUAL RECEPTIVE VOCABULARY
WORD IMITATION
SPEECH SOUND IMITATION
MOTOR IMITATION
VOCAL RESPONSE
ARTICULATION CORRECTION
SYMBOL-NAMING
EVENT-NAMING
OBJECT NAMING
SENTENCE PRODUCTION
EXPANDED PHRASES
TWO-WORD PHRASES
MORPHOLOGICAL STRUCTURES
REINFORCEMENT PROGRAM STARTED
DISCRIMINATION PROGRAM STARTED
MEMORY PROGRAM STARTED
VOCABULARY PROGRAM STARTED
IMITATION PROGRAM STARTED
ARTICULATION PROGRAM STARTED
SYNTAX AND MORPHOLOGICAL PROGRAM STARTED

incorrectly. Following group time the children push their chairs over to small tables for a period with puzzles or other form and color discrimination activities. During this time children complete puzzles or drop objects in appropriate holes such as a circle in a round hole. Since the children vary in competency level, the puzzle difficulty and shape box given to a child is slightly above his competency. For example, if the child has learned to insert a circle appropriately, the next step would be to program square insertion. If the task is too difficult, all the holes except the square hole can be taped shut. Gradually, as the child develops competency in inserting the square, the tape is removed to make the task more complex. After the child has learned to insert the square consistently, the circle and square are presented simultaneously making the task more difficult. This procedure is repeated if necessary with each new shape that is introduced. Often the teachers use backward chaining to help a child master a puzzle. That is, all the pieces are left in place except one and the child's job is to insert that one piece. Since there is only one empty hole, the task is less complex than facing several empty holes with as many pieces. Once the child can consistently place the piece in the hole, two pieces are removed and the child's task becomes to insert both pieces. Again this procedure is repeated until the child can complete the entire puzzle.

After the table training tasks the children are allowed to personally select other activities. The teachers also use this time for specific skill training. To teach these specific skills a program was developed for each child. Programmatic changes from week to week were dependent on the child's performance on the movement cycles.

The classroom program is not really a research program. We set it up essentially as a demonstration or a service to the parents. Our interests are in cognitive and language development. We feel that without this kind of a service capability we are not going to have good research, and the parents are not going to bring their children. We find that the classroom is a fairly important part of our project. We have to maintain control of that and control of the parent training program to keep things internally consistent, and it allows us also to be very careful about our confounding in our experimental designs.

We can have the teachers work on important areas of development for these children, such as in motor development. One of the big ones is the use of the index finger-thumb opposition, so teachers can use that as a pinpointed target. There are many important forms of behavioral development at this age, and by having the teachers concentrate on that rather than on language we can keep our language research under fairly tight experimental control to show that, in fact, the manipulations that we are making in the laboratory are the ones that make the difference in the behavior of the child. Therefore, our experimental conditions are single-subject designs with each child. We replicate across children. We don't have this class versus some other kind of intervention class as a control. We wouldn't mind such a control, but we don't have the resources to do it at this time.

At the end of the year, we refer the children back to the infant evaluation clinic for independent assessment. We found accelerations in Baylev scores for each of the normal children, which you wouldn't expect on regression effects. However, these data are tenuous since we had no controls. But it showed us and the parents of the normal children that participation in the classroom with the delayed children did not seem to have a negative effect on the normal children. Each child showed acceleration. Each child was above the mean when he started, so he was further away from the mean when he ended.

The Toddler Project staff is convinced that the success of any intervention program with a group of moderately to severely handicapped children will depend on the involvement of the child's parent or guardian in that intervention program. If the people who are primarily responsible for the child's care are working at odds with the program or not reinforcing and emphasizing what occurs within the program, the gains, if any, will probably not be maintained. The child is in the classroom for two hours a day while the remainder of the time is spent with the mother. Consequently, the project has attempted from the beginning to include the parent as an integral part of the program; however, the participation of the parent has shifted.

Initially, it was decided to have weekly parent meetings. Parents of the delayed children were encouraged to attend while the parents of non-delayed children were allowed the option of attending. These meetings were established for three specific purposes. First, the meetings were to provide a source of information for parents on child development and problems of retardation. Parents were encouraged to ask questions of general and specific nature. Second, the meetings were used to establish a carry over of classroom behavior into the home. The parents were requested to select a response and attempt to teach this response at home. Further, parents were encouraged to chart the child's progress in acquiring this response across days. Third, a weekly meeting was to provide an opportunity for the mothers to meet and discuss problems pertinent to the project. A student in clinical psychology conducted the afternoon meeting while the classroom teacher conducted the morning parent meeting.

In May an evaluation by teachers, parents, and an objective parent-child interaction scale revealed a general dissatisfaction with the format of the weekly meetings. A parental questionnaire concerning: (1) the child's participation in the program, (2) the combining of nondelayed and delayed children, and (3) the parental meetings was given to each parent. According to the parental responses, the majority desired more direct contact with the classroom and specific training in techniques for working with their children. An evaluation of the parent-child interaction scale revealed that although the parents were able to verbalize many of the principles of reinforcement and behavior shaping, they were unable to translate these principles into their repertoires. Consequently, in June a new approach was begun with the parents.

To help the parent become a more effective teacher with his own child it was decided to train the mother as she trained her child. The mothers began bringing their children one-half hour before class. One staff member (trainer) was assigned to one or two mother-child groups to serve as a trainer-observer. With the trainer's help the mother selected an educational task for her child. The children were generally trained on either motor imitation, receptive or expressive verbal tasks. An appropriate pretest was administered to the child and then training was begun with those items the child was unable to produce correctly. As the mother trained her child during these daily sessions, the trainer prompted the mother. The trainer pointed out principles the mother should be using (for example, reinforcement of an approximated response). The trainer demonstrated alternative shaping procedures, how to reinforce the child more quickly, how to identify an approximation, etc., whenever necessary. During these sessions video tapes were made of the parent teaching her child. These tapes were used in weekly critique sessions. The tapes were rerun and the mothers were able to observe themselves in action. Initial feedback on these parent-child sessions has been positive from both the parents and the staff. Posttest analysis for the child's responses and the maternal-child interaction scale are yet to be done. These results will be reported later.

As mentioned before, the parents were given questionnaires to assess their feelings about the project. Of the 20 children in the program 19 questionnaires were returned. An analysis of the parental responses indicated that these parents were overwhelmingly positive about their reaction to mixing delayed children with normal children. Only one parent indicated that he would not be willing to enroll his child in a mixed program and one parent did not respond to this question. None of the parents of nondelayed children indicated that they observed any negative effect on their children from interacting with less capable children. The parents of the delayed children agreed that their children benefited from interacting with normal children. The project staff will readminister this questionnaire following the completion of each year's program. If the response by the parents of both nondelayed and delayed children continue to be as positive and if the parents continue to report that mixing children produces no observable negative effect, it would seem safe to conclude that this approach will have demonstrated that young handicapped children can be carefully integrated with nondelayed children without harm to either group of children. Further, if this project can continue to produce data that indicate both the nondelayed and delayed child are making expected or better than expected developmental progress as measured by objective criterion, then two of the major obstacles for combining young nondelayed and delayed children have been passed.

We have about three research projects per class per period of time. In other words, at any one period of time we try to keep three lab projects going. Two of them will generally be in language while the other will be in cognition.

Another point that Don Stedman wanted emphasized was our attempt to integrate operant procedures with linguistic and cognitive theory. We are operant in the ways that we work with the children in terms of motivating their behavior and in the way we set up the task for learning. Our interest in what behavior we are trying to establish and how that behavior can be broken into components is taken from the linguistic and the cognitive domains, so we feel that we have a very legitimate intersection of the two positions. We don't look at this integration as an eclectic enterprise. We consider it to be using the best of what each has to offer. Although our reading of Piaget leaves unclear how one gets from one stage to another, he has the stages and the substages well defined. The operant approach insists that we need to operationalize what Piaget means by behavior at each of these stages and to figure out more effective strategies for getting the children from one stage to the next.

For example, when we were working at Clover Bottom we used the Uzgiris-Hunt Instrument to show us that a lot of our older severely retarded children did not have an object permanence concept. Once an object was out of sight, it was, in effect, out of mind. The child would not work to retrieve it. If it was partially hidden, he would go after it. So we set up a situation where children were asked to hunt for tokens. The child was shown a token, and the token was then hidden in one of the three places and his subsequent behavior was analyzed. What we tried to do was shape up search behavior. The one way to know objects exist when you no longer see them is to look for them, find them repeatedly, and soon you start to search systematically. As you do this, you start to believe more firmly that things exist when you no longer have sense contact with them.

DR. BERING: At what age does this concept of permanence become apparent?

DR. BRICKER: It starts to develop about the fourth month of life. It is pretty well developed by the eighth month. Children will systematically search for hidden objects about eight months of age. Our delayed toddlers in the project did not have an object permanence concept when we started.

One of the things we are doing in this project is teaching a child two different modes of searching. In one case, the child can see a token hidden, and it will be found there, so where the token was last seen is where it will be found. But there is another token, that is not found where you see it placed. It will be back in the same well, so this token is always found in the same place no matter where it is hidden. Searching in the same place is the more primitive form of behavior than looking where it was last seen which is the more advanced form of behavior.

There is an implication in Piaget's theory that these various forms of search behavior can be placed in a developmental hierarchy, and one of my students, Corry Robinson, is using this question for her dissertation. She has been testing these children for the last five months to find whether these are two different forms of behavior or whether they are equivalent, whether it's easier to find objects where they were last seen or where they were last found. The data she has indicate that the children can learn to search appropriately in both situations. Show the two-year-old child a green token, hide it, and then let him search for it. With the green token the child will learn to look where it was last seen. The next trial might be an orange token that will be found in the same place each trial. Then you reverse the tokens. You make the orange appear where it was last seen and the green appears where it was last found, so the child has to flip-flop his discriminations.

DR. HELSEL: At the two-year level?

DR. BRICKER: Yes, two-year-old Down's Syndrome children are performing a very complex memory task. Essentially the implication of this kind of short-term retention is that it involves a mediator, probably a verbal mediator, to differentiate between green and orange and remember that the green one is where you last found it and the orange one is where you last saw it. So the implication would be that such a task would be very hard. Luria would have this view, for example, that this task would be very difficult for a child who wasn't verbally mediating. The task is very hard but the children learned to do it.

DR. BERING: When you say "very hard," how much—

DR. BRICKER: I'm talking about 45 to 50 training sessions to get the behavior at the level where the children can make simultaneous discrimination. That's about 15 to 20 minutes per session.

DR. BERING: This is how many times longer than—

DR. BRICKER: The normal child?

DR. BERING: Well, the normal or Down's—

DR. BRICKER: If our evidence from Clover Bottom is useful at all, we have children who have Down's Syndrome who are 14 years old who don't have search behavior in this situation, who behave as if objects don't exist when they don't see them.

Another Piagetian type experiment is being conducted by Gisela Chatelanat in the Toddler classroom. Essentially, the children are provided with opportunities to interact with objects and then we attempt to classify the ways in which they use those objects, whether they bang them together, crumple them, put them in their mouth, throw them, hug them, make them walk, or do something relevant to them. As the objects are presented, each act of a child is carefully recorded by two observers. This way we get a kind of map of how the children are classifying these objects. By comparing the delayed child's use of objects with his chronological age mates who are normal, we are able to determine what we have as a baseline and what we have as a terminal form of behavior.

I would also like to discuss another one of our more precise experiments. This is in the area of operant audiometry. It's a procedure in which we use an automated apparatus to present auditory signals to children to test their hearing. Essentially, it is a multiple schedule where, when you have tone on, you get reinforced for pressing the button and in tone off, you are under extinction. By carefully grading your tone-off/tone-on periods, the child's behavior comes under the control of tone which allows evaluation of the hearing sensitivity of the children. We will be working on a new procedure this summer using two buttons that passes what one of my graduate students, Jerry Treadway, calls the "deaf child's test"—meaning deaf children could not perform appropriately with this procedure. In the initial stage we provide a lot of reinforcement for very few responses. Very quickly the rate picks up. The child learns that when the tone comes on he should press the button and when the tone goes off, he should press another button. When the child responds only in the presence of the tone, he is under what we call tone control and is ready for audiometric assessment.

DR. STEDMAN: Bill, there may be some questions with regard to how the parents view the project and how they participate in it. I would be interested, for example, in what the parents think is happening in this project, and whether that is important in terms of how useful they are in the project, maybe whether it is even related to whether or not the child moves ahead in the project.

DR. BRICKER: We have three levels of interaction with our parents. We started at what we consider to be the most important level this summer, and that was to bring the parents in a half-hour before class to put them with their child in a diadic teaching situation with a trainer working with them. We were working on their skill as a shaper, the way they were using reinforcers, the way they were establishing a task for the child, the way they were setting up approximations to the task—in other words, breaking a complex task into simple steps. We videotaped the parent training sessions and used the tapes in our critiques to evaluate the teaching style of the parents.

DR. STEDMAN: Could this program be part of a regular day care program that might appear?

DR. BRICKER: Yes, because what you are doing in the process of training your parents is making them into effective nursery school teachers. We find our parents do differ in terms of the roles that they will take on. We have a parent who has served informally as our social relations director, who is much better at meeting with other parents than working in the classroom, while other parents are just great in the classroom with the children. Some of the parents aren't particularly effective in the classroom but are good in the individual training sessions.

Even after the parents have had several months of training with us, they still make some major errors in the shaping process. For example, they overload the children with verbal information. Let me just summarize these data very quickly. If we take, let's say, 40 tasks or 40 particular movements we want the mother to do with the child, roughly 30 out of the 40 movements will involve verbal directions by the mother. She will tell the child what she wants, and she will tell them a couple of times. Sometimes, roughly about 50 percent of the time, she will use physical encouragement by somehow manipulating the object to make it more visible. But in terms of breaking things down into approximations, only about 27 percent of the time will she take a rather complex task and show the child just one component of it. She usually shows the terminal behavior when she demonstrates it at all. Usually she just tells the child.

Our receptive vocabulary material indicates that our delayed children aren't responding to words yet. There are a lot of facial gestural cues and situational cues that key off the child's response. So while it looks like he is responding to language, we have good evidence that often he is not. Yet verbal instruction is the method the mothers most often use to instruct their children. You wouldn't want to cut down on the linguistic interaction I'm sure, but, on the other hand, you would want to couple it with more physical demonstrations of behavior that the child is to engage in. Children emit the appropriate movement only about 30 percent of the time. They will give you the approximation of the terminal behavior about 42 percent of the time. Yet the mother will never reinforce the approximation; therefore, she has to wait for the total terminal response before she will give her child a reinforcer.

DR. STEDMAN: Can we take a concrete behavior and translate what that means?

DR. BRICKER: Let's say you want the child to raise his hands and put them on his head. Now, an approximation of this would be where the child starts to go up and you say, "Good," and you reinforce just the movement of the arms. Then you wait for more and more closer approximations until you get the child to put his hands on his head. Instead of reinforcing the approximation, the parent will wait for the full-blown behavior which may not occur. The child is in a sense then under extinction for approximate movements. Nothing happens when he moves his arms halfway, so he might as well do something else, like look out the window.

MR. IRVIN: I didn't understand what you said a minute ago. Did you say that you would not show the terminal behavior to begin with? It seems to me the mother would be demonstrating the terminal behavior of this rather than whatever the steps may be that would lead to this.

DR. BRICKER: The thing she would be more likely to do is say, "Put your hands on your head." The next most likely thing is she would show the terminal behavior but not an approximation.

MR. IRVIN: Is it ever helpful to show the terminal behavior and then work up through approximations?

DR. BRICKER: Yes. We haven't of course, gotten to that kind of analysis yet. We are just in the process of building ourselves a scale that will work reliably to represent each of these various facets of the training exercise. But, generally, if you are using shaping procedures, you show the full-blown behavior and then an approximation, giving the child the opportunity to engage in as much of the behavior as possible before you back up.

DR. STEDMAN: So you are developing a training program then for mothers? You say to the mothers, as you just said to us, "These are the things that happen," and she essentially is asked to implement that kind of style, which for her might be a new style?

DR. BRICKER: Yes.

DR. STEDMAN: Are there other examples of that kind of thing where you feel you have to consciously build into parents awareness?

DR. BRICKER: Yes. Some of the skills that aren't readily obvious, things like backward chaining, the idea that you start at the end of a behavior and teach the last component first before you teach the next to last in the chain. So if it is pulling up your pants, the first thing you teach the child is just pull it up the last few inches. Then you may get it down as far as the knees, then pull it up; and down the ankles and pull it up. The concept of backward chaining is not obvious to people and so we try to teach it.

The second skill parents often don't have is to take a task and break it down into its approximations. That is a difficult task. It is also important to learn to use physical prompts to get the behavior going, like taking the child's hands and putting them on the head.

Another skill that is hard for parents to learn is immediate reinforcement of a behavior. They will be hunting around for a Fruit-Loop after the response has occurred, so by the time the reinforcer is delivered, the child has engaged in ten different behaviors other than the one the parent is trying to reinforce. There is a critical time relationship in developing early forms of behavior, and the parents often miss that critical time relationship. It's hard to get them to be sensitive to the fact that a second may be the difference between getting it and not getting it.

DR. SOLOYANIS: In teaching these mothers, do you shape their behavior or is it all verbal? I wonder what they are learning from you that is carrying over into what they are doing with the children.

DR. BRICKER: That's where the videotape comes in, and that's what we will be doing this semester—showing them the videotape and demonstrating exactly when they are doing something right or something wrong, showing them what the alternatives would be, and discussing these alternatives. The parent must recognize that in the early learning of a new skill you have to deliver many reinforcers accurately. As the child learns the skill, then you can become less precise in both your delivery and your frequency. We are also trying to teach parents to work on behaviors that are critical to the child's development. Don't teach him a bunch of nonsense that looks cute since such training will use up learning time in the process. For this reason, we use cognitive or linguistics theory to try to help define useful behavior.

DR. HELSEL: Could we see those instruments you have? You apparently have some instrumentation for evaluating parents' skills as teachers.

DR. BRICKER: Yes.

DR. HELSEL: That one in particular is something I have never seen, some kind of instrumentation for evaluating how well the parent is doing in whatever tasks you are setting for him.

DR. BRICKER: This is the instrument for evaluating whether the parent is using the verbal domain or the physical domain, the nature of the child behavior, and the way this is done episodically. We have it set up in three parts, first an antecedent event, that which the parent provides for the child to do, and the way he provides it. Then we have the movement characteristic. That is what the child is doing in relation to that task, whether it's appropriate or inappropriate, then whether or not it is an approximation. Third, we have the subsequent event involving the potentially reinforcing and punishing consequences of behavior.

We find with parents that it is sometimes useful to stay away from some of the jargon, and we find Lindsley's system helpful in this area. Lindsley makes a distinction between the "is" language and the "does" language. The "is" language is what you are doing physically. Giving the child an M&M is "is" language. Giving the child a "reinforcer" is "does" language. "Does" means that it functions as a reinforcer. An

Table 1—List of Definitions of Maternal Teaching Responses

VERBAL	PHYSICAL
Directions and/or Instructions Mother verbally requests the child to emit some behavior which may be task relevant (denoted by +) or task irrelevant (denoted by -) or mother provided information which may be relevant (denoted by +) or irrelevant (denoted by -).	**Task Oriented** Prompt. The mother makes contact with objects involved in the task to encourage the child. Demonstration. The mother demonstrates the response. Can be divided into approximation in which mother demonstrates a component of the task or terminal in which mother demonstrates the terminal behavior. Guidance. The mother physically assists the child in the response. Can be divided into approximation in which mother assists the child in a component or the task or terminal in which the mother assists the child in completing the response.
Feedback May be positive (denoted by +) or negative (denoted by -). May occur to an approximation of the terminal behavior or to other behavior.	**Feedback** May be positive (denoted by +) or negative (denoted by -).

Table 2—List of Definitions of Child's Responses

VERBAL	PHYSICAL
Task relevant For example, child imitates mother's directions (denoted by +).	**Toward object** Child manipulates object Approximation. Child emits an approximation of the terminal behavior. Terminal. Child emits terminal behavior. Task relevant-terminal behavior is correct (denoted by +). Task irrelevant-terminal behavior is incorrect (denoted by -). Other. Child emits behavior irrelevant to task.
Task irrelevant For example, babbling or crying or requesting to leave (denoted by -).	**Toward mother** Child makes physical contact with mother Task relevant. Child elicits mother's assistance (denoted by +). Task irrelevant. Child tried to get mother to leave (denoted by -).

M&M may or may not operate as a reinforcer. The parent doesn't care whether you call it a reinforcer or an M&M as long as it functions. Parents can remain at the level of the "is" language and not be too caught up with whether they are meeting the operational definitions that allow it to be called a reinforcer or discriminative stimulus.

DR. HELSEL: Who is doing the evaluating? Your staff?

DR. BRICKER: Two graduate students have assumed the basic responsibility for this project.

DR. HELSEL: Somebody is having to do a lot of looking and counting.

DR. BRICKER: Corry Robinson and John Filler are the two students developing this instrument from the videotapes, and we find the videotape is valuable because our reliability was low at first.

DR. HELSEL: You are evaluating the tape, not the actual interaction. You can run it back if you miss something?

DR. BRICKER: Right. Events are often too transitory for immediate correct classification.

DR. HELSEL: That's what I'm worried about.

DR. BRICKER: That's why it's important to get the mother-child interaction on tape. It's important to have a good videotape cameraman.

DR. STEDMAN: What about long-term consistency? They may be perfectly consistent or effective in terms of your criteria for two months in the project, but what about a year down the road? They can't always be involved with this project.

DR. BRICKER: We are taking this instrument and working with the parents over the course of this year. We will be following them during this year, and also we are planning to follow these children until age nine. This keeps us linked to the entire early developmental sequence. We are going to try to go the Eichorn-Stedman route and be able to specify the intervention, not only changes that happen across time, comparing institutionalized and community-based children, but being able to show what produced those changes, by linking into the parents, linking into the classroom, and linking into the laboratory.

MR. KAPLOW: Were the fathers involved in any way?

DR. BRICKER: Yes, I was mentioning that this interaction type of training was just one facet. We have a second one which involves principles of child development and child rearing. This group meets about once a month in the evening. We bring in videotapes and slides of the children in the classroom for the fathers to view. We go through principles of child rearing and discuss problems in the home. Another facet that has been interesting to me is the political activism of the parents. The group was becoming interested in improving the services available to their children and whether they should form an independent group or become members of the Davidson County Association for Retarded Children to stimulate these improvements. They decided to pick the latter. Four of our parents now are officers in the Association.

DR. STEDMAN: You are working within the system.

DR. BRICKER: Yes, leadership training.

MR. KAPLOW: The fathers were not involved in working with the children like the mothers, though, in any kind of session at all?

DR. BRICKER: They do over the weekend. The mother has one-half hour training session at school. Then we send her home with a couple of other things to do, and she is supposed to involve the father in it.

MR. KAPLOW: She is supposed to train the father?

DR. BRICKER: Yes.

MR. GULA: –Or any other active caretaker at home? Sometimes there is a grandmother who is having a lot of interaction with that toddler, and unless she is brought into the ken, you know, there are some real differences in approach there.

MR. KAPLOW: I wonder what happens in the home situation. When they are on the project, this is one thing. But the child spends most of his time, of course, at home with whoever is there, with whom they interact, other children in the family and so on.

DR. BRICKER: Right.

MR. LYNCH: Speaking of labeling, this is essentially an MR unit. I gather you have mostly Down's Syndrome children and one child you indicated was brain damage. And you also have autistic children?

DR. BRICKER: No, we haven't. The Regional Intervention Program (RIP) exists in the same building as the Toddler Project, and RIP targets the so-called behavior disordered child who is between one and three.

MR. LYNCH: Your program couldn't serve autistic children?

DR. BRICKER: I see no essential difference in educational strategy for any of the lower functioning children. I think once you have an idea of how an educational content is to be put together and presented to the child, you can make accommodations for specific defects and adjustments for modification of physical impairments.

DR. HELSEL: But you don't have any children like that in this sample?

DR. BRICKER: We have a program just down the hall which deals with multiply handicapped and rubella children under Dr. Verna Hart. We are in contact with these other kinds of programs and we exchange information.

DR. STEDMAN: I think Fran was going to highlight something I noticed you religiously avoided–

labels. You just talked about toddlers. Is that consciously arrived at?

MR. LYNCH: I had picked up that you were referring to Parsons and work done with autistic children, and I didn't know whether you were dealing with them in this. That was the sense.

DR. BRICKER: We are not. But you would have a tough time pushing me into a belief that the autistic child is really a different kind of organism. There are some things that he can do well, but this is true of other low-functioning children as well.

DR. BERING: How do you find these children? How do they get to you?

DR. BRICKER: We started out with the Developmental Evaluation Clinic.

DR. BERING: How do they get to that clinic?

DR. BRICKER: Through public health nurses, pediatricians, and other community agencies. Both poverty groups and the middle class groups have access to the clinic.

DR. BERING: So they know there is someplace they can go?

DR. BRICKER: Yes. Nancie Schweikert, pediatrician and director of the Infant Evaluation Clinic, is working industriously in Davidson County in trying to get every possible child into at least some kind of contact with a developmental index like the Denver Development Screening Test, something very simple that can be used by public health people. Although the Denver is only a screening test, it gives us enough information to suggest that pediatricians not tell the parents, "Maybe he'll grow out of it," or "Let's wait until he's three." Data being reported by infant researchers are turning up implications for early education.

DR. STEDMAN: Can you give an example?

DR. BRICKER: Yes, for example, visual tracking is an important early behavior, and you can deliberately stimulate tracking. You give the idea to the parent of moving an object slowly across the child's visual field. When he looks at it, do something that makes the world exciting. Then move it a little bit more. If he looks at it, make the world exciting—in other words, reinforce him. We can work on tracking. We can work on head movement. We have been working with a couple of profoundly retarded children this way. Contingency awareness is one of John Watson's constructs that he has developed at Berkeley, and it is the idea that children have to learn to respond to contingencies of reinforcement.

Infant researchers are telling us that the kids can see the world pretty much as we see it. It's just they haven't many ways to tell you about it. So what you have to do is give them some armaments to make the world change, to make it less boring. Infant perception research shows that even a neonate gets bored. We have a new staff addition from Boston, Steve Friedman, who has been studying infant perception. From all indications about habituation curves, babies can become bored with fairly complex stimuli as early as 36 hours after birth. One thing that can make the world interesting is your ability to control it and to make it change.

DR. SOLOYANIS: Bill, may I ask you about what happens in the project? From what you showed us, it looks as though you have what we call a developmental day care—

DR. BRICKER: Yes.

DR. SOLOYANIS: —just things happening. Then you had another group of activities where these children are taken into a box and somebody structures some activity also.

DR. BRICKER: Yes.

DR. SOLOYANIS: Is there some of this that also takes place in the classrooms with these teachers or activity center that is also a structured activity geared to a particular child but that you are not measuring or researching?

DR. BRICKER: Yes. Teachers have lesson plans, and they are flow-charting. They take data on particular forms of interaction.

DR. SOLOYANIS: Are they all operant-oriented, these teachers?

DR. BRICKER: Well, not religiously.

DR. SOLOYANIS: I was trying to determine what is different in terms of what you have said of this activity center and something that somebody might set up in his back yard, for example.

DR. BRICKER: Nothing. We don't assume that anything we are doing is necessarily different, but we are trying to get a data base, a good way of evaluating what is happening and what is associated with those changes, so we have to tighten up on the lab in our critical questions like the Piagetian sensory motor processes or in some of the language research. We go to the lab level only because that is the place to get data that people will believe. If it doesn't look like it's a critical form of behavior or that training the behavior is a real problem, then you can work with the behavior during classroom activities.

All of these children will be ambulatory, and it probably won't take much of a stimulation program to get them to walk. So that's one where you can have a loose kind of interaction with the child. Getting the meaning of words is a much more precise skill, and some of the children may not get that one unless it is carefully programmed.

DR. SOLYANIS: It seems to me this has a lot of implications, which is what I am trying to get out, for what you might expect the generic, ordinary center to do to develop these handicapped children, just do their things, and what component must be added if they are going to take on handicapped children, differentiation of the two different kinds of inputs that you have to put into the program. This is what I am trying to do.

What can anybody do that is also kind of useful in kind of a crude way and what is the essential element if these children are going to progress that you are going to provide? We get asked this a lot, you know. "Can we do this for these kids? We don't know anything about them. We don't know how they grow. We don't know how they learn." And I think you're beginning to differentiate here for us saying it's the same in all these nine places, and in these four areas you have to do something else.

DR. HELSEL: The place where it's really going to become significant is when we get this tremendous day care push because of the two, House Rule #1 and the child development stuff, and then all of our handicapped children, you know—Can these children participate in this program? And what do you have to add?

DR. BRICKER: This, of course, is one of the places we have done a lot of thinking that the critical need is in the area of materials and procedures carefully specified but readable by people without much education. But one of the things that we found as we watched several projects unfold and develop is that there is not enough of a market in the public sector to make it commercially profitable to go into publication. Consequently, we have to find ways to get materials into the hands of parents.

I think that the entire developmental disability structure looks like it is going to have capability of providing these kind of centers—materials and procedure centers, instructional materials centers—but we are finding that just using the Kennedy Center as a base, we could put materials in the hands of people all over Tennessee at very little cost.

Larry Larsen and I wrote a manual that was set up for institutional aides to teach them how to work on dressing, talking, things like this, and we have printed up about 5,000 of these manuals in the last two years. We find that we can produce them and mail them, including handling charges, for about one dollar per copy. We can throw in a lot of free ones besides.

The other thing we are doing with our parents is developing a teacher manual for parents in interaction with their kids. The parents are testing whether they are right or wrong and saying how you teach a particular skill with a child. By going through these flow charts, especially on what you should do when the child doesn't do what you ask him to do and by having the parent sensitized to how to make flow charts, it teaches them how to break it down. They also give us honest feedback when they don't understand what is happening or don't understand the purpose of this activity.

MR. COURIC: I'd like to ask something about the group of delayed children. Are these from middle-class homes? I missed that if you said it.

DR. BRICKER: Not intentionally. Most of the children are middle class because of transportation problems. We didn't build into our request to NICHD transportation costs to get the children in, so we take who comes.

MR. COURIC: I was just thinking from the case finding though, did you get most of these from private physicians, pediatricians? Is that why you don't have any black kids in this group? I didn't see any in the pictures.

DR. BRICKER: We had two delayed black children last year. In both cases the parents pulled them out because of transportation difficulties and they couldn't compete with the dress. All the other children had different clothes on every day, and their children only had two outfits, and they were not going to compete with that. We hope to export the project to the North Nashville Day Care Center which is in the ghetto. It is a good facility. We have had a long history of interaction with them.

Our parents now have what you would say is an educated orientation toward what to do for children, what's possible, and they have some political understanding as to how you get the system to move to produce good programs. They are instrumental through the Davidson County Association in getting the State to do things that they think are necessary.

MR. COURIC: Do you foresee some particular problems in getting the black parents involved even though they may leave the children in this other center?

DR. BRICKER: The Demonstration and Research Center in Early Education has a long history of working with poverty level people, and they are good at selecting teachers, for example. They don't send in middle-class academic types into the homes. You pick an individual from the Black community to help stimulate training there.

The same thing is true as the service system is developing around the State—nobody is talking about sending a group of experts from Nashville to Tullahoma. The idea is to find a nurse in Tullahoma and bring her back for some training in child development and education, and teach her some social welfare skills as well. Then she has both the medical and the educational knowledge to go back and practice with people she knows and people who trust her.

DR. SOLOYANIS: Do you think that is going to be any good, Bill?

DR. BRICKER: I think it's the best idea I have heard about how to get good services into the community.

DR. SOLOYANIS: I have a reason for asking that. If, for example, there is some dilution of distortion between you and these very highly motivated, very intelligent, etc., parents, and they don't always do a very good job—I'm thinking of large masses of people—if you're having difficulty even though you don't know exactly what to do and all that, by the time it gets to the parent, these choice parents, considering the difficulty you will have with still another social class, how much more distortion might you get, how much more dilution, et cetera?

This is why I say do you think it will really work, the exporting of something that you are not sure about even now? That's why I'm very interested in how you are training the parents or the substitute teachers. How are you looking at that problem? Because that will be the key problem regardless of what social class you go to.

And, you know, I don't think you guys are particularly interested in that as much as you are in the other stuff, which is your choice. But to me this is, in part, in response to what you are saying, John. This, too, we'd like to know something about. It's like keeping something you don't need. We want to know more about how effective this is before we can even conceive of where it might go.

DR. BERING: Before you answer this, let me add another kind of random question.

One of the problems we see in Washington where we work with the parents is in particular groups, particularly among the poor sections and blacks—And part of my question is: Is this true in all poor people? They don't talk to their children at all, or very little. My question is: Do you find there is resistance among these parents to get them to work and spend too much time trying to talk to these little kids when they don't do it to their normal ones? Is this a problem in getting them to work with the children? And how do you deal with it?

DR. BRICKER: I have to say I don't know, because we don't have that kind of interaction with enough parents to draw any kinds of general conclusions.

DR. STEDMAN: It's true from a lot of research that there is quantitatively less said in the lower socio-economic level home, and it doesn't seem to be a racial factor determining that.

DR. BERING: I was not sure about that.

MR. GULA: Is there any communication between this and the kind of thing that Rick Heber is doing in Milwaukee? He started out with 50 low-income blacks. Presumably the target group that could benefit from his activities would have been, you know, three or four times larger than the suburban or the rural group. And I was wondering, is there any communication—and maybe this ties in with your question—between the kind of findings he was making with the low-income black vis-a-vis the suburban white kind of children that you are dealing with? If there isn't this kind of communication, there should be in terms of whether pieces of what you are doing can benefit that, whether ultimately that can be targeted into the greatest vulnerable population we have in terms of low income ghetto black, for example.

DR. BRICKER: I have to separate the two hats I consider it important for me to wear. One is as a person, in the Davidson County Association for Retarded Children, a member of the board, to try to get that organization to produce services. There I think information from Heber would be very important in terms of what could be done, how is it best done, but that is not my professional hat. My professional hat is in terms of language and cognition, how it can be stimulated. I deal with people who are doing language programming, where they are very careful about their variables and how they affect the dependent variable.

DR. STEDMAN: You are raising the larger question of not only just these two projects and the extent to which they are interacting, but a whole host of people really—

MR. GULA: Communication among the pieces that are going on that never have this gestalt that you are referring to.

DR. BRICKER: I think a part of it is finding some system of representing an intervention program concretely, because we all use different styles of presenting it. If there is one place where the educational research is bad, it's not clearly specifying the intervention.

Pretest and posttest and statistical designs are great, but it's what you're doing and how it is working that is important, and you don't see very much of that represented in the literature. Our journals aren't structured to handle it.

DR. QUINN: There is a whole area there of strategies for dissemination, diffusion and adoption, and this is R&D work, and I think that it shouldn't take his time, Bill Bricker's time, you see, but there should be a consideration of that somewhere within the project. This is one of the most critical issues in any of our fields of endeavor.

DR. STEDMAN: Part of it is built in because of the categorical funding formats of the different agencies and the competition at the local level.

I have observed, as many of us I am sure have, there is almost religious avoidance of other projects because of the source of their support, moral or financial, and there is a built-in confusion of that kind.

MR. GULA: May I add one more point to this? We are trying an experiment in the Office of Child Development—not in the mental retardation field—but right now throughout the nation there is a spawning of so-called child advocacy concerns, organizations, activities, etc., going on so we decided we were not going to put all of our money just to having A, B, C, D, E variations going on, but we would put some of our money into trying this kind of a gestalt pulling together.

We have asked Al Cohn at Columbia not to get into any one vertical mine anywhere relative to strategy, but to sit on top of this thing and try to get a base line overview of what is going on, what kind of communication is there, what kind of communication isn't there, etc. This is one very tiny kind of crude, peasant approach to trying to get at this kind of pulling together of the pieces.

I think we have to do more thinking about how we use our money, whether if we have $100 we put $100 into vertical mines or whether we save $10 and put that into the overview kind of thing. That raises some interesting policy questions.

DR. BRICKER: George's question earlier hit me in terms of how to get this out to the people, too.

The way I see developmental disabilities developing from the point of view of the grass roots is that you build in the capability at the State level to evaluate your service delivery system. What they did in Omaha was to develop an evaluation system that puts priority figures on certain kinds of activities.

For example, do they take data on the child's progress in the program? That's a high priority item. The programs that do that have greater likelihood of being funded than programs that do not do that. They are able to take all of the different events that a program can contain and put different numbers representing variations in priority, and they can then control it. Programs that use, let's say, internally consistent procedure for reporting what they are doing with the children might get a higher priority than ones that invent their own system that is internally sufficient but doesn't communicate to the outside world.

MR. HORMUTH: How essential, you know, to the total program is the clinical service through which you pull the children? And when you talk about exporting the program which goes on in the classroom to this other area, do you have to utilize the clinical base? Is this part of the package? What do they contribute in addition to getting the children into it? I mean I assume they provided certain base line data.

DR. BRICKER: A couple of levels. If you are talking about medical clincial services, Dr. Schweikert in her activities is educating a group of people who have contact with children throughout the county, for example. In return for this, she gets back referrals for educational evaluation. We have a neurologist, we have a pharmacologist, we have a geneticist close at hand, and we use their interactions both in our training program and in our own interaction with the children. Of course, all the children are medically checked and worked with outside of our program. We don't have a built-in physician. But if we have some question about behavior or about drugs, we know where to go, and the people there have research as well as service and clinical interests.

MR. HORMUTH: I guess what I'm asking is, when you talk about exporting your standards and your program to this other area that you mention, are you saying that these clinical services are there or that this would have to be exported as a package or what?

DR. BRICKER: Well, our input to this system is simply taking those program boxes that we have on our lattices and saying if you want to get a child to develop receptive vocabulary, here's the most effective way we have found to do it. If you want to develop his discrimination, here's the way to do it. If you want to get him to speak in sentences of phrases grammatically correct, here is the efficient way to do it in terms of our experience. That's pretty good input by itself, if you could link up with other people's inputs from other domains. But I think that some of the packaging end of it has never been looked at as our responsibility to try to pull together the total gestalt of all the possibilities that exist for a day care center.

DR. HELSEL: It isn't just a responsibility. It's the essentiality of it. At least I thought this was what Rudy was trying to get at. If you are trying to give this to the wider world, how essential is that component in order to give this package to the wider world?

DR. BRICKER: That's a good question.

THE USES OF LITIGATION:
THE RIGHT OF RETARDED CITIZENS TO A FREE PUBLIC EDUCATION

Thomas K. Gilhool, J.D.

On January 7, 1971, twelve retarded children, suing by their parents, went to federal court in Pennsylvania to claim their equal right to a free, public education. They went with the Pennsylvania Association for Retarded Children, suing for themselves and for all retarded children in Pennsylvania who were being denied access to schooling. They took with them as defendants the Commonwealth of Pennsylvania, the Secretary of Education, the State Board of Education, the Secretary of Public Welfare, twelve named school districts and all of the school districts in the Commonwealth. Thus began the present line of litigation by retarded citizens, now busting out all over.

In turning to the courts, these children and the Pennsylvania Association placed themselves in a very old American tradition—the use of the courts to secure social change (or, from the perspective of the citizen, to secure justice). That tradition dates back at least to 1904 and the founding of the National Association for the Advancement of Colored People when W.E.B. DuBois and the others determined that a significant element of their strategy would be a planned, self-conscious resort to the courts. The effort culminated, decades and many cases later, in

Brown v. Board of Education.[4]

In the years since *Brown,* in the late fifties and early sixties, we are familiar with the use of the courts by the civil rights movement. In the mid-sixties, as lawyers became in some number available to the poor, welfare recipients and public housing tenants, poor consumers turned to the courts to alter their situation. In the late sixties, women have begun again to go to court. That is the tradition in which twelve retarded Pennsylvanians have now placed retarded citizens generally and their families. That is the tradition upon which we are building.

The black, the poor, women, the retarded and their families are knit together in this tradition not merely by historical accident, but by social fact. These citizens share common experience, and a perspective, and their resort to the courts is in significant part a result of the similar position each of them occupies in society.

Society's response to these persons is grounded in the judgment, so very widely exercised in the society, that "*they* are inferior, and *we* are superior." The judgment results in the attribution of stigma to these citizens,[5] and is acted out in pervasive patterns of discrimination—a failure to hear, to heed or to act upon their claims. Carried to its conclusion the judgment has resulted in institutionalization or its functional equivalent for these citizens. In addition, the person subject to the judgment—"you are inferior"—comes to believe it, and to internalize it, from which flows feelings of guilt and shame, timidity in action and unusual, self-denying acquiescence to authority.

There is a jurisprudence which takes account of these social facts and which gives expression to the tradition we are speaking of. Perhaps its most famous statement is in footnote 4 of *United States v. Carolene Products,* where Chief Justice Stone suggested that

"prejudice against discrete and insular minorities may be a special condition which tends seriously to curtail the political processes ordinarily to be relied upon and which therefore may call for a correspondingly more searching judicial inquiry.[6]

It is in this tradition that the Pennsylvanians turned to litigation and the courts.

There are at least four uses of litigation and as we proceed through the Pennsylvania case you will, I hope, see each of them. First, litigation may be used to achieve certain substantive objectives: in this case. access to schooling for all retarded children: what has come to be called "zero-reject education." Second, litigation may be used to create new forums, forums in addition to the court in which citizens may assert and enforce rights or even define and establish new rights: in this case, the due process hearing. Third, litigation may be used to raise new questions for public discourse or to raise old questions to new visibility or perhaps to redefine questions and to get the facts out front. And fourth, litigation–like any petition of the government for redress of grievances–may be used by citizens to act out, to express themselves, perhaps even to redefine their notions of themselves.

The substantive objective of the Pennsylvania suit was zero reject education. The claim to a right to education for all retarded children rested upon two rather straightforward notions–one legal, the other factual.

The legal argument rested on *Brown v. Board of Education.* In that case, holding segregated schooling unconstitutional, a unanimous Supreme Court wrote as follows:

> "*[Education] is required in the performance of our most basic public responsibilities.... It is the very foundation of good citizenship. It is a principal instrument for awakening the child to cultural values, in preparing him for later... training, and in helping him to adjust normally to his environment. It is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education. The opportunity of any education, where the State has undertaken to provide it, is a right which must be made available to* all *on equal terms.*[7]

If "it is doubtful that any child may reasonably be expected to succeed in life if he is denied the opportunity of an education" then surely it is certain that the retarded child, denied the opportunity of an education, will not succeed. For the ordinary child may learn, willy-nilly, wandering in the world, on the street, looking at television, riding the bus. But the retarded child, if he is to learn, requires a formal, structured program of education and training. And the retarded child, denied an education, is not merely in jeopardy of "success," but of liberty and of life. Without an education, the likelihood that a retarded child will be institutionalized and deprived of his liberty is significantly increased. And without those self-help skills which education can bring the retarded person, as the "accidental" death rate in institutions shows. is in jeopardy of life itself.

That was the legal argument: since the state has undertaken to provide an education to some (and indeed, to some retarded children also), it must provide an education to all.

The factual premise of the argument was equally straightforward: the fact is that all children are capable of benefiting from an education. The fact is that there is no such thing as an "uneducable and untrainable child." The fact is that, with an education, 29 out of every 30 retarded citizens are capable of achieving self-sufficiency, 25 of them in the ordinary marketplace, 4 of them in a sheltered environment. And the remaining one of every 30, with an education, is capable of achieving a significant degree of self-care. The fact is that children who are crib cases in Pennsylvania, and in most states, are *not*, in Southbury Training School, in parts of Colorado and in Scandinavia. That was the essential factual premise of the claim–to which the best of your profession as expert witnesses were prepared to testify, in as many varied and expressive statements of that fact as could be imagined.

The truth is that when many of the statutes contested in the Pennsylvania case were written that fact–the educability of all retarded children–was not so clear. Indeed, 18, 20 or 30 years ago, the fact was reasonably held to be to the contrary. But, as the Supreme Court indicated years ago in the *Carolene Products* case, "The constitutionality of a statute predicted upon the existence of a particular state of facts may be challenged by showing to the court that those facts have ceased to exist."[8] Thus the expert witnesses took the court on a tour through the last 100 years, of the expanding realization that all retarded children are educable. Whatever facts may have misled a legislature sometime ago those facts were no longer true and to speak now of children who were uneducable and untrainable was to speak of a null class.

Pennsylvania's constitution, of course, like the constitutions of most states, carries a ringing declaration that the Commonwealth will provide an education to all of its children. Indeed, the Pennsylvania School Code itself, like that of most states, in one section speaks of "providing a proper education to all of the Commonwealth's exceptional children." But despite those declarations, and despite the effort of the chief administrators of special education in Pennsylvania, large numbers of retarded children were being denied access to schooling. (The precise number of out-of-school children remains uncertain. Despite the School Code's requirement of an annual census, in Pennsylvania, no less than in other states, the census is either not conducted or is unreliably conducted. The best estimate based on conservative incidence data and upon the numbers of children without educational program in institutions or other facilities is that while 50,000 retarded children are in school in Pennsylvania 20,000 to 25,000 are not.)

The same School Code that said the Commonwealth shall "provide a proper program of education to all of its exceptional children," a few paragraphs later whittled its exceptions: "uneducable and untrainable children" may be excluded from schooling; "children unable to profit from further education" may be excused; the admission of a child who has "not yet achieved a mental age of five" may be postponed. (The latter provision, of course, means that those children with attributed IQ's under 35 will never be admitted to schooling, because as the calculation goes they will never attain a mental age of five.) In addition to the statutory exclusions, there existed a host of practices excluding retarded children from schooling: "not toilet trained? go away;" turning compulsory school age provisions against the child: "not eight yet? go away. 17? go away;" waiting lists: "we'd like to, but not now," and the great inventive array of devices.

Those were the circumstances that confronted the Pennsylvania Association for Retarded Children, the twelve children (children in the full range of circumstances, for by no means is exclusion limited to the profoundly or severely retarded) and their parents when they resolved to go to court. For twenty-three years the Association had attempted itself to provide schooling for the excluded (in the process they had demonstrated again and again the essential factual premise recited above), but they had for sometime realized that they could not, with their limited resources, provide schooling on the scale required and that their job had to be instead to insist that the public accept and act upon its responsibility. But still neither the legislature nor the executive had acted.

Thus, suit was filed on January 7, 1971. In April, argument was held on the question whether there was so serious and substantial a constitutional challenge to a state statute raised to require the convening of a three judge court to hear the case. In May the three judge court was convened. Intensive discovery followed in May, June and July. And the case was scheduled for a hearing on preliminary injunction on August 12 and 13. After testimony from four of the eight witnesses plaintiffs had planned to call, the defendants called a halt and announced they wished to settle the case. (As the Court later put it in its Opinion approving the consent agreements, "The Commonwealth's willingness to settle this dispute reflected an intelligent response to overwhelming evidence against their position.")

On October 7, 1971, the Court issued a series of preliminary injunctions based on the consent agreements and binding upon all of the defendants requiring them:

(1) "To provide as soon as possible but in no event later then September 1, 1972, to every retarded person between the ages of six and twenty-one, access to a free public program of education and training appropriate to his learning capacities."

(2) "To provide as soon as possible but in no event later than September 1, 1972, wherever defendants provide a pre-school program of education and training for children aged less than six years of age, access to a free, public program of education and training appropriate to his learning capacities to every mentally retarded child of the same age."

In addition the court issued certain injunctions prohibiting the use of particular statutes and practices to deny children access to schooling and requiring that homebound instruction and tuition reimbursement be available to retarded children as it has been to others.

But words, of course, do not automatically translate into reality. Thus, the consent agreement provided and the Court ordered that the defendants in timely fashion prepare two plans: one, a plan to identify, locate and evaluate all out-of-school retarded children, and second, a plan (including the particulars of funding, program, space, recruitment and the regulations under which new programs would function) to deliver the education and training on or before September 1, 1972. To oversee the development of the plans and their implementation the Court appointed two Masters, a special educator and a lawyer familiar with retardation. Plaintiffs were to have the right to be heard on the adequacy of the plans, and in fact the Association has participated in their formulation in extended negotiations conducted under the aegis of the Masters. (Several school districts objected to the agreements and the Court's preliminary injunctions, and on May 5, 1972, the Court issued an extensive Opinion approving the agreements, making the injunctions final, and adopting the findings of fact and legal arguments discussed here.

That's zero reject education, the substantive objective of the lawsuit. Let us turn to the second function of litigation: creating a new forum. Note that the discussion thus far has been solely in terms of *access* to education. The case was carefully framed to raise only the access question. The federal courts have indicated in several recent decisions that they will not consider questions of the quality of education. The measures and the determinants of quality of education, the courts have said, are not sufficiently clear or precise for them to make the sort of principled judgment courts are in the business of making. Yet the plaintiffs—children, parents, and Association knew that access to schooling might be to no avail if the program provided a retarded child were of low quality. Plaintiffs, unable to turn to the federal court directly for such judgments, had a choice: to rely upon their clout (now considerably increased, since the defendents had at least to provide *some* program) in bargaining with or lobbying the school authorities; or to seek to create a specialized forum where expert judgment could appropriately be brought to bear, parents and others heard, and questions of the quality of program resolved. They chose the latter.

The argument for the new forum, for a hearing on educational assignment was as follows. Garrison and Hammill had recently reported (Sept. 1971, Journal of Exceptional Children) the results of their study of placements in "retarded educable" classes in five county metropolitan Philadelphia. They found that at least 26% and probably as many as 68% of the children assigned to RE classes should not have been there. They had been misclassified. They should have been in regular classes or in regular classes with resource room support. That rate of misclassification is not peculiar to metropolitan Philadelphia; similar studies across the country, including Jane Mercer's in Riverside, showed a similar rate of misclassification. The consequences of misclassification are twofold: effective denial of an education and stigma.

There is hallowed legal doctrine, recently reaffirmed in cases concerned with the termination or reduction of public assistance and eviction from public housing, e.g., that before the government may withdraw from a citizen a substantial benefit it has accorded him, it must provide him with notice and the opportunity to be heard. And in the winter of 1971, the Supreme Court rendered its opinion in ***Wisconsin v. Constantineau,*** a case very much in point. Wisconsin had a statute authorizing the local sheriff whenever he judged someone too often public drunk to post the person's name in the town square and outside the local pubs. Mrs. Constantineau found her name posted, and didn't like it. "You can't do that without giving me a chance to fight it," she said. The district court and the Supreme Court agreed with her. In its opinion, the Supreme Court pointedly said:

"The only issue...here is whether the label or characterization given a person by 'posting,' though a mark of illness to some is to others such a stigma or badge of disgrace that procedural due process requires notice and an opportunity to be heard. We agree... that the private interest [here] is such that those requirements must be met.

"Only when the whole proceedings leading to the pinning of an unsavory label on a person are aired can oppressive results be prevented."[9]

Thus, the consent agreements provided and the Court ordered that notice and the opportunity to be heard must be extended before the educational assignment of any retarded child or any child thought to be retarded may be changed. And notice and the same opportunity to be heard must be extended automatically every two years thereafter, and, upon the request of the parent, every year. Thus before any assignment from regular class to special class, among the varieties of special class, to tuition reimbursement or homebound instruction, or vice versa notice must be given and the opportunity to be heard extended. The hearing is to be held in front of the Secretary of Education of the Commonwealth or his designee. (In fact, hearing officers, special educators mutually acceptable to the Pennsylvania Association for Retarded Children and the Department of Education, have been appointed.) The notice given the parent must indicate the recommended assignment (or the present assignment in the periodic notice after assignment) and state in detail the reasons which support it. It must state with particularity how the parent may secure the hearing; it must provide the parent with the address and telephone number of the nearest chapter of the P.A.R.C. The parent is entitled to full access to all of the child's school records before the hearing. He is entitled to an independent evaluation of the child by the Commonwealth's Office of Mental Retardation. He is entitled to be represented at the hearing by any person of his choosing—a lawyer, a friend, a member of P.A.R.C.'s educational advocacy committee. He is entitled to call and examine any person in the employ of the school district and to present any evidence or to call any witnesses of his own. The decision of the hearing officer must be based on the record and must be supported by written findings of fact. The sole criterion for decision is whether the educational program in question is the appropriate program for this particular child.

Thus a new forum—for the first time in American education, an opportunity for the parent in formal and defined fashion to hold the schools accountable for the nature of the educational program afforded his child. And, it need hardly be said, an opportunity for questions of resource and educational practice to be raised by the professional educator, as well as by the parent, to the attention of the Commonwealth's highest educational officer. And, just by the way, an opportunity for the P.A.R.C. to offer a service (advocacy) with a very clear hard-goods result to its clients (the parents and children) and thereby to grow in strength. And finally an opportunity for parents to express themselves, to assert themselves and to have significant influence in the education of their children—but more of that in a moment.

The third function of litigation: to get the facts out front, into public discourse. . . . The media comes to court with public interest litigation, and back out through the media to the public, the legislature, indeed to teachers and to parents goes a message. Gunnar Dybwad waiting to testify cleanup is interviewed on the courthouse steps. Ignacy Goldberg, Jim Gallagher, Don Stedman, Burton Blatt testifying, and report. The central fact–the educability of all children–has a new visibility. And so does the notion that retarded citizens may have rights.

The fourth function of litigation: to express one's self and, indeed, to change one's conception of one's self. The orders of the Court, as the arguments themselves and the very presence of children and parents in court, meant that certain language that many had been using was not longer appropriate, that a new language had to be adopted, a language which reflects a different conception of persons and relationships. Two stories will illustrate the point; both occurred within the week after the Order of October 7 requiring that the twelve plaintiff children be placed in a suitable program of education and training.

In one case, the school psychologist went to the parents of one of the plaintiff children to tell them of the court order and announced: "We're going to do you a favor, we're going to give John another chance." "No," the parents said, "you're not going to do us a favor. You're going to give us what we are entitled to have."

In the second case, the school psychologist visited the house of another plaintiff child and said to the mother: "We've got an order that says we have to put your child in school. Now, we're good people, and we'll obey that order, but you should understand the facts. You remember two years ago we had Jim in a class and after two weeks we had to call you and tell you he was acting up and take him home. That class was not for him; the children in it were high trainable; they were doing things different from what Jim needed. Well, we have that same class, and we'll put Jim in it–if you want us to. But you and I know that after two weeks we'll have to call you again and tell you he's disrupting the class and take him home, and of course we'll give you the notice and the hearing and all the rest. But what good mother would put her child through all of that?" Well, the mother said many things in response, all of which in essence said: "You're talking the wrong language, to the wrong person. It is no longer the case that the child must fit the class. Now the class must fit the child."

The language is different—and so is the reality, or so it may be. The retarded child is person, citizen, with rights and places to enforce them.

Several conclusions suggest themselves.

One, the use of this sort of approach–to the rights of the retarded, through litigation–is going to multiply.

Two, this approach depends deeply and seriously upon *professional inputs*—whether it was the expert witnesses, whether it was the AAMD, CEC, and NARC presenting themselves to the Court as amici curiae prepared to argue, elaborate, explain the facts that characterize the world of the retarded.

Three, "advocacy" can now be invoked by the retarded, not in some analogous, poetic, watered-down sense of the word but in its strict and historic meaning. The evolution of this new forum, of the due process hearing, its multiplication, may be counted upon in the other cases now pending across the country. The significance of this forum, if we have the will and the tools to use it, cannot be overstated.

Four, effective use of the new forum requires widespread, well-trained lay advocates in the retardation movement–ARC's will have to develop "education rights handbooks" (Pennsylvania has the beginnings of one) that layout in language understandable to all how to claim a child's rights, where to go, what to say. ARC's will have to become proficient in using the hearings.

This may require a shift in funding patterns. ARC's are out of the business of delivering education now, and into the business of advocacy. H.E.W. funding will have to reflect this new role.

Five, the facts about which the experts testified—that there is an effective program of education for every child—will have to be "packaged." It's one thing for the expert to know it can be done; it's quite another for the teacher to know how, with what materials, after what diagnosis, and with what continuing evaluation. That knowledge, both of program design and delivery, is not as widespread as it must be. Nor is knowledge of how and where to find out-of-school children widespread. It must be.

Six, H.E.W. has the power to promulgate regulations, under the Education of the Handicapped Act of 1970 and otherwise, requiring zero reject education and due process hearing opportunities as a condition of federal funding, and arguably it has the obligation to promulgate them.

EXCERPTS FROM QUESTION AND ANSWER SESSION

MR. IRVIN: You know, the thing Tom is addressing himself to in Pennsylvania (*the default on census*, perhaps bad methodology for census, and the confusion in incidence data), not only will this thing have implications beyond Pennsylvania, but this particular issue to me is the central issue facing us in the education of the handicapped today. And we are no better off nationally than the State of Pennsylvania is locally.

We keep saying that of the 7 million handicapped kids, 40 percent are being served, and no one knows where the other 60 percent are.

But I think the day is going to come when we can't go up and just use statistics with OMB and with the Congress. I think it is particularly significant now because Commissioner Marland has called for commitment, a national commitment, for the education of the handicapped, that by 1980 all handicapped kids will be served, whatever "served" means, and it's pretty hard to know who you're serving or how or anything else unless you have some kind of more reliable numbers.

But the same thing is happening–I made some calls, because I am on the task force that is involved in this. I called, for example, the State of Oklahoma and asked them how many–because they indicated they were serving only about 15 percent of the estimated handicapped kids.

I said, "How many known bodies do you have who are waiting to be served?"

They said, "We'll call you back tomorrow."

So they called Tulsa and Oklahoma City. They called me back and said, "We don't have any."

At the same time then I said, "Well, how is that particular Act that we have, Title VI or Part B of the Education of the Handicapped Act? What kind of luck are you having with that?"

They said, "Man, that's the best thing we have had ever. You know, this year we got 220 more units for the handicapped."

I said, "What was the basis?"

They said, "We don't know where the kids are. Now we have got the units, we will go find the kids."

And this is the kind of thing that goes on around the country right now.

I'd say 99 percent of the States use the old Mackey figures, the 12 percent and so forth, and very few States can actually identify kids in that same sense.

I think there are some other kinds of assumptions we can go into that of the so-called 60 percent a heck of a lot of those kids are in regular classes and probably can remain there, and to me the implication when you are talking cost and so forth to Congress and the kind of training that may be needed for some of the kids in the 40 percent group is kind of overwhelming.

I am glad to see that we are beginning to get away from the lock step of the segregated special class. I mean a concept of a continuum of services is beginning to grow more and more.

MR. GULA: You know, the British in 1957 did a nose count of every child born, and they actually followed those kids. Maybe somebody here knows more about this than I do. But I think that probably would be the closest to a real head count of what has actually happened, and we may be able to get some rural, suburban and ghetto counterparts out of that.

It's kind of second-handed. It's a shame to go overseas.

I think North Carolina did a house-to-house kind of court.

DR. HELSEL: Yes.

MR. GULA: Did they not?

DR. STEDMAN: That was the Alamance County study, but they came up with 14 percent.

MR. GULA: Prince Georges County or somebody did a door-to-door count.

DR. SOLOYANIS: Maryland.

MR. KRAUSE: The same with Riverside, California.

MR. GILHOOL: You have Riverside and New London and other studies, and all of the figures are very different.

And even if we could justify those figures, that of course wouldn't satisfy the burden here because the burden here is to notify each of those children—to find each of them, not merely to estimate how many there are.

DR. STEDMAN: Right. There are some opposing problems there, too.

I have been involved myself, and probably people have here at least a dozen times, and with other groups in going to systems like insurance companies to ask for actuarial studies, and those are systems that can do that kind of thing, but they can't do it without a definition.

They say, "You tell us what a yellow-bellied sapsucker looks like, and we will find him for you."

Then we're up a tree.

Literally.

And that becomes part of the problem.

The other side of it is that if you do try to go the definitional route, then you almost immediately are in a psychometric slot which is running counter to a major movement in the area of labeling and effects of the use of psychometrics as far as, you know, self-fulfilling prophecies and the kind of thing Jane Mercer is involved in and the rest.

So it is really a can of worms. Tom is right, you know. And I suggest this was really probably a big jolt for you, Tom, when you got into the area and started talking to some of the so-called captains of industry in this area, that we had managed to hold out for so long and to move from $1 million in 1960 to $300 million in 1970 on the strength of our definition and our ability to articulate who the group was. It's not an easy one, and we have to resolve that.

MR. GILHOOL: I didn't know whether we had a case or whether we didn't, whether we were talking about something real or not.

MR. LYNCH: I had a question about this, Tom. I gather this will be considered a precedent move. Is there no mechanism that the Supreme Court can write an affirmation on this or a universal— Does it have to be fought in every jurisdiction?

MR. GILHOOL: The case was heard by a three-judge court, and the appeal from a three-judge court is directly to the United States Supreme Court, and on appeal the Court either has to hear the case or they have to affirm.

MR. GETTINGS: The broader question that Fran is getting to is what kind of precedent do you have in this case for what is happening around the rest of the country?

You have said to us now, for example, the Boston case might end up in the same kind of consent agreement. Are we being put off by—

MR. LYNCH: By consent?

MR. GETTINGS: By consent?

MR. GILHOOL: Hard question. Hard, hard question.

My clients were not anxious to settle this case from the beginning, partly for that reason. The precedential value of a decision even in a three-judge court, however, would have been doubtful. It would have been binding in that district—that is to say, the Eastern District of Pennsylvania. But it would not have been binding in any other district around the country.

If we were in the circuit court and it were affirmed there, then it would be binding in Pennsylvania, in New Jersey, in the Virgin Islands, et cetera.

The Supreme Court is binding everywhere.

So one can't say as a technical matter that it is precedent in the sense that it is binding precedent. But it is persuasive. And its persuasiveness depends upon the record, the facts as they were set out.

It depends upon what questions were argued in front of the Court.

The Court, after all, did decide that there is a serious and substantial constitutional question here.

MR. LYNCH: One of your statements also is that it depends a good deal on the court.

MR. GILHOOL: Exactly.

MR. LYNCH: I gather from your conversation that part of your success was the intelligent questions that the Court asked that you may not get in other jurisdictions.

MR. GILHOOL: Quite. And in the same sense, the clout that you have when you walk in with this document in another court depends on the identity of the judges, and it happens that Judge Adams is among the most respected of circuit court judges, so it would carry some weight.

MR. LYNCH: One of the best informed judges there is on the circuit court.

MR. GILHOOL: Yes.

DR. STEDMAN: As a footnote to that, I was impressed with the tightness and precision of some of the quickly formed summary statements made by Judge Adams and the others, Masterson and Broderick, of a massive amount of expert testimony that was poured in in an hour or so.

There are some summary statements in the transcript that are really exquisite and ought to be preserved and used.

MR. LYNCH: Another thing that disturbs me is–fine, the kids are going to be served. Now, in northern Virginia they are breaking down a special class system and they are putting the kids back in the normal class without any provisions. How are you going to prevent that in Pennsylvania?

MR. GILHOOL: I don't know, nor am I sure that question is justifiable for the reasons I indicated earlier. Resort would be the due process hearing.

MR. LYNCH: In a community like Wilkes-Barre or Scranton, you are going to be facing that all the time.

MR. GILHOOL: Quite. That may be where that 60,000 kids are.

DR. SOLOYANIS: How retroactive will these be? How far back? Suppose the decision about a child was made 15 years ago, you know. Will the parent be able to reopen this in his local school?

And, secondly, what do you suspect parental attitude will be now on all these past judgments where, in effect, the problem is solved, the grief is over, and the case has been settled?

MR. GILHOOL: As with some of the plaintiffs, one of the plaintiffs is 17 and now at (Ellwyn), and somebody said, "You know, it's much too late for us."

The question of the effect of this on someone who was excluded 15 years ago is as yet undetermined. If that person is still less than 21, the person can claim whatever is remaining to him until he is 21.

The agreement explicitly reserves the rights of the parties to argue and to a hearing on the question of compensation. If a child is now 19, should he get two years or should he also get the five years he was denied?

If a person is now 28 and missed it altogether, shouldn't he get it starting now, year for year?

I'm very uncertain about the outcome of that decision for reasons that are probably fairly obvious. In the desegregation cases, the courts have begun to talk about compensatory education now that we are integrating to make up for deprivations from inferior schools in the past.

In the *Knight* v. *Board of Education* where the court in New York City ordered 400 high school students who were expelled without a hearing restored because it was wrong to expel them without a hearing, they also directed if the children wished it, they should be provided with compensatory education for the four or five months that they missed.

On the other hand, in the criminal area, *Gideon* v. *Wainwright*, on right to counsel, retroactive. If you were convicted in 1934 without counsel, you can raise it now and get a new trial.

In *Miranda*, the right to be warned of your rights before you are interrogated by police and have counsel present if you want, the court said, "No, we are not going to apply that retroactively, partly because a reasonable, well-thought-out police official couldn't have seen it coming," whereas somebody really should have known as to *Gideon* and the right to have counsel at trial was so fundamental.

O.K. Now, this is kind of fundamental, but could they have expected it? And what is the cost? So that question remains to be argued.

MR. KRAUSE: Some of the other implications here I would like to note. Do you conceive this is going to have any drastic effect upon the so-called delivery of services in Pennsylvania such as the institutions themselves?

Second, how will this be able to be interpreted in the way of future legislation for the creation of additional services or, secondly for the amount of funds that are going to have to be provided or appropriated in this case?

MR. GILHOOL: As to the institutions, the children in the class include the children in the institutions. It goes directly to the institutional programs. And there was much evidence in front of the court about who is in and who is out of school in the institutions and who is in one hour a day three days a week, and so on.

Second, as to quality, as I indicated, much of it remains still to be defined.

DR. QUINN: It is quantity more than quality, isn't it?

MR. GILHOOL: That's right. Had we gone to judgment, the court would have said, "You have got to provide them an education." I'm not so sure what else they would have said, except that we would have come back in and said, "What you are providing isn't education."

But there we get in trouble, and that is the second place where some things have to be developed before we can with confidence face courts down on all of these questions.

But in the consent agreement we discovered—indeed Fred Weintraub at CEC discovered—a provision in the Pennsylvania Code that neither DPW nor the Department of Education had ever been aware of, and that was the provision that gave the Department of Education the right, indeed the responsibility, to supervise programs in institutions.

DR. SOLOYANIS: We knew about that.

MR. GILHOOL: O.K. Your successors didn't. At least your counterpart.

MR. KRAUSE: I mean the further effect of this consent agreement in terms of the clients, the plans in Pennsylvania which have to be considered for 30 days? What will this create in terms of future legislation? Has the Pennsylvania Association of the State there determined, for instance, the additional appropriation of monies for these classes, for day care development centers?

MR. GILHOOL: I indicated earlier the absence of money is no defense if they show up in September and say, "We can't do it."

"Why can't you do it?"

"We don't have the money."

Then they are liable to contempt.

They can do one of two things. They can raise the money or they can take the money that they are spending on education and spread it out evenly, whatever that means, so that everybody gets in. O.K.?

With respect to new legislation, it's unclear. The consent agreement was drafted especially to avoid—because the court didn't want in a consent agreement posture to strike down any statute—to avoid doing that. We interpreted statutes under this constitutional threat that was lurking there that required that you read the statutes a certain way, and the statutes are indeed rather fungible. And, of course, the evidence went to those considerations that would require you to move the statute around a little bit.

MR. HORMUTH: As a further implication of this, I gathered there had been an attempt on the part of the Commonwealth to essentially say that whatever this program that the department of welfare is offering meets the needs of these children and therefore, you know, there is no real question, and I gather this is something that the court basically did not accept.

MR. GILHOOL: No, the question was never joined.

MR. HORMUTH: It was never joined?

MR. GILHOOL: Right. We did our best to avoid that question. When we talked about DPW programs, we talked, for example, about the 1,800 children in interim care facilities with respect to whom it is sometimes breathed on reports and elsewhere that they are receiving an educational program because the regulations that govern interim care facilities have two paragraphs that say you have got a duty with this $11 a day to provide education.

The fact of the matter is that they are not getting any formal, structured program of education and training. We so asserted it. There was no contrary assertion.

With respect to the children in institutions, Bernice Baumgartner has been for a good many years the clearest critic on that question herself, so that one had available state self-evaluations that indicated how many kids were in programs five days a week, five and a half hours a day, and we put in front of the court the number of kids who weren't in that kind of program, kind of defined in quantitative terms again.

We did not put in front of the court the qualitative question.

The same thing with respect to day care.

So that that question is lurking here. Had it been raised, who knows?

MR. HORMUTH: I wonder, you know, what the precedents or the implications of that might be, for example, in a State like Ohio in which they have relegated responsibility for any child with an I.Q. below 50 to the welfare department.

MR. GILHOOL: In one set of their regulations Pennsylvania said, "We do that for everybody with an I.Q. under (20)," but in fact that wasn't uniformally applied, and they had another set of criteria, too, that they invoked.

MR. HORMUTH: I could see implications in terms of other kinds of programs as well which exist in a State in which one particular State department presumably has responsibility for providing a specific kind of service and then you begin to make exceptions in terms of the retarded, you know, and assign them elsewhere.

MR. GILHOOL: With Goldberg's testimony we tried to anticipate some of these questions, not with— For example, Ignacy Goldberg testified that one of the things he would look at to determine whether it is schooling, whether it is a structured, formal program of education and training, was whether there was someone there who was kind of the engineer who was setting goals and evaluating whether they were met and laying out how you go from here to there.

And we even got him to breathe the word "certified special education teacher", once or twice on the record. That shows you where my mind was tending.

If I was forced to that question, I would have said. "Well, surely one of the things that remarks education is the presence or absence of a certified special education teacher structuring the process."

MR. GULA: I also wonder whether the role or the presence of departments of welfare and the responsibility that some of them hold for the training and education of retarded is not an accident of history.

Because, remember, number one, that State institutions including those for retarded, long preceded State departments of public welfare and, number two, with the reluctance of departments of education to have a downward extension of responsibility, the Department of Public Welfare was kind of, you know, moved into that role whether they liked it or not.

And it seems to me conceptually this should not be the travesty that ought to project itself into the future.

MR. HORMUTH: This is why I was wondering what this kind of precedent might envision for us, what this might ultimately lead to.

MR. GILHOOL: It seems to have some dynamic about it that presses in the direction of generic responsibility.

DR. QUINN: In education?

MR. GILHOOL: Yes.

DR. QUINN: Right.

MR. HORMUTH: There are implications in terms of a variety of other kinds of programs.

DR. STEDMAN: Service delivery in general.

MR. HORMUTH: Right.

Well, a simple example. We have had problems in terms of the crippled children's program, for example. A State defines conditions and eligibility, et cetera. In a number of instances if a child is admitted to an institution which is in the jurisdiction of another department, those services don't necessarily follow that child. They are no longer available.

You know, I can see the implication of some of these comments for programs of that kind.

MR. GILHOOL: Yes, you see, in some ways it seems to me that that kind of question is one that courts will be very reluctant to resolve.

MR. GULA: Yes.

MR. GILHOOL: If there are principled reasons for resolving that question or reasons that approach the principled, probably that should be resolved by HEW through regulation, through regulation going to the plans that must be submitted.

MR. GULA: Or if not by regulation, by the kind of strategy used for financing of grants, et cetera.

And the other thing is this would be really one of the most atypical states one could conceive of to have this kind of reorientation occur, because for over 100 years Pennsylvania was governed by what was called the county institutional districts, which was the vehicle that carried all the service delivery in a very impaired kind of way, and it is only within the last two or three decades that that was abolished and the State system has come to bear.

So you are up against all kinds of obstacles there which perhaps you wouldn't face in some of the more progressive kinds of states.

DR. SOLOYANIS: Tom, I'd like to comment on this division of responsibility between the department of welfare and education in Pennsylvania. Because in the '50's I used to get those school exclusions. They used to come to me, and I used to take them and put them in a file.

Every time education would speak and say, you know, "We have turned this case over to the department of welfare," I would say, "Bull," because what it really was was a device to excuse that local jurisdiction from having to spend any money on this child, and the department of welfare. had no responsibility whatsoever.

It was in the school code that it said we had the responsibility, not in ours. And there was no way you could call a parent up and say, "Your child has been excluded. We're ready to give him services." That was also a mockery. And we were quite bitter about this practice of educators in saying, you know, "We have done a positive thing," when in fact they hadn't.

For a long time also even though they had supervisory responsibility in their school code, there were other acts that were in conflict with this, and in point of fact they didn't want us. We had the children they excluded.

And we used to claim—this is a very emotional thing for me because I was in the middle for many years—that they didn't know what to do with these kids, that they didn't recognize the occupational therapist and the physical therapist and the behavior mod and all the other people. And, in fact, we were willing to give them fiscal responsibility and were willing to meet their standards but we didn't want them in there.

Because, in fact, the Commonwealth doesn't provide anything but grants and guidelines, and so on, from all the districts, and we were also willing to go this route.

But for Title I and for some other things that gave you that count that Bernice was able to give you, you know, we wouldn't even have the facts that we have now.

Another thing. If you went the route of the special education teacher, the welfare institution would have passed. We had as many— The percentage of qualified special ed teachers in our institutions was as high as in the community—about 70 percent. What you had on us was that not all these kids were under these programs.

DR. STEDMAN: Two points. One is loaded, and I will save it until the last.

We slid very quickly over the master, and it might be worthwhile to say who he or she might be. But what is a master? What is going to be the role of this person? What is his responsibility? So when one is named, we will know what it is, and we will need some criteria for evaluation.

MR. GILHOOL: A special master is appointed under Rule 53 under the Federal Rules of Civil Procedure. A master acts in place of the court, though reporting to the court.

The master has the usual powers of the court to summon witnesses to call people, to make a record, and so on.

And he has, in addition, whatever other powers or duties the court chooses to give to him.

The closest analog is the use of a master in desegregation cases, most often used when a school district under order to formulate a plan to desegregate refuses or fails to formulate an acceptable plan. Then the court will appoint a special master. Most often in those cases to draw up the plan.

In this case the master is not appointed to draw up the plan. Rather, that responsibility rests on the defendant. The master is appointed to monitor that process, to make the original judgment about the adequacy of the plan and monitor the implementation.

He is appointed to another purpose, the most important purpose I think, and that is to *inform the process*. The court is very aware of the fact that we are dealing here with untrod territory. They were equally aware of the fact that both of the very small bureaucracies that bear chief responsibility are overextended, and therefore the master was there to exhort and to inform and to bring to bear on the process such resources and experience from elsewhere as he might.

MR. KAPLOW: Does the master make decisions on the adequacy of the plan and are his decisions final?

MR. GILHOOL: His decisions are not in any sense final. They are subject to report to the court and final decision by the court. And they are subject as well to argument in front of the master by the parties and, if appropriate, argument in front of the court.

DR. STEDMAN: Now the loaded one. Do you think you could construct a successful defense for the Commonwealth?

MR. GULA: As one more point, in terms of action implication or policy that have come out of this, it seems to me the Pennsylvania Association for Retarded Children is obviously seriously handicapped by the lack of adequate data, machinery, et cetera, relative to identification of retarded individuals, especially children, whether you are looking at the ghetto, the suburbs, or the country.

With that in mind, and recognizing that this is a universal need throughout the country, would it not be important for us to recognize as an HEW group here that whether we do this individually or in some kind of a jointly funded operation— Should we not address ourselves to this as one of the high priority needs in any future financing of projects, grants, or what have you, so we do get enough of these pilot kind of identification things so that they would have transfer value from State to State, not only for purposes of court deliberation of this kind but ultimately for administration of this kind of thing?

Because your State agencies will need to really know what the head count is, and I think the process of arriving at an adequate head count will probably be an interagency kind of responsibility both on the State and on the Federal level.

So maybe there is some moment for considering the possibility of some joint funding.

MR. KRAUSE: That's true. That's why my one question about legislation. There are many State school census laws.

MR. GILHOOL: We have one. It says the county superintendent shall know the identity of every child who is exceptional in the district. He shall be evaluated early. A report shall be made. And my understanding is that virtually every State code has that provision.

But it's not carried out. And many of them use the reason, the excuse, of lack of financing.

MR. GILHOOL: Just one further word to go all the way back to the precedent question. Exactly the same case is pending in the District of Columbia, *Hobson and Hanson III.* Skelly Wright declined to sit on *Hobson and Hanson III* because it was now five years away from the period when the District of Columbia didn't have its school board and there was an excuse for a circuit court judge to sit.

In the course of declining, he said, "It's outrageous."

There are cases under preparation of the same sort in California and New Jersey and cases under preparation in Michigan.

THE PROBLEMS OF AGING AND PROTECTIVE SERVICES FOR THE RETARDED ADULT

Leroy H. Jones

It is very significant that we find on the agenda of this "family focused" meeting consideration of the older individual who is in need of special assistance.

As mentioned, traditionally and historically, the focus has been on the most visible of the mentally retarded members of our society, namely, our children. Volumes have been written on the subject of mental retardation. Yet, when we review what has been written we find that it is nearly all focused on children with almost nothing in the area of the aged or older adult.

In reviewing one of the latest publications which listed all of the current studies in the field of mental retardation, there were only two related to the older person.

In some ways in this field, it seems to me we are going through the process of rediscovering the family. As we focus on the older person, as we talk about the family constellation, we need to recognize that statistically we have a four and a half generation family, soon to become a five generation family. As the population grows older and lives longer, we need to recognize that if an estimated 15 percent of the population is mentally impaired then this also includes the older adult. So, rather than the problem diminishing, we can anticipate a *substantial increase* in the numbers and in the types of the problem.

I would like to focus on two groups in this discussion; the older person, who himself is incapacitated to the point of needing intervention and assistance; and the older adult in his 50's and 60's, or even possibly down into his 40's, who is faced with the loss of a parent figure or parental support and guidance.

It is my speculation that this second group would be larger if we were to focus specifically on mental retardation. As we talk about this group of older adults, we are primarily focusing on the moderately and mildly retarded individuals rather than the extreme of the profoundly retarded.

Stedman's profile in his report[10] clearly illustrates the point that beyond the age of entry into the educational system, our programs, our services, and our concerns begin to drop off very rapidly. It is almost as if once we get a child into the educational system—be it in the community or be it in some type of institution—that we feel that we have solved most, if not all, of the problem.

Concerns for the retarded individual may be reactivated again at the age of entry into the employment market and yet as we look around in most of our communities, we find very little in the way of sheltered workshops, very little in the way of programs geared to training the young adult for the job market, and very little concern for the problem.

Despite all of the folktales and the myths, the retarded do not die off in adolescence and young adulthood. They continue to live in the same proportion as the rest of the population. If we think in terms of the average community that has between 10 and 12 percent of its population over the age of 65, we can begin to get some feeling for the numbers of older retarded people who are in our midst.

The advances in medical skills and industrial technology that are prolonging life include all of the people regardless of their intelligence level, and, as the population continues to grow in numbers and we live to a more advanced age, we are going to have an ever-increasing number of older people with limited capabilities and an increasing number of families who are touched by the problems that this creates.

Recognizing that it is only in the last decade or so that we have given much concern to this medical and social phenomena as to focus on prevention and non-institutional services, we need to be aware of the fact that a large number of less severely retarded people remain in the community and are taken care of by the family.

It should be noted, for example, that the disability insurance program of the Social Security Administration lists *15 percent* of its recipients as receiving disability insurance because of retardation. Additionally, there are a large number of older retarded people in our society who have never been accounted for because at no time did they ever enter into this or any other system. This, then, is where I think we need to begin to focus some attention.

If we look back 40 years, for example, we do not find programs for the retarded in our school systems. In all probability this individual never even got into the school system or, if he did, remained there a year or two and never was identified. Some of them may have participated for a brief period of time in various vocational training programs, but at that point in history we really had no accounting, so that today the only older retarded people that we can account for are those who are in our institutions.

When we consider that in recent years we have also placed increased emphasis on community services that will enable the retarded child to remain at home, we have to project that the number of retarded adults in our communities willl continue to grow. Many of the children who a decade or two ago would have gone to an institutional setting are now growing up in the community. Even though we are aware of this, our concerns continue to focus on the pre-school and school age child. Once the individual has gotten through a school program or possibly through some type of a job training program, it is as if that is the total solution and our concern just falls away.

This group of people who are being cared for by their own families will come to our attention again when they are faced with the loss of a parent figure. If we survey many of our social agencies, we get some feeling for the extent of this problem. For example, the people who come to an institution for the aging, needing that service are often faced with the problem of making some provision for a 60-year-old "child"; or the individual who comes to the social agency in his late 60's asking for assistance, again, with a sibling who is maybe 50, 60 or 70, because the individual who has been the caretaker has now retired, is now on reduced income and is no longer able to provide the care. So, we do find many of these people re-entering our social service system. However, we have not done a very good job of identifying them or accounting for them, or meeting their needs.

We need to develop a method of intervention as well as a system of monitoring to determine the extent of the problem. To what extent do we really follow the child once he completes a schooling program and moves on back into the community or remains at home with the family?

What happens after completion of job training program and movement into the employment market? I find very little in terms of agency follow-through on those who complete a job training program.

How long does the retarded person remain in a job once placed? Does he continue employment or does he eventually find his way to the unemployed rolls; and possibly even public assistance?

In terms of looking to the future, perhaps we need to give serious thought to a monitoring system for young adults and for children who come into our system either through the school program or through the job training program, and actually provide for a good follow-up system. I recognize that this may not be a very happy solution, as many people would not like the idea of a lifelong monitoring or intervention system; however, we know that the retarded individual is at some time or other, even though he may enter the job market, again going to need some service. It is one of the things that we ought to be considering for the present group whom we have already identified and begin to develop the services needed in the future.

Such a monitoring system might also provide a base which can become a checkpoint for the family when and if they need any assistance. It could also provide a great deal of assurance to families in terms of "what is going to happen to Johnnie, or to Suzie, when I am no longer here." This is a lifelong anxiety for the parent and many of them never really resolve it. We really do not help families of the retarded individual beyond young adulthood with this problem and this anxiety. It is only at a point of crisis and then only if the family seeks the assistance of a community service agency.

We need to look also at what we are doing in our communities in terms of providing comprehensive community mental health centers. We have had a great deal of talk about this service in recent years. Much legislation has been passed and many programs have been developed across the country. Yet, as we review these, it is very questionable as to just how comprehensive these programs really are. Even though some of them are first-aid stations to provide help to an individual or a family in a crisis, most have not given much attention to the problem of the retarded. As we tend to focus on mental illness rather than on mental health and adequate functioning of people, retardation related problems are often left to other groups to handle, especially the retarded older person.

The comprehensive mental health centers need to have input from the group that is assembled here today. We need to bring your knowledge, expertise and skills to strengthen these mental health centers to enable them also to focus on the retarded. Recognition must be accorded to the difficulties or potential difficulties, which the retarded individual (or his family) may face in functioning in today's society. The mental health center could become the point from which supportive services come to the retarded and to his family and it should develop programs to provide these on a continuing basis.

There are several additional groups which give us cause to focus our concern and federal efforts on the older retarded citizen. Many individuals of limited ability who fall into the classification of the mildly or moderately retarded have managed to get by, to survive most of their lives. They have been fortunate in finding suitable employment and in most cases have lived reasonably satisfying and productive lives. However, as the age of retirement is reached, they are very often the group who are without pension or without any financial support other than social security (and many times that is a very limited amount based on their small earnings). These are also the people who frequently do not have emotional resources to fall back on and become perhaps one of the most vulnerable groups in our society.

In our programs of services for the aging we do a lot of talking about the problems of consumer interest and the problems of fraud that beset the older individual. If we would critically examine this group of victimized people we would find that the group of people who are the most likely to become involved in some of these problems are those older individuals of limited intelligence.

A look at the rolls of public assistance would possibly reveal many intellectually handicapped individuals on these rolls. I do not know that we have ever attempted to analyze the capabilities or the intellectual capacities of the individuals receiving old-age assistance. These are often people who have had limited work experience because of their limited education or perhaps because of limited capacities. However, under no circumstances do I want to create or leave the impression that all people on old age assistance are retarded. I merely call to your attention another means of identifying these people.

If we move to the institutionalized group, those in our institutions for the mentally ill, and our institutions for the retarded, we find a substantial percentage of individuals over the age of 60. I checked at the largest institution serving the retarded in Illinois and more than *one-third* of the population of this state school is over the age of 60. As we look at our institutions for the mentally ill, we also find that many of these people are over the age of 60. We would probably find that many of these people are not mentally ill, but are people of very limited capacity. I would speculate that many individuals in our state hospitals are there because the diagnosis is really one of retardation rather than mental illness and it has become a permanent lifelong caretaking situation.

The overlap between the mentally ill and the mentally retarded institutionalized in this country is natural under the system of custodial care that emerged in this country for the mentally incapacitated. Furthermore, and this is supported by studies, long-term institutional care actually causes retardation. It turns the person back in on themselves to a state of dependency. If retardation did not exist at the beginning, it is going to be there in 20 years. In reality, a loss of self-identity results.

A former Director of the Division of Mental Health in Philadelphia did a beautiful analysis of this loss of self-identity which he called the "Seven Steps" through which you move back to the point of being like everyone else and literally become nothing. It then really becomes a matter of functioning at the retarded level.

When we look at our nursing homes and homes for the aging, we are very quick to apply the term senile to the older individual, and you again have the same kind of problem situation on which we have just touched. Senility becomes a label that we are much too quick to use. The individual who has been less able to cope all of his life often will find himself regressing in terms of his coping ability in the community, and if institutionalized, will continue to regress. Even in our most progressive nursing homes, these individuals are often relegated to the back ward or receive very little service and are not drawn into the mainstream of the activities of the institution.

We have conducted a lot of research and have held a lot of discussions on just what senility is and on the whole question of arteriosclerosis. However, we have not really taken a look at the impact of arteriosclerosis on the retarded individual or to what extent we are dealing with a senile individual. To what extent are we dealing with an arteriosclerotic condition or to what extent are we dealing with a retarded person? I see homes for the aging and nursing homes dealing collectively with these three categories as one and the same. This is something we also need to be taking a look at.

We need to stop and think for a moment about some of the kinds of changes that older people are called upon to make. What is the impact of change and what is the ability of older people to adjust and cope. To list just a few of these changes: 1) retiring from meaningful job—it is hard even for the most capable individual; 2) adjusting to a reduced income—if we examine the income level of older people, depending upon which studies you review, we find somewhere between a half and two-thirds of the older population living on incomes *below* the federally prescribed poverty level. More than 50% of people over the age of 65 in this country have less than a $2,000 annual income; 3) giving up a family home or moving to a different community or moving in with children; 4) living with physical limitations. Older people are not only less agile, but many of the bodily functions have begun to deteriorate; and 5) living without a spouse.

How well the individual adjusts to these changes and how well he can accept the trauma of these changes depends greatly upon how well he was able to cope as a younger person. If we are to consider those people of limited capacity. We need to recognize that each one of these changes becomes increasingly traumatic and difficult.

The basic needs of older people whether limited or normal are really no different than for any one of us in this room, except as the needs may become accentuated.

These are the phrases that the older people themselves use: "A sense of being needed; a need for fellowship to take the place of families; a chance to give expression to our thoughts, hopes and desires; a sense of belonging; a sense of usefulness; and a feeling of importance." We find these to be the things that we all have known, and which are identified so succinctly by the late Charlotte Towle in her well-known book, *Common Human Needs*, which may be familiar to some of you. These apply not only to the young; they apply to the old and they also apply to the retarded. It seems to me that all of the things we have said in our literature and our discussions about the needs of the mentally retarded child can also be applied to the needs of the mentally retarded adult.

If we would spend just a few minutes in talking about some of the basic needs of older people and begin to see how these relate to the retarded individual, we will find that there is very little difference, except perhaps that with the retarded older person these become more accentuated.

If we think in terms of the physical and physiological needs of older people or the problems that arise, one of the major problems that afflict the older person is malnutrition. Many individuals coming into care or coming into the social services system are identified as being malnourished. In a society of affluence in which we live, this is a very difficult situation to accept; and yet, by the same token, we must recognize that many times it is not only a matter of the economic level of the older person but also the factor simply of not being able to manage shopping and cooking or the lack of sociability in eating. I have heard nearly everybody say they eat much more here than they eat at home. At home, it's a cup of coffee and a glass of juice for breakfast, but here you sit down and have a stack of pancakes followed by sweet rolls. Perhaps it is the sociability that goes along with it; whereas if you were sitting in some little restaurant by yourself, you might not eat as much.

Another major problem in the physical area is that of hearing. Hearing begins to decrease very rapidly as one gets older. It is already decreasing for most of us in this room who are past the age of 30. Once you reach a more advanced age things may become more muffled. Often the older person does not recognize the limited hearing which he has. If you had to sit here with your hands over your ears and try to hear any discussion or hear anything that I was saying, you would have a difficult time. Many times the problems that are identified in and around an older person, e.g. the strange behavior or withdrawal, are really related to his inability to hear. If you cannot hear anything, then you just gradually withdraw.

Another area which I think we often overlook is that of vision. Vision is unfortunately a problem with many of our older people. They are still attempting to wear glasses that were prescribed 20, 30, 40 years ago, and wonder why they are unable to see. So if you are living in a world with blurred vision and diminished hearing, it becomes a pretty sad world and you pull out of it.

One of the physical incapacities which frequently has not received much attention is the loss of the ability to smell. Many times what we ascribe to forgetfulness in situations of an individual leaving the gas turned on is really the fact that he is unable to smell it. Studies have indicated that the loss of the ability to smell becomes very acute for the older person and what happens for example is that he thinks he knows what rose smells like rather than actually smelling it. We remember smells. When you deal with an older person who is dirty or who has body odor, it is not a question of his not being totally aware of this, but rather a question of not being able to smell.

The impact on older people when losing a spouse, or satisfying the sexual needs of an older individual when a spouse is no longer available, also merits our attention. You know, this is one need that I think we just totally ignore. It is as if it does not exist any more after the age of 40 to 50. To allow sexual freedom in a home for the aging sounds sordid to some. Staff get very uptight about this. When you have an older man or woman taking an interest in a member of the opposite sex, it is very interesting to observe what happens, i.e. how staff and other residents react to this.

We need to look at many of the other kinds of phychological problems that confront the older person, such as being less agile. The loss of agility many times will result in the attempt to move more quickly than an individual is physically able and the end result is a fall and a broken hip and a long hospitalization period.

An aspect of physical breakdown about which we know very little is that of strokes. The incidence of strokes rapidly increases with advanced age. However, one of the things which we do know is that this does not mean permanent incapacitation. If the stroke victim is moved into a rehabilitation program early, he can be up and about and regain almost full use of arms, legs and speech, which are the three things generally affected.

For example, I think of a woman who moved into one of our nursing homes after having spent a year following a stroke in a hospital, in a small community which offered no rehabilitation services. This woman had not been out of bed in almost a year and was totally dependent on the nursing staff and the personnel of the hospital. The doctor who made the referral suggested that she be kept warm, dry, and fed; that there was very little hope for her. Our rehab team felt that in discussion with our own medical director this woman could be helped. Within two weeks, this rehab team had this woman up in a wheelchair and she was the bowling champ of the infirmary.

This transformation takes a concentration of manpower and a concentration of effort, but it does mean that this woman was no longer totally dependent upon someone to feed her; she was no longer dependent on someone to comb her hair or to help her with toileting and bathing; she could re-enter some of the mainstream of life. Granted, on a limited basis, but nevertheless, in there.

Other areas of need of older people include financial and economic adjustment. As we look at the programs of social security, public aid, and private pensions, we must conclude that many of these really are not meeting the needs to today's older person. As noted earlier, a large percentage of these older people actually are living below the poverty line.

The need for housing is enormous. We must recognize that present public housing programs are a mere "drop in the bucket," in terms of what the actual needs are in any given community. When a new building in Chicago opens for low-income housing for the aged, it usually has many times more applicants for the building than can possibly be accepted.

We also need to recognize the psychological and the social needs of older people, their loneliness and what it does to their ability to function. The major reason that people apply to or enter a home for the aging is the great fear of "What if something happens to me." This fear, coupled with the loneliness of the world in which they actually exist, has an impact on the individual's ability to function. If we think in terms of the retarded individual who has less capacity, fewer emotional resources, and lower intellectual resources on which to draw, the problem becomes much greater and much more accentuated.

The question now becomes one of how do we begin to meet some of these needs of older people, particularly the more limited older people, in our communities. Many of the services needed are really very basic and are very simple kinds of programs. For example, a friend visiting program is one that does not cost a great deal of money, but yet one that is so vitally necessary. Yet, we have so few of these kinds of programs. We could spend an entire session exploring the development of services to meet each of these needs. Interestingly though, would be the recognition that each of the service programs would not be strikingly new!

We also need protective services oriented to the older person and more specifically oriented to the impaired older person. A great deal has been discussed and written about this service, and yet, when we look into our communities and actually see what we have, we find almost nothing. A protective service agency is essentially an umbrella agency or a catalyst to seek out those people requiring service and to bring to bear those services already existing in the community. One of the basic services which we lack in nearly all of our service areas relates to the problem of how we identify the individuals in the community who are in need of services, be it the mentally retarded child who needs a school program or be it the older person in the community who needs protective services.

I would like to comment on some of the highlights of the protective service project in Chicago, which was one of several pilot projects across the country.

Several of the basic findings of the first year of its operation are noteworthy. The median age of clients was 75.8 years; 73% were female; only 9% were still married; 63% never had children or had no children who were living. This is frequently seen in homes for the aging, i.e. many older people have outlived their children. In the community, one also finds a substantial percentage who have no living children. This underscores the point that these people are really very much alone. Not only do they no longer have families, but they no longer have close friends.

We talk in terms of protective services as basically being geared to those individuals who are no longer able to manage themselves, who need some type of assistance, and who are very often those who will need some type of guardianship. This is where many of the voluntary agencies begin to shy away. They are reluctant to get involved because it may entail a legal action. It often involves the assumption of responsibility for the individual. There have been books written on fiduciary management—assuming the guardianship to manage the financial affairs for an individual. A well-to-do individual can simply turn this over to a bank, but an individual who is receiving an $80.00 social security check needs someone who can really help him in management of his money. Money management and financial assistance are one of the major areas in which these people need help.

We also find a need for assistance in other areas. We need to build into a good protective service system a counseling program that is available not only to the older person, but also to the family of the individual; a counseling program that can help the individual seek and get the necessary services that are needed.

The protective service agency needs to incorporate in it a housing service to help the individual find suitable housing. The protective service program in a community should encourage services in the area of nutrition, e.g. home delivered meals or a hot meal program through a "senior center". However, often we are talking about the impaired individual who is also restricted in his mobility. A large percentage of these people are people incapable of getting out of their own homes, so that whatever services we are going to provide in the community will have to be brought into the home.

If we are to have a comprehensive protective service program in the community, it must include homemaker service, home health care. A visiting nurse service is generally not enough. Many times it does not require a registered nurse but really a home health aide. We have done a little bit of work in this country to develop a few pilot projects in terms of home health aides.

A community system to provide protective services for the mentally impaired needs to involve a comprehensive program of in-patient as well as out-patient medical, psychiatric and rehabilitation services. We need to be thinking in terms of a day center for those individuals who can get out.

Many times we need to evolve within our existing agencies programs in which people could use that part of its services on a day basis rather than becoming institutionalized. For example, our homes for the aging should be providing day care. I think this also would be true of some of our medical and psychiatric facilities where patients can participate in a part of the program and still remain in the community.

A comprehensive protective service program needs to include recreational services, both in the community as well as in the individual's home. It needs to include a spiritual service, utilization of the churches in the area, and the whole area of legal services needs to be incorporated.

Now let us talk about some of the specific findings of the Chicago Pilot Study. Fifteen percent of the people are in the mentally impaired group in the older population. When you get into a city like Chicago, we are talking about 56,000 people, a substantial number of people. Problems identified and the projected need include 24,000 needing casework service; 53,500 needing physician house calls, which is almost unheard of these days and it is a rare doctor who will make house calls; 2,900 home delivered meals; 3,900 needing housekeeping or home maid services; another 3,900 needing homemaker service; 2,700 needing legal services; 2,100 needing legal guardianship.

One of the other things which came out of the protective service project in Chicago was a look at the gaps in the services. Just using this small target area, which included four community areas in Chicago, it was estimated that 1,500 people needed some type of casework service; and that the number actually being served was 200. There was an estimated need for 4,200 physician house calls in this small target area, and the number actually served in this way was 250. In the target area which is not more than 48 blocks north and south and about 48 blocks east and west, a relatively small geographical area, for example, there are over 400 physicians.

We need to develop much more research oriented towards the older retarded individual. We already know many of the kinds of programs and services which we should be developing, and it is really a question of getting enough action and enough movement in our communities to begin to develop and provide these services.

It is time we started to really push for the kinds of service programs that are going to provide help for the older retarded individual as well as for older people. In most communities, there exists a network of services which could be brought together into a constellation of protective services for the older retarded individual. It involves a commitment on the part of existing agencies. It involves an expansion of existing services, not something totally new. As we look at the components of protective service, with perhaps a few minor exceptions like home health aide or home delivered meals, nearly all of these services are already there in the community.

As the Federal Government continues to move ahead in focusing on the retarded and on the handicapped individual, it is a positive sign that we are finally beginning to include and talk about and think about where the older adult who is retarded fits into this whole scheme of concern. If we are really to be focusing on a family centered approach then we really have to recognize where we are and just what "family" means as we plan for services. Family, as I said earlier, is at a four and a half to five generation level at this point in history, so that we must incorporate the older person. We even need to do this in working with a child and his extended family.

In some respects, it may appear that we are mixing two groups of people—namely those that are losing their faculties along with those who did not have them in the beginning. However, I do not think this is entirely true. Several factors should be kept in mind—services for the retarded must be family oriented and must be an integral part of the fabric of community services—not isolated as a separate part. As an increasing number of retarded remain in the community, we need to assure them of a continuum of services. As we begin to recognize the scope of needed services to serve the mentally retarded, we need to address ourselves to our responsibility for the older mildly and moderately retarded person. Is this the responsibility of the gerontologist or is it the responsibility of the mental retardation specialist? I would suggest it is both and that there needs to be a more cohesive coordinated community effort to serve these individuals. Many of the services required are the same as for the older person of average ability. Our responsibilities extend far beyond the point of helping an individual enter the employment market.

Footnotes:

1. Dr. Stedman is Professor and Chairman of the Division of Behavioral Sciences in Education in the School of Education, The University of North Carolina, Chapel Hill
2. Dr. Gilhool is now Associate Professor of Law at the Law Center, University of Southern California, Los Angeles
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4. 347 U.S. 483 (1954)
5. E. Goffman, STIGMA (1965)
6. 304 U.S. 144, 152 (1938)
7. 347 U.S. at 493
8. 304 U.S. at 153
9. 400 U.S. 433, 436-37 (1971)
10. Stedman, Donald J., "Mental Retardation Programs in the Department of Health, Education, and Welfare," a report to the Secretary's Committee on Mental Retardation, April 1971 (mimeo)