

Beyond the Ordinary

The Preparation of Professionals to Educate Severely and Profoundly Handicapped Persons **Toward the Development of Standards and Criteria**

Governor's Planning Council on Developmental Disabilities Minnesota State Planning Agency

300 Centennial Building 658 Cedar Street St. Paul, Minnesota 55155 A Compendium of Conversations

Edited by Robert Perske and Judy Smith



Beyond the Ordinary The Preparation of Professionals to Educate Severely and Profoundly Handicapped Persons Toward the Development of Standards and Criteria

A Compendium of Conversations by

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Foreword

On Responsibility

IT IS NOW THE RESPONSIBILITY of our public schools to educate the severely and profoundly handicapped. This responsibility must be shared by the institutions which prepare professionals to serve this population, and which should collaborate with educational and community agencies in establishing comprehensive programs for them. To become answerable, we must acknowledge the need for a set of rigorous training principles. Although much remains to be discovered about educating the severely and profoundly handicapped, one truth has emerged that can guide our future endeavors. That truth is that the education of these individuals requires training, talent, skill, and precision beyond that required in the preparation of professionals for other groups of exceptional children.

FOR THE PRACTICING PROFESSIONAL AND THE TRAINEE, this means a unique set of responsibilities to students and to parents. The professional must be proficient not only in the competencies expected of the educator or ancillary professional, but also in behavioral technology and systematic instruction, the teaching of basic life skills, interdisciplinary teamwork, diverse work with parents, and coordination of programs across communities. Many must also be prepared to intervene with these children from birth, and many others must be expert in prevocational and vocational education.

FOR THE TRAINER OF PROFESSIONALS, this means responsibility to the trainee, to those who will employ him, to the community that must absorb the handicapped individual, and to the profession. In guaranteeing that a trainee has developed the necessary competencies, the trainer must himself exhibit these same skills and he must use adequate procedures for measuring and proving competencies. From this basis of substantiated competency, the trainer may contribute effectively to research and development in this evolving area of special education.

FOR THE TRAINING PROGRAM AND THE INSTITUTION OF HIGHER EDUCATION, this means responsibilities to the trainee, the trainer, the community and state, to many professions, and to society. The training program must ensure a network of collaborative interfaces and relationships, judicious recruitment of trainees, the development and implementation of a well rounded competency-based curriculum, and continuing responsibility to the practitioner in the field. In guaranteeing that training programs are fully supported and integrated, the institution must furnish the services and facilities required for the preparation of these particular professionals, and should use its unique resources to bring about progress and change, not only in behalf of handicapped individuals, but in the interest of society as a whole. In short, our institutions of higher education would ideally make a moral, as well as a financial, commitment to the education of the severely and profoundly handicapped, and to improving the quality of American life.

THIS BOOK HAS BEEN WRITTEN through mutual concern that these responsibilities be fulfilled. Its contents were developed through a conference of seven participants in New York City in January, 1977, and subsequent conference calls with the six other participants, who also submitted reference materials for the text. This information was, in turn, translated into the narrative that follows, which is intended to establish areas of competence and responsibility in the education of the severely and profoundly handicapped.

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Public Education for Severely and Profoundly Handicapped Persons

Introduction

Beyond the Ordinary

Parents

The Courts

have the right to a

public education.

could be no dividing

that excludes children

c education services.

A severely handicapped child is one who, because of the intensity of his physical, mental, or emotional problems, or a combination of such problems, needs educational, social, psychological, and medical services beyond those which have been offered by traditional regular and special education programs, in order to maximize his full potential for useful and meaningful participation in society and for self-fulfillment... Such severely handicapped children may possess severe language or perceptual-cognitive deprivations and evidence a number of abnormal behaviors including failure to attend to even the most pronounced stimuli, self-mutilation, self-stimulation, manifestations of durable and intense temper tantrums, and the absence of even the most rudimentary forms of verbal control. They may also have extremely fragile physiological conditions.¹

SINCE 1971, SEVERELY AND PROFOUNDLY HANDICAPPED INDIVIDUALS have slowly gained the right to a public education and, consequently, the opportunity to live in the best of all learning environments—the reality of their own communities, homes, and schools. "For whatever reasons, prior to 1971, the professional community did not exercise significant leadership in providing adequate public education services to the severely handicapped. As had been the case with children with other types of disabilities, it was finally the parents who once again led the way, forced the point, and initiated action."²

The changes that have occurred stemmed largely from a policy statement by the National Association of Retarded Citizens regarding the education of mentally retarded children. Its pivotal concept was that:

Public school education must be provided for all mentally retarded persons, including the severely and profoundly retarded. There should be no dividing line that excludes children from public education services. If current educative technologies and facilities are inappropriate for the education of some retarded, then these existing regimes should be modified.³

This statement, and others by that same organization of parents, served to guide the remarkable legal and legislative actions that have followed.

IN A 1972 COURT ACTION IN PENNSYLVANIA,⁴ a three-judge federal court signed a consent decree that included these notable mandates:

- All retarded children in the state were assured the right to a publicly supported educacation appropriate to their needs.
- The state was required to locate all children who had been excluded from school.
- Local school districts were called upon to evaluate all retarded children within their jurisdictions, and to re-evaluate all children in special classes every two years.

Subsequent court orders broadened the scope of the right-to-education movement. A 1971 decision in the District of Columbia⁵ ensured education to *all* children previously denied this benefit, and required that a free and appropriate public education be provided no matter how severe the degree of a child's mental, physical, or emotional disability. The North Dakota State Supreme Court⁶ in 1974 reaffirmed that the state constitution guarantees the right of all children to a public school education. It also ruled that a child's residence determines the identity of the school district that must serve him, and that placing a child in a special program outside that district does not change his legal residence. Another 1974 court order gained by the Maryland Association for Retarded Children⁷ underscored the right of all handicapped children to a free education and ruled that mental retardation does not justify home teaching instead of classroom instruction. The Maryland decision also outlawed placement of any student in a private facility if that facility could not provide an accredited educational program and guarantee immediate admission to it. These and other court actions motivated federal, state, and local government agencies to make way for a more democratic form of education.

of Education for the Handicapped the severely and profoundly handicapped as a national priority. The Bureau's intent was much more far-reaching than merely to see that these students were in the classroom. Deputy Commissioner Edwin W. Martin called for inthe severely and profoundly handicapped must struction of the highest caliber, directed that funding be refocused, and made the Bureau a catalytic force for the development of effective educational programming for the severely and profoundly handicapped. Since then, model demonstration centers have been underwritten, successful technologies have been sought and supported, and universities as well as state education agencies have been stimulated to begin training programs for personnel on many levels, from the teaching associate to the doctorate.

The Congress

Those who have not been served before must be served now.

The Profession

Our own competency is the most crucial issue.

PUBLIC LAW 94-142, passed by Congress and signed into law by President Ford in November 1975, legally assures quality education to every severely and profoundly handicapped child in the United States. Among the new directions outlined by the law are these:⁹

- There is a strict due process guarantee to the handicapped child and his parents as they seek the right to education.
- Federal funding authorized by the law should exceed \$3 billion by 1982. To qualify for funds, state agencies must carry out a series of procedures directed toward establishing effective programs.
- Each state must submit to the U.S. Office of Education a plan for serving all handicapped children, specifying the date by which full services will be available for all such persons between the ages of 3 and 21 —and that date may be no later than September 1, 1980.
- Each state must describe the kind and number of facilities, personnel, and services necessary to meet the goal of full educational services.
- For each handicapped child, an individualized educational plan must be developed jointly by the local school representative, the parents, the teacher, and the child himself when appropriate. This plan shall specify in writing the child's current level of educational performance, long-range goals and short-term objectives, and the types of services the child is to receive. This plan must be reviewed at least once each year.
- Each school district must devise a comprehensive program of personnel development in the education of handicapped children.

Most federal and state officials do not see an immediate full-service posture as possible. Part of the reason for delay is the need for well prepared professionals to develop programs for and carry out the instruction of the severely and profoundly handicapped in the public schools.¹⁰

THESE, THEN, ARE THE CONCERNS of those members of the special education profession who have developed this volume:

- The supply of competent professionals is much smaller than the current demand. It is possible that personnel may be employed to work with the severely and profoundly handicapped without sufficient competence to do the job well.
- Although training institutions are beginning to produce personnel to work with these students, many training programs are themselves in the process of evolving. Moreover, because this area is new, there are trainers who have not had experience with this population, and therefore lack the competencies for which they are endeavoring to prepare trainees.
- As local education agencies hire our trainees, they will have high expectations. If they hire people who are not completely competent, their programs will become hollow in content, lacking in systematic procedures, and ultimately unproductive.
- If we are ever to engage communities in making a place for the severely and profoundly handicapped, we must possess every skill necessary to bring about their full educational potential, and we must carry out the measurement that is integral to proving their progress.
- Unless we create and maintain only the highest standards for ourselves, for our institutions, and for those we train, unfulfilled expectations will over time lead to a regrettable loss of faith in this educational enterprise and a lack of belief in the potential of these students. This will in turn lead to diminishing support from school and community, doubt about the practicality of hard-won legislation, and withdrawal of funding for programs.

Most graduates of those programs which prepare teachers of the mildly handicapped are simply not going to have the skills to toilet train, to eliminate self-destructive and self-stimulatory behavior, to train eye contact and imitative responding, to systematically teach community survival skills. To hire teachers who lack these requisite competencies is to guarantee that schools will produce few significant changes in the life-style of the severely handicapped.¹¹ Staffing a classroom for the severely and profoundly handicapped with a teacher who has no preparation in this area is somewhat akin to staffing a surgical unit with an intern.¹²

Professional Preparation

we must have special skills in order to meet our singular responsibilities. This book explains the need for specific competencies of trainer and trainee alike, beyond those ordinarily required of the special education profession. It also offers methods by which the trainee, trainer, and training institution may execute their singular responsibilities in advancing the education of the severely and profoundly handicapped.

These guidelines are intended as a stimulus for program development and as a general system of evaluation for a variety of people who have interest in the preparation of professionals for this work. Among these are:

- OFFICIALS OF UNIVERSITIES AND EDUCATION AGENCIES who are seeking to develop training programs.
- PROFESSIONALS ALREADY WORKING IN THIS SPECIALTY AREA who are interested in assessing their own skills and who are determining the next step in their own professional growth.
- SCHOOL ADMINISTRATORS who seek to hire professionals for the education of the severely and profoundly handicapped and need to understand the competencies they should look for in their candidates.
- CERTIFYING AND LICENSING AGENCIES in need of guidelines by which to develop their own standards for programs serving this population.
- PARENTS OF SEVERELY AND PROFOUNDLY HANDICAPPED CHILDREN who want simple, understandable criteria through which to judge the quality of their children's educational programs.
- STUDENTS who are interested in careers in the education of the severely and profoundly handicapped and want to know what is entailed in a good training program.

"Because a vast amount of professional talent has been directed toward improving services to this population, the area of the severely handicapped is emerging as one of the most resourceful in the field of special education."¹³ With this resourcefulness, we have a splendid opportunity to plan carefully and to chart thriving directions for this educational specialty. If this is done well, persons with severely and profoundly handicapping conditions will be able to compensate for the barriers that have kept them from the fullest human experiences they could know. It is to this end that this book has been written.

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Specific Competencies Required for the Education of Severely and Profoundly i Handicapped Persons

Behavioral Technology and Systematic Instruction

Beyond the Ordinary

"Our business is changing behavior. It's not changing other things. It's changing target behavior. We have a new kind of education to carry out, but we are on our way. And we constantly build on the new information that we gain from our measured data. This is far from being some sort of fad. It is precise. It is scientific. Our people don't go out with a mere bag of tricks' They go out with a precise instructional technology that they can demonstrate."

The Science of Teaching

view learning as behavior change is to make possible - measurement of learning.

Accountability

Competency and account-Ability go hand in hand. From per measurement we gain accountability. Without it, there is no way of gauging competency. THE SEVERELY AND PROFOUNDLY HANDICAPPED DO NOT LEARN INCIDENTALLY, nor automatically, nor rapidly, nor easily. They do not learn through the methods that education has traditionally employed. Those who have succeeded in improving the functioning of these individuals have done so through procedures based on the principles of precise behavioral technology. In fact, the effectiveness of such principles has perhaps been best documented in the education of the severely and profoundly handicapped. For example, the profoundly handicapped typically display a minimal response level and few reflexes. Yet, through behavioral strategies these people can learn such human behaviors as using speech ,¹⁵⁻¹⁶ walking,¹⁷ feeding themselves with utensils, 18-20 dressing and going to a bathroom area on command.²¹ The severely handicapped (who manifest extremely limited intellectual functioning, sensory defects, serious communication problems, multiple physical and motor disabilities) can nonetheless be taught language and communication, ^{22,28} self-care and self-help skills,^{29,034} pre-academic and academic skills,^{35,037} prevocational and vocational skills.

The methods used to produce this learning have been based on the premise that behavior can be observed, reduced to small components, understood and changed in terms of a dependable relationship between cause and effect. To view learning as behavior change is to make possible the measurement of learning. And the ability to measure learning gives the professional an objective, systematic means for teaching. Measurement of change is, in fact, the variable that separates the sciences from the arts. When measurement became the basis of psychology, this discipline moved away from philosophy and became a science in its own right. Similarly, as measurement becomes the basis for our educational technology, we also approach a more scientific role.

The more severe the handicap of the student, the more precise the measurement of change must be, and the more precise the professional competency must become.

THUS, WE MUST PREPARE PROFESSIONALS not for the traditional task of imparting knowledge to students, nor even for the special task of remediating learning problems, but for the complex step-by-small-step work of teaching severely and profoundly handicapped individuals:

TO LEARN BASIC FUNCTIONAL BEHAVIOR; TO USE FUNCTIONAL BEHAVIOR PURPOSEFULLY; TO USE PURPOSEFUL BEHAVIOR TO MASTER THE ENVIRONMENT; TO UNDERSTAND AND USE THE RESOURCES OF THE ENVIRONMENT; TO CONTRIBUTE TO THE ENVIRONMENT;

TO ATTAIN ONE'S FULL POTENTIAL FOR AUTONOMY AND SELF-DETERMINATION. Most children gain these skills through experience and have most of them before they ever enter school. For the severely and profoundly handicapped, however, education means the learning of these skills. Their instruction depends on ^uthe creation or arrangement of an environment that produces specified changes in the behavorial repertoires of the students,"⁴² through precise descriptions of each response that the student must learn to make, exact specification of the type and sequence of activities that will enhance his behavorial repertoire, and verification of changes in behavior as a basis for proceeding to the next response level.

"Trainees must be able to measure. They must be able to pinpoint where a child is in his functioning. From that point, they select a higher level, a reachable goal. They build an instructional sequence from the easy pinpoint to the harder goal. A wide variety of activities is planned which will help the child achieve the new behavioral functioning. The teacher must be able to record the child's progress throughout that sequence. The teacher must be able to know where the child is in his sequential progress, how fast he is learning, and to what degree his rate of learning is accelerating."

"The only way we can analyze change with a straight line is to convert from the addsubtract' concept to multiply-divide'. So we use semi-log paper, but the logarithm is vertical only. The days are plotted horizontally. With this kind of paper, you can draw trend lines through data. Teachers can plot like this, and they are able to tell whether they are making a difference. They become so skilled, so proficient that it almost becomes automatic. This requires quite a bit of training, but once trained they tend to maintain this skill. With a trend line like this that shows the acceleration of change, we can find youngsters who are not as handicapped as we thought. With this type of trend line, we won't spend much time keeping a kid misclassified."⁴⁴

Teaching a severely handicapped child to acquire a new behavioral function is in itself a challenge, involving the use of such procedures as cueing, modeling, prompting, physical guidance, and shaping. But acquisition is only the first phase of learning: the professional must also be adept at techniques for teaching fluency building, maintenance of skills, application, and adaptation or generalization to other tasks.⁴⁵

"First, the trainees have to be able to determine minute behavioral pinpoints. They must be able to take a larger task, like walking, and break it into smaller components: the balance, the head control, the arm movements, the movements of the trunk, legs, and feet. Then they have to specify all the environmental contingencies. When a child emits a certain kind of behavior, my trainees must almost automatically be able to specify the many consequences that happen to the child, those around him, and the environment itself. There are many specific consequences that are evident even when a child messes his pants or he hits another child. All must skillfully be taken into account. Third, a trainee must be able to preplan for a wide range of possibilities that can follow a certain behavior. Then, knowing all these possibilities, the professional must be skilled at determining which one is the preferred behavior and decide how best to reinforce it."⁴⁶

An outgrowth, in the applied sense, of behavioral research is the very important procedural development of the systematic instructional process. This is a fundamental, orderly educational process that teachers can use with all exceptional children. With the severely and profoundly handicapped, however, systematic and intensive instruction is crucial. The systematic instruction process includes eight steps:

1. Assessing children for placement in a curriculum.

The professional administers and interprets the results of an assessment tool to determine initial performance level.

- 2. Formulating, in writing, long-term objectives. There may, for example, be good hand and arm motion and, thus, every reason to believe that the child can learn to feed himself, which becomes a long-term objective.
- 3. Formulating, in writing, short-term objectives. One of the first behaviors to be learned in self-feeding is grasp, and so the first short-term instructional target is to teach grasp. The most efficient teaching method would be to teach the child to grasp an actual utensil. His next objective would be to learn to pick up the utensil, then to learn to scoop up a bite offood, to take the bite of food from the utensil, and so forth.
- 4. Writing a comprehensive individualized instructional plan for each objective. This involves the planning of procedures that can be used with the child in question to accomplish each short-term objective, including task analysis, sequencing, arrangement of antecedent and consequent events, arranging the environment, using materials.
- 5. Writing an ongoing evaluation-measurement plan for each objective.
- Evaluation requires that the professional establish a criterion performance level for the child.
- 6. Implementing the instructional procedures and measurement plan in the classroom. This programming provides for continuous and consistent teaching and evaluation that will lead to the long-range objective, and includes training parents to carry out the procedures at home.
- 7. Using collected data to evaluate the adequacy of child gains and make decisions regarding program modification.

Charted data showing rate of progress will reveal whether the instructional plan devised is working with the child in question and will, in turn, suggest modifications in the plan if progress is minimal.

- 8. Periodic collection of child outcome data to evaluate the overall program.
- As instructional plans are implemented for various target behaviors, the whole of the data collected will provide immediate information on the child's progress through developmental milestones, and will also furnish a means for evaluating the effectiveness of his entire learning program.

Competence

Unless a professional can demonstrate a very high level of competence, he simply won't be able to make effective interventions. THE ABILITY TO CHANGE THE BEHAVIOR OF THE SEVERELY AND PROFOUNDLY HANDICAPPED rests upon not one but many competencies. A major set of competencies are those required for systematic instruction. Other vital clusters of competencies include:⁴⁷

- Fluency regarding the rationale and terms of applied behavior analysis.
- Demonstrable knowledge and skill in the design and interpretation of research.
- Skill in such instructional procedures as: Arranging antecedent events, behavioral slicing, and arranging consequent events.
- Application of functional analysis skills: Pinpointing behaviors, selecting appropriate measurement systems, determining reliability and validity of observations and procedures, selecting devices to collect data, devising appropriate data displays, isolating critical variables affecting the pinpointed behavior, collecting and charting data, using collected data to make educational decisions, analyzing trendline behavior, arranging environmental events.
- Development of individualized curricula: Establishing instructional objectives, delineating curricular constructs, performing task analysis, sequencing learning tasks, using commercial materials, devising learning materials, evaluating pupil data in relation to objectives.
- Assessment: The use of formal and informal instruments for determining the functional level of the student.

Although the trainee needs to develop prerequisite knowledge competencies through coursework, performance competencies in behavioral technology are attainable only through direct experience with the actual behaviors of students, in a practicum setting where the trainee's proficiencies may be observed and supervised. Moreover, many informational and performance competencies may be demonstrated as an outcome of a single classroom teaching situation. For example:⁴⁸

Given at least two students, each exhibiting behavioral excesses that interfere with the delivery of instruction (e.g., self-injurious or stereotypical behavior), the trainee will design, write, and carry out an instructional program to eliminate or decrease the frequency of the target response. The completed instructional plan will include the following components.

- a. Behavioral statement of problem.
- b. Specification of program objective(s).
- c. Measurement procedures.
- d. Baseline performance data.
- e. Description of the intervention.
- f. Charted pupil performance data and evidence of formative evaluation.

Procedures must document behavior change or show systematic program revision on the basis of performance data and be acceptable to the supervisor/instructor.

We as trainers need to have the same concern for the measurement of behavior change in our trainees, in terms of the development of competencies, as we expect them to have for the measurement of behavior change in their severely and profoundly handicapped students. Just as it is not sufficient to describe a child as "somewhat improved" in his ability to communicate or feed himself, neither is it prudent to send into the field professionals whose competencies have not been precisely measured, evaluated, and found to meet high standards. A competent behavioral technologist must know and live the principles of behavior. He should have a mind set. He should automatically do the opposite from the natural thing the average layman would do when a child is causing problems; he should automatically refuse to respond to certain negative behaviors. Knowledge of these principles is not enough; the professional must demonstrate these competencies in his performance over time and varying situations. Our guarantee of competence must represent the highest of performance criteria.

. . . "potential teachers must be able to demonstrate that they can change behavior in prescribed ways before they receive a license to teach."

"Precision can pay off. It can be a two-edged sword. It communicates upward to the consumer, the administrator, and the school board. It also, of course, communicates to those who work with the child."⁵⁰

"Classroom research, as it comes to bear on the severely handicapped, is one of the most exciting considerations that I've experienced in my career."⁵¹

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The Teaching of Basic Life Skills

Beyond the Ordinary

"I remember when I began teaching severely retarded kids in an institution after four years in a regular class. On the very first day, a five-year-old girl had a seizure. This was the first I had seen in my life. Other kids had toileting accidents, and I had to clean them up. Only three out of the six could say anything understandable. Only one could walk. I remember saying to myself, "What can I teach these kids?' Imagine that. Here were six children with loads of things they needed to learn, and I was wondering what I could teach them"⁵²

To Define an Individual as Human

Such behaviors as laughing, communicating, playing are cultural traits of civilization. Most children have already mastered basic self-help, communication, and ambulatory skills when they enter school. By and large, the severely and profoundly handicapped have not. Many come with medical, orthopedic, and psychological problems, as well. Since the training of these individuals is so often prolonged and difficult, their parents or their caretakers in state hospitals often prefer to feed them, carry them, leave them in cribs, and keep them in diapers, rather than attempt to help them circumvent the barriers that impede their functional skills. Thus, many have not only failed to learn, but have atrophied and regressed. Yet these are the children who have recently become candidates for an appropriate public education.

Education is the process whereby an individual is helped to develop new behavior or to apply existing behavior, so as to equip him to cope more effectively with his total environment. It should be clear, therefore, that when we speak of education we do not limit ourselves to the so-called academics. We certainly include the development of basic self-help skills. Indeed, we include those very complex bits of behavior which help to define an individual as human. We include such skills as toilet training, dressing, grooming, communicating, and so on.⁵³

Professionals seeking to work with these children will not be competent without expertise in a number of procedures for teaching functional skills and for handling medical problems.

Fundamental motor and sensory or perceptual training techniques must be among the compe-

tencies of the professional who works with the severely and profoundly handicapped. If the trainee does not learn the full implications associated with motor and sensory problems, he will not be able to help the child and might actually harm him. Collaboration with therapists and specialists involved in motor training and sensory stimulation procedures will require the ability to complement their programs. "The physical therapist who tells the teacher to exercise the child's deep tendon reflexes four times daily may be of little assistance unless the teacher knows what deep tendon reflexes are and how to exercise them. Conveying useful information is not solely the responsibility of specialists. The teacher must consider that the development of a functional relationship is his responsibility as well."⁵⁴ Special competencies are also required in the proper lifting and positioning of handicapped children, and in the use and design of adaptive and prosthetic devices.

Since a great proportion of the severely and profoundly handicapped have extremely restricted communication and language abilities, the trainee also needs to develop skills in a variety of options for communication, including training for acquisition of eye contact; the use of signing, symbols, and communication aids; operant procedures for eliciting and shaping speech; and speech remediation.

"We are training educators to develop broad competencies in communication. There was a day when the experts chose only one medium and ignored the others. For example, if you went to one school for the deaf, they taught the oral method only. At another school, it was signing. Today we consider every option."⁵⁵

Feeding problems are also common among this group of handicapped children. Abnormal feeding patterns may stem from a lack of reflexes to facilitate sucking, chewing, and swallowing, or from motor problems that hamper normal mealtime responses. Some feeding problems represent the severely handicapped individual's bizarre reactions to food. But very often, feeding problems are due simply to the fact that no one has used effective procedures to teach these children how to chew, swallow, drink, move their hands from plate to mouth, use a spoon, lift a cup.

"We're having now, as you might imagine, enormous feeding problems. And our teachers and physical therapists are teaching kids to feed and actually feeding kids. Now that's a substantially different model than has existed in the rest of the country. In most places they have aides to do this, right? . . . Some of the teachers out there don't see this as their role. We have to stop that. We're going to work on that with inservice training. Some people are going to do these things on their own, but I think the point is that we should never turn out another teacher who doesn't see that one of her roles in working with severely handicapped kids is working with mealtime skills."⁵⁶

Professionals must also be competent in procedures for training normal toileting behavior in severely and profoundly handicapped students. This skill involves more than a physical response; it represents a complex operant and social learning process.⁵⁷ It should be part of the repertoire of even the most seriously disabled child because he will be less prone to disease, because he will require less care and supervision if he can do things by himself, and because he will be more readily accepted by others.⁵⁸

"If you had a choice to make on behalf of a child as to whether he needed toilet training or reading skills, it would be clear that toilet training would have the most immediate value and the top priority."59

In addition to teaching self-feeding and toileting, the professional should be prepared to teach such other self-care skills as bathing, grooming, personal hygiene, dressing and undressing.

Trainees may gain skills in the teaching of self-care and self-help skills through a combination of informational and performance competencies, e.g., the trainee "should apply the information acquired through the readings of the Self-Help Programs Module by:

- Evaluating the instructional objectives, teaching strategy, evaluation procedures, and potential effectiveness of existing programs for use in teaching an eating skill, a personal hygiene skill, a grooming skill, and a toileting skill to individuals with severe or profound impairments in self-help skills.
- Implementing an instructional program designed to teach an eating skill to an individual with severe or profound impairment in self-help skills.
- Implementing an instructional program designed to teach a personal hygiene skill to an individual with severe or profound impairment in self-help skills.

- Implementing an instructional program designed to teach a grooming skill to an individual with severe or profound impairment in self-help skills.
- Implementing an instructional program designed to teach a toileting skill to an individual with severe or profound impairment in self-help skills."⁶⁰

HEALTH PROBLEMS ARE PREVALENT among the severely and profoundly handicapped, many of whom lead precarious medical existences. The trainee must develop an understanding of how various conditions may affect learning and other behaviors, and must develop the facility for incorporating medical advice into the educational plan. Coursework in this area should include principles of general physiology, neurophysiology, neuroanatomy, and procedures of nursing.

Extensive training and experience with regard to convulsive disorders is quite important in preparation for teaching this population, and adequate practicum time in the classroom is necessary for learning action in handling this emergency.

^uThe teachers will see more seizures than will physicians, or even an epileptologist. They have to. They are with children for the longest period of time. I've learned to tell the difference between a psychomotor seizure and a behavioral manifestation. I can train people to tell the difference, too, when I get them in a practicum setting. When a child has a seizure, I make sure my students know exactly what's going on. It's here that an educator learns to sense when a child is ready to go into a seizure, and what to do when it happens."⁶¹

When students must take medications, those working with them need to understand how to administer the medicines and how to monitor their effects.

"The educator is in one of the best positions of all, outside of the parents, to observe and report what a certain medication is doing to a child. The teacher needs to keep a profile chart showing what medicines each child is taking. During the day, the teacher may have to administer certain doses to some. But most important of all, the educator must be strong enough to speak out when he or she sees a certain medicine is having adverse effects on the child. Teachers must be strong enough to give sincere feedback to a physician when a child is overmedicated or undermedicated."⁶²

Professional preparation programs should also include attention to first aid training for common emergency situations, nutrition and its relationship to total functioning, and guidelines for safety, such as things to check before leaving a student alone in one part of a classroom.⁶³

Finally, the medical problems of some severely handicapped students will be irreversible, progressive, and terminal. Trainees should be prepared to face this eventuality, through sessions that focus on working with individuals who are deteriorating, on handling one's own feelings about death and dying, and on dealing constructively with the families of children who have terminal ill-

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Medical Emergencies

Teachers will see more seizures than will physicians.

Interdisciplinary and Transdisciplinary Teamwork

Beyond the Ordinary

Alignment With Many

education teachers can work

effectively in a vacuum is over.

The day when special

Disciplines

"It doesn't do anyone any good to have a physical therapist walk into a classroom and take a child out for a short time to work with him elsewhere and then bring him back That kind of mobility training should go on in the classroom where the child needs to be mobile. Head control and positioning are very necessary in the classroom, so it's best that this training go on there, as well. The teacher needs to be the central person who coordinates and sets priorities for all the skills. She even needs to manage the physician. That's quite a role reversal"⁶⁴

THE NEED FOR PROFESSIONALS FROM MANY DISCIPLINES to work with the handicapped has been advocated for years, but never has this need been as critical as it is in educating the severely and profoundly handicapped. Because of the complexities of these children, their heterogeneity, their multiple handicaps, and their age ranges, effective programming for them must be based on a cooperative effort by a variety of experts.⁶⁵

As we become more competent, we tend to align ourselves more closely with basic medicine, physiological phychology, the social sciences, those in bioengineering, and other therapies and sciences. If our handicapped students are to be served well, then we must not only be able to participate coherently with these professions, but we must also win our authority with them and be prepared to take a coordinating and managerial role in organizing their contributions into integrated programs that will be of the maximum benefit to the severely and profoundly handicapped.

THE TRADITIONAL PRACTICE of professional teamwork has been the medical model's multidisciplinary approach, in which the child is seen by a number of professionals at different times, usually away from the classroom. The professionals involved seldom communicate, collaborate, or make common agreements, nor does the teacher have major input. The teacher is, rather, the receiver of many recommendations, usually in writing, that may represent conflicting views, but which the teacher is expected to interpret and carry out. Parallel to this is the practice of removing a student from the classroom for evaluation or therapy, without involving the educator in the process, and without sharing the rationale and procedures by which the educator might complement the work of the specialist.

"I had a trainee who was having people come into her classroom and remove children for special services elsewhere. I let her know that she had a problem to solve. How she solved it would demonstrate her level of functioning as a team manager. She saw the need to become an advocate for her children and to put a stop to this sort of educational kidnapping. Her first plea was that those representing the disciplines necessary for a particular child would meet with her and plan the program together. Her second plea was to have the physical therapist come into the classroom and work with the child there. She lost on the first one, but she finally convinced the physical therapist to function in the classroom. On the basis of the energy invested, I felt that the trainee was competent, after considering how scattered the rest of the specialists were."⁶⁶

THE INTERDISCIPLINARY APPROACH, on the other hand, does bring the team together, thus reducing the fragmentations of findings. As a group, the team focuses on one child's functioning, shares its findings, and develops an individualized educational plan. However, the educator's role may be minimal, and team recommendations may be more ideal than practical because they are based on isolated views of the child, not on his day-to-day functioning in the classroom.

"... team members often end their responsibilities by only making recommendations. Actual implementation is not considered and is dismissed as not being a part of their responsibility. Implementation then falls to the person often the least able to carry it out because of lack of power, the classroom teacher."⁶⁷

THE TRANSDISCIPLINARY TEAM⁶⁸ arrangement seeks to correct some of the weaknesses of the other approaches. Within this team, one or a few people are responsible for direct contact with the child, and the teacher is one of them. The composition of the team depends upon the specific needs of the child and will include any type of professional whose expertise is needed in planning for a particular student.

To implement the plans of the team, role release permits that training and authorization to carry out a particular specialty function can be given to others: to the teacher, to a paraprofessional, or to a parent. Direct care is thus handled by those persons who are closest to the child and who work with the child most regularly, while the team offers consultative backup.

The Multidisciplinary Team

The teacher receives isolated and perhaps conflicting recommendations that may be impossible to carry out.

The Interdisciplinary Team

Lacking experience with the child's day-to-day classroom functioning, the team may make recommendations that are more ideal than practical.

The Transdisciplinary Team

Other disciplines offer consultative backup.

"The only model I've ever been comfortable with has been the transdisciplinary model. A case Im thinking of was one in which two adults interacted with the children. Everyone else was channeled through them. These were a teacher and a cottage parent. When push came to shove, the cottage parent would prevail. Both of them became extremely skillful in carrying out procedures from many different disciplines represented on a team. Also, the team members for a particular child comprised only disciplines needed by that child. This means that one team might have eight or nine people on it, while another might have only three."⁶⁹

This approach has been translated into an integrated therapy model which advocates four basic approaches:⁷⁰

- Functioning should be assessed in the student's natural environment. Valid assessment cannot be achieved by a person who is unfamiliar with the student and lacks stimulus control.
- Clusters of skills, not isolated developmental skills, should be taught, in that it often reguires many months to teach a severely handicapped student an isolated skill.
- Therapy should be incorporated continuously and naturally into a student's daily activities. Skills taught in short episodes once or twice a week will not result in significant gains.
- Skills should be taught in the student's natural environments, with a variety of instructional materials, persons, and cues. Skills taught in one environment by one therapist, using one set of instructional materials, will not necessarily generalize to the student's natural environments.

"We favor a self-contained, integrated model, rather than an isolated model. We would have the people from other disciplines doing what they do in the classroom, training the teachers or at least including the teacher as part of the educational process, and becoming a consultant more than a hands-on therapist for the handicapped. We do foster the idea of a team, but it's a team of consultants to the teacher. The teacher is the hub and focus of the activity, whatever the therapy. The teacher has the responsibility for the educational processes, and other people are advising, recommending programs, and teaching the teacher to be able to do the things that they can do. There are, of course, some activities that only a physical therapist can do with a child, but these are done within the context of the classroom. We recommend that a child never be removed from the classroom for an educational activity, with the exception of high school and career training classes."⁷¹

Educational Synthesizer

Trainees must be prepared to become the hub of activity generated by a number of other disciplines. THE CENTRAL ROLE FOR WHICH WE MUST PREPARE PROFESSIONALS to work with many disciplines may be termed the role of the educational synthesizer, e.g., one who can draw relevant information from a variety of sources and then incorporate it into daily intervention procedures for children. Conseguently, an educational synthesizer is any interventionist who: Seeks appropriate information or techniques from professionals in other disciplines;

Applies such information or technigues to develop effective intervention strategies;

Implements such strategies in order to remediate problems (e.g., ensuring special diets for children with allergies, monitoring seizure activity) or to facilitate the acquisition of new skills (e.g., implementing muscle relaxing activities or special language training procedures)."⁷²

"The educational synthesizer needs skills in acquiring, organizing, evaluating, and implementing (in a practical sense) inputs from disciplines that either are not or cannot be included as daily, integral parts of an intervention program. The educational synthesizer becomes the pivotal force in the overall educational program by seeking and coordinating the necessary resources to produce growth and change in the severely impaired child."⁷³

The development of the various competencies necessary to bring the education professional to this - focus of team activities requires a number of learning experiences.

"Trainees must develop skill in coordinating many different disciplines. They must have a working knowledge of the other disciplines with whom they work. They must know the principles that guide the communication specialist and various other therapists. They must learn the vital psychology of coordination. They must be capable of being interdisciplinary

or transdisciplinary. This means they may carry out specific functions that a physical therapist may do, or, on the other hand, they may develop instructional programs that other persons will carry out in their stead."⁷⁴

Professional preparation programs should offer practical opportunities for trainees to gain competencies in team functioning and management, and comprehensive coursework leading to the requisite knowledge competencies. For example:

Competencies.

To successfully complete this course of study, the student must be able to:

- Describe the roles of the various disciplines in serving the various categories of severely and profoundly handicapped individuals, i.e., the deaf-blind, the severely and profoundly retarded, the severely disturbed, the severely physically handicapped, and infants, in terms of the purposes, methods, and techniques. These disciplines include: medicine, nursing, physical therapy, occupational therapy, social work, speech therapy, audiology, behavioral psychology, psychometry, clinical psychology, psychiatry, dentistry, recreation, nutrition.
- Serve as an effective member of an interdisciplinary team.
- Define and describe the essential features of the interdisciplinary model, transdisciplinary model, and multidisciplinary model.
- Meet the expectations that each discipline has of the effective teacher, including: Referring individual students and/or their parents to the appropriate discipline, as required.
 - Conducting specialized programs and implementing specific procedures in the classroom setting that are prescribed by professionals from other disciplines.
 - Communicating educational information regarding individual students to members of other disciplines.⁷⁵

Trainees are expected to gain academic knowledge to prepare them for team leadership. Then many trainees are placed on a functioning team, perhaps beginning immediately as team manager but remaining under the clinical supervision of the trainer until he feels that the trainee has achieved the required competency.

The trainee also needs to develop a special skill in bringing parents into team interaction as much as possible. The writing of the individualized educational plan should, in fact, begin with parent input. Moreover, the trainee should become skilled in effective group communication.

"These are refined skills the educator will be needing. In some cases, educators have found themselves working by themselves because they committed a few social errors. Others, because of the interactions they have used, have found themselves working very happily with several other disciplines."⁷⁶

"There are some courses in the School of Business that deal purely with getting the most efficient output possible from the manpower at hand. To be sure, it is impersonal, but they know how to get measured results. Too often, in all of our human services courses, we tend to get softhearted for others around us. That's nice, but I think the handicapped child tends to lose when this happens. We have to take the interests of that child so much to heart that the rest of us keep our own egos and feelings out of the way. The name of this game is his measured change, and that comes before anything else. I think the School of Business could help us at this point to be that kind of efficient manager."⁷⁷

Finally, training institutions need to find ways of recruiting members of other disciplines into traming programs that prepare educational professionals. As nurses and therapists become educators, as well, the education of the severely and profoundly handicapped will gain new stature and will offer the maximum in comprehensive service.

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Parent-Professional Relationships

Beyond the Ordinary

Generalization of Learning

The professional must be able to train parents to guide learning activities. "Some parents have struggled to keep their children out of institutions, but often at a great personal cost when the struggle is carried out alone. 1 have had parents tell me that they haven't been out of the house together in twelve years, because their severely handicapped child was there 24 hours a day, and one or the other had to be there to look after him!"¹⁸

. WHEN NORMAL CHILDREN LEARN SOMETHING NEW IN SCHOOL, they ordinarily practice it in some of their out-of-school activities and they usually remember it when they return to the classroom. The severely and profoundly handicapped, on the other hand, have great difficulty in generalizing their learning. If they are to transfer the skills they learn in the classroom to their home and community situations, it is imperative that their parents become skilled in guiding these learning activities. To accomplish this, the professional must be skilled in parent training techniques, in methods for incorporating parents into classrooms in the paraprofessional role, in using parents as resource persons, and in making overall plans that can be generalized into the home.

"An hour of teacher-child instruction, coupled with an hour of parent-child reinforcement of that instruction is more effective and efficient by a twofold measure than is a straight two hours of teacher-child instruction with no parent reinforcement."⁷⁹

Accordingly, parents should become increasingly active as participants on interdisciplinary and transdisciplinary teams, as primary hands-on teachers and therapists with their own children. The professional needs skill in eliciting parental suggestions for the development of the individualized educational plan, and in encouraging parents to taking the responsibility for helping the child to achieve certain objectives written into the plan. Under the skillful supervision of a competent educator, parents can also become reliable data recorders, contributing to, as well as having full access to, information about their child's progress.

"Before anything else, it is the parent's active involvement as the primary program

Parent Counseling

The complexities of these children are reflected in the complex problems their parents must face.

Parent Alliances

Parents have brought about significant changes in services for their children in the past, and they can continue to do so.

Helping Parents to Help Their Children and Themselves

The needs of the family are often as great or greater than the needs of the severely handicapped child. manager that should be facilitated. There is a remarkable tendency for the parent in the early stages of an infant program to model his or her behavior very closely on that of the educator. If the educator pulls the infant to sitting in the course of an examination or talks to the infant, the parent almost invariably will pull the infant to sitting during the next interactions—and will talk to the infant if talking has been modeled, using the identical words used by the educator.⁸⁰

WHEN CRITICAL SITUATIONS ARISE or decisions for the future are being made, the professional must have competencies in counseling and guiding parents, and in referring them to appropriate agencies for the help they and their child need.

To be an effective counselor, the professional will need an intimate understanding of family dynamics and of the depth and types of reactions parents can have to a handicapped child.

"The impact on parents of having a mentally retarded child typically precipitates reactions which, though not necessarily pathological, tend to frustrate professionals. These reactions may interfere with effective parent-professional interaction and may, in some cases, impair parents' capacity to deal constructively with their having a retarded child. Common parental reactions to having a retarded child include loss of self-esteem, shame, increased ambivalence, depression, self-sacrifice and defensiveness. Extreme degrees of any of these reactions can obviously interfere with helpful parent-professional relationships."

The professional's concern with family dynamics and the impact of the severely handicapped child on the family must extend also to the brothers and sisters of that child. Not long ago, one reason commonly offered for admitting the severely and profoundly handicapped to institutions was the fear that their siblings often suffered from their presence in the home. When parents had little or no support from the school or community, this fear may have had some validity. However, many siblings are seen as stronger because of their relationship with a handicapped brother or sister, and are also capable of helping that brother or sister to learn.⁸²

THE PROFESSIONAL CAN ALSO PERFORM A VALUABLE FUNCTION in helping to establish and structure parent-to-parent activities. These include group sessions for the sharing of feelings and concerns, visits by experienced parents to parents who have just learned that their child is severely handicapped, contact between parents who are veterans of a certain educational program and parents whose child is newly enrolled.⁸³ Such activities can be a strong force that gives direction and provides options that a parent of a newly identified handicapped child may need.

Parent-to-parent activities also encompass lobbying for services for the severely handicapped within the community, and concerted efforts in child advocacy. The professional will find that parent collaboration can be quite effective in the integration of the handicapped that must be a part of their educational programming.

"As parents and families . . . move out into communities and seek to establish new programs for other handicapped children and their families—programs that are badly needed but that are not now provided by any agencies—we applaud their efforts to extend services and feel a deep commitment to help them with this work . . . There can hardly be a more appropriate 'testimonial' to the parents' involvement and partnership than their determination to extend services that they have benefited from to other families. Their interest and their many forms of support are richly rewarding to us all."⁸⁴

OUR TRAINEES NEED a variety of information and a number of practical experiences in working with parents if they are to develop the knowledge and performance competencies that they will need to fulfill their professional responsibilities to parents. They must learn how to:

• Communicate openly, clearly, and intelligently with parents. This involves a comprehensive understanding of the child's diagnosis and prognosis and of the educational and treatment plans prescribed. It also involves the ability to accept parents where they are, to be a good listener, to encourage full disclosure, and to translate professional jargon into everyday language.⁸⁵

"It is important to communicate with parents on the basis of good measurement. What we tell parents must be accurate. We must not tell them something that's based on bad measurement."⁸⁶

• Elicit and interpret family history and information on the home environment. A requisite skill is an understanding of the importance of past and present environments and events

as potential determiners of behavior.⁸⁷

- Counsel parents with objectivity and compassion. On the one hand, the professional must be able to empathize with parents' sense of disillusionment, aloneness, and vulner-ability, without seeing them as patients.⁸⁸ On the other hand, the professional must understand interpersonal, group, and family dynamics, the various analyses of group and interpersonal behavior, and the various techniques to elicit and maintain behavior change.⁸⁹ In addition, the counselor must have knowledge of referral sources and the ability to match them with the individual needs of child and family.
- Assist parents in becoming focal members of the educational team and in interacting with the various team disciplines, by encouraging and reinforcing their activism and decision-making.⁹⁰
- Design, implement, and evaluate training programs for parents to provide educational experiences for students with severe and profound handicaps.⁹¹
- Collaborate with parents in constructive action in child advocacy and social change. This will require full knowledge of the litigation and legislation which affect the rights of handicapped children and their parents,⁹² as well as an understanding of the community and the ability to help parents in dealing with long-term objectives for their children.

"Educators tend to be future oriented in their preparation of their pupils. Parents, however, are often threatened by what they fear the future holds in store for them and their (handicapped) children."⁹³

• Develop ethical attitudes toward work with families, particularly an understanding of the child's and family's right to privacy and dignity, and the professional conduct necessary to maintain these rights.⁹⁴

"Parents need guidance, they need comfort, and they need to be periodically freed from their heavy and lonely burden of providing for a child whose care requires more than the usual amount of parenting and nurturing. The needs of the children are great; the needs of the family are often even greater. The needs of the children are frequently met; the needs of the family are too seldom recognized or satisfied."⁹⁵ The professional needs to be skilled in meeting these needs, in helping families move from a position of despair to a position of participation in the maximum possible development of their children and activism in making the community the best possible place for them to live.

"The first and hardest thing to accept is that the problem is severe, unrelenting, and lifelong. The second realization is that there are few, if any, services for the child. Shortly comes the third realization—that unless the system changes, most of these children will never get what they need ... A growing number of parents come to yet a fourth realization, that the system is changeable."⁹⁶

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Community Coordination

Beyond the Ordinary

"There are three things to consider in developing curricula for the severely and profoundly handicapped. We begin by looking at immediate needs that are oriented to child management — 'Mother, father, what is the major problem you're having right now?! The second thing is to consider short-range goals, determining what the child's next developmental level might be. Third, you look at long-range needs. You figure out long-range needs by examining the environmental community within which the child will ultimately function, and then you make an instructional seguence that will lead to successful placement in the environment.

"Now, we have no trouble with the first two, but we're getting nowhere on the third because the community is not organized and professionals in education are not taking leadership in creating the lifetime environment. This makes it contingent on administrators and teachers to become environmental determinists, to go out and work with agencies, to be deterministic about the kinds of adult environments that will exist"⁹⁷

Model Communities to Enhance the Lives of all Citizens

There is a tremendous educational job to be done with many members of any community. THE OBJECTIVE OF EDUCATION for the severely and profoundly handicapped is to prepare them to become as independent as possible, so as to prevent their ever again being relegated to the back wards of state institutions. The achievement of this objective requires far more than the provision of a public education for these individuals; it also requires long-term collaboration between the disciplines concerned with them and the citizens, groups, and agencies of the communities which must be their homes, toward these ends:

Community awareness of the needs and potentials of the severely and profoundly handicapped.

Positive attitudes about the handicapped, in general, and the severely and profoundly handicapped in particular.

Direct services to the severely and profoundly handicapped and to their families. The opening of existing community resources and services to these individuals. The adaptation of community resources and facilities for their use.

The provision of employment experiences and opportunities, as well as other avenues by which the severely and profoundly handicapped may develop their potential for autonomy and contribute to society.

The cooperation of the community at large in integrating these people into everyday life.

The effective education of the severely and profoundly handicapped in those skills that will enable them to function within the community and use its resources.

From an educational standpoint, it is paradoxical to train the handicapped to use public services and facilities if they are denied access to them or face obstacles when attempting to use them.⁹⁸ For example, a survey of one, probably typical, urban area revealed the following difficulties faced by the severely handicapped and their parents in obtaining the services and benefits that most of us take for granted, that are not special in any way:

- Many physicians and dentists hesitate or refuse to treat the severely and profoundly handicapped for such routine complaints as colds and dental problems.
- Medical insurance is almost impossible to purchase unless the child was insured from the moment of birth.
- Churches do not uniformly offer supervision of severely handicapped children, as they do provide for other children, during the hour when their parents might attend services.
- Restaurants often refuse to admit the severely and profoundly handicapped.
- Public transportation systems are not well suited for use by handicapped persons, particularly those with physical disabilities.
- Parents of the severely handicapped report difficulties in placing them in community recreation and leisure activities, such as swimming classes, day camp, Sunday School, Camp Fire Girls, Boy Scouts, and community sports activities.
- Day care centers and babysitters often reject the severely and profoundly handicapped.

"There is a tremendous educational job to be done with many members of any community—the architect, the physician, the employers, the people who serve others."¹⁰⁰

Generic Services

We must reach out and change the concept of training to include many professionals, executives, and community leaders.

Special Services

You have to do more than pass legislation to secure the rights of individuals.

THE JOB OF THE PROFESSIONAL BEGINS with the interpersonal and public relations skills that will let the educational community and the public at large know what is going on in the education of the severely and profoundly handicapped, what they are achieving, and what they need in order to continue to grow and develop.

"We need to prepare comprehensive information packages for the politicians who are the decision-makers within the community. We need to be going before city councils and explaining the problems which the handicapped are encountering within the community in a concise fashion. We need to understand the fiscal arrangements that exist within a community so that we can speak to the decision-makers about how to get this job done fiscally. We also need to develop training programs that will allow administrators of programs and services in the community to become better trained in providing these services and programs for the handicapped. We need to reach out to these persons and develop special workshops —for example, for persons in charge of a city bus transportation system."¹⁰¹

Activities of this type imply a change in the concept of training, or a movement from the traditional idea of teacher training to the more universal concept of professional training. Thus, training facilities and trainers need to begin to look at the community, recognize the various professionals, executives, and leaders existing in the community, and put together training programs that will reach out. Thus, the professional trainer should develop workshops and seminars that will have an impact on people whose scope of influence is far beyond that of the educator. Our effectiveness with this kind of training will lead to increasing opportunities for the severely and profoundly handicapped to participate in the everyday life of the community.

"Both handicapped and nonhandicapped citizens will reguire longitudinal and comprehensive exposure to one another. Such exposure will enhance the probability that the skills, attitudes, and values so necessary for tolerance, understanding, and absorption will be realized."¹⁰²

IN ADDITION TO OFFERING GENERIC SERVICES to the handicapped, communities must also be assisted in providing the specialized services needed by the severely and profoundly handicapped and their families. "This is a new endeavor, and we must carefully plan a network of services and a delivery system that does not become overly bureaucratized and which retains its original commitment to meeting the needs of individual consumers."¹⁰³ Among these essential specialized services are: ¹⁰⁴

- Programs of early identification and early intervention.
- · Specialized public school services.
- Community residential services, composed of such alternative living arrangements as group homes, developmental homes, staffed apartments, cluster apartments, intensive training homes, foster homes, crisis care centers, and the like.
- · Family counseling.
- In-home services and equipment, such as appliances or equipment that circumvent architectural barriers for the physically handicapped; time-saving appliances that would make it more possible for parents to devote more of their energies to teaching and caring for their children; and medical and behavior modification equipment, such as oxygen tents, alarm systems to alert parents if their child is in need of something or wandering, and special toilet-training apparatuses.
- Protective services, including operational advocacy (for the delivery of full and accessible services), case advocacy (for serving individual consumers who are unable to represent their own interests, and to protect their human and civil rights), and legal advocacy (for interpreting laws through legislative action, court decision, or administrative rule-making.)

This level of comprehensive community service will not become possible until all agencies are working together. At this time, no single agency has taken responsibility for the severely and profoundly handicapped in the conversion from institutional services to community services. The education profession can exert great leadership in this responsibility, from the level of the training institution to the level of the classroom teacher.

"This is responsibility at the professional preparation level that exceeds that of college educa-

tion. It involves the cooperation and coordination of many colleges and divisions within universities. And big universities have the capabilities to do this, to evolve a university-wide committee that draws on the technology of bio-engineers, the technology of architectural engineers, of urban planning, of the colleges of medicine and health science affairs. Then we can begin to make sense in terms of overall plans for these individuals. You have to do more than pass legislation to secure the rights of individuals. You really have to get your major impact institutions to say, 'All right, we've got the legislation—let's get the job done.' "¹⁰⁵

It is also necessary for professionals to become involved in the work of each state's Developmental Disabilities Council, and to create continuity of planning between these councils and public education. The formation of such relationships and alliances, as well as the other activities necessary for conversion to full community services, are very much a part of the role for which professionals must be trained.

"Conversion means societal efforts to eradicate handicapist attitudes and practices. Obviously, teachers, as members of a larger society, can play a role in such efforts. Conversion means rechanneling funds to support community placements for the handicapped. This process will ultimately provide resources for the schools. Conversion means retraining institutional staffs and community personnel. Teachers can play major roles in such programs. Conversion means creating noncategorical systems of educational treatment. Such policies will eventually affect the design, the appearance, and the functioning of all school classrooms and curricula. Conversion means changing attitudes of school acliministrators toward acceptance of zero reject policies. Conversion means planning community services, of which education is a major component. Conversion means the appointment of professional and consumer advocates for community programming. Last, conversion means developing classroom strategies that focus on promoting integration of disabled children."¹⁰⁶

THUS, A MAJOR RESPONSIBILITY of professionals will rest with the development of effective educational programs to guarantee that the severely and profoundly handicapped will be able to use appropriately those community services, facilities, and programs that can gradually become available to them as a result of our efforts and collaboration.

'The instructional materials, tasks, consequences, objectives, and criteria to which severely handicapped students are exposed in educational settings should resemble those that students will encounter and need in community, domestic, social, leisure, and vocational settings. However cumbersome, time consuming, inconvenient, or expensive it may be to do so, the pegs, felt squares, pictures of money, tokens, pictures, edible consequences, and many if not all of the commercially available kits and irrelevant paper-and-pencil tasks should be faded out. Real money, real streets and cars, real people, real stores, real sounds and smells, real tools and objects, real group homes, and real ridicule, rejection, and disappointment must replace them. An empirically verifiable naturalized life space curriculum designed to teach the skills required in heterogeneous community environments is the order of the day."¹⁰⁷

Our trainees need to be skilled in translating systematic instruction into individualized educational programs that will lead to community integration. They also should demonstrate knowledge competencies on such topics as: the human management model; attitude change; the bases for denial of generic services in the past; the process of integration of handicapped individuals into the mainstream of society and criteria by which they can be said to have achieved integration; factors by which the physical and social integration of a service facility into the mainstream is determined; methods by which the handicapped can be integrated into community programs, industry and housing; architectural and environmental design and operations to be avoided; implications of the normalization principle for group residential services; the compatibility of behavioral procedures with the normalization principle; administrative mechanisms which will increase the probability that normalizing services will be provided; the relationship of citizen advocacy to the principle of normalization; accountability tools used to assess agency performance in relation to implementation of the normalization principle.

Through such knowledge competencies, trainees can develop performance competencies via such practical experiences as:

- Developing a human management model applicable to a special education class for severely and profoundly handicapped persons that maximizes the application of the normalization principle.
- Delivering a speech to a group of professionals countering the factors which usually account for the resistance to acceptance of the normalization principle.

Teaching Community Living Skills

Learning to use community resources requires instruction experiences in the natural environment.

- Serving as an advocate for a severely or profoundly handicapped child in attempting to secure the provision of normalizing experiences for that child.
- Using accountability tools to assess the performance of a specific agency in relation to implementation of the principle of normalization.
- Attempting to get a commitment from the appropriate agency representative to revise any non-normalizing practices identified through such an assessment device.¹⁰⁹

"The specific community services that are required for the severely and profoundly handicapped do not have to be constructed from nothing. There are a number of exemplary programs throughout the country that have demonstrated the efficacy of early identification and intervention, public school programming, and community residential services that can guide us in this task. These model programs can be adapted to and emulated by other states and regions to create comprehensive and effective services in community settings. To date, not a single state nor region has developed a service network that uses the knowledge and technology that is already available. With your help, perhaps your state will be the first to accomplish this important task."¹¹⁰

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Early Intervention

Beyond the Ordinary

Education From Birth

A severe handicap can be detected at birth; we don't have four or five months to waste. ""The earlier we get there with intervention, the more likely we are to make change. There is a need to establish systematic strategies on obstetrical wards, and with obstetrical nurses and obstetricians, for identification and for making sure that services begin immediately after identification has been made. That impact is going to influence professional preparation to the extent that we're going to have a new infant discipline, with individuals trained to be able to spot the profoundly handicapped and severely handicapped at infancy.

THE DISABILITIES OF THE SEVERELY HANDICAPPED CHILD interfere significantly with his development from the very beginning of his life. Moreover, our work with both normal and handicapped children has led to the conclusion that the first three years of life are crucial to later development.¹¹² However, Public Law 94-142 specifies education beginning at age 3, and, although some states offer education and training from birth, infants and toddlers have seldom been considered candidates for public education.

To put off intervention for several years delays the opportunity to deal with developmental problems when they are least complex.¹¹³ Moreover, the progressive nature of many severely handicapping conditions causes the child's developmental status to become worse as he grows older, and can lead to atrophy of his sensory abilities and to general regression.¹¹⁴ Because early intervention is usually more effective than later intervention, it is also more economical.

"It has been clearly shown that, although the human brain growth spurt begins in fetal life, about the middle of gestation, it continues at least until the second birthday and probably beyond . . . The recent finding that the human brain growth spurt occupies a long period of development, and that most of it is postnatal, has practical implications. It is during this period that good brain growth should be actively promoted by ensuring good environmental conditions during its only opportunity to grow properly."¹¹⁵

Neurologists and pediatricians are beginning to place more importance on the possibility of early intervention and its effect on structural development of the central nervous system. The infant, with proper programming through the principle of successive approximation, is ready for teaching. With very well coordinated team intervention, it is indeed possible to begin this early instruction that can prevent some serious effects of a severe or profound handicap on later functioning. This is not to say that we can prevent severe handicaps, but it is possible to prevent some of the progressive

deterioration through early intervention.

The educator will probably become the professional with primary legal responsibility to facilitate development in the infant.¹¹⁶ In fact, the Deputy Commissioner of the Bureau of Education for the Handicapped, U.S. Office of Education, recently recommended that a single agency should become responsible for delivery of services to preschool handicapped children, and named the public education agency as the most logical entity to perform this service.

CENTRAL TO EARLY INTERVENTION is parent training, as much of the stimulation and intervention activity with the infant must be carried out daily and consistently in the home. "Early intervention should help the family move in small steps toward successfully handling their own problems, as well as learning to work with their severely handicapped child."¹¹⁸ Initial intervention objectives focus on normal developmental milestones, including motor skills, sensory development, communication, and adaptation.

Twelve Down's syndrome infants participating in an early intervention program were taught specific gross motor and cognitive/adaptive skills. All training was conducted by the child's parents in the home, with assistance from a professional parent trainer. Data presented from illustration programs indicate that parent-implemented training procedures appear functionally related to developmental gains made by infants and appear to have resulted in more accelerated development than would be expected without intervention."¹¹⁹

PROGRESS REPORTED by existing programs¹²⁰,¹²⁴ indicates that early intervention has a very positive influence. However, professionals must carry out the kinds of studies that can prove this influence. This will require skill in collecting and interpreting longitudinal data over a period of years, as a severely handicapped student proceeds from an infant program to adulthood, and a comparison of this data with matched groups of students who did not have the benefit of early intervention.

"I would not hesitate to tell some of our young, bright students to dedicate five or ten years to studying the effects of infant intervention." 125

The data are not in that will tell us that structural changes in the nervous system can result from environmental intervention strategies and effective programming from birth, but it is an important question for research. And it represents only one of the crucial ways by which our trainees, if well prepared and competent, can serve the research and development needs of our emerging discipline.

ALTHOUGH THE TRAINING OF PROFESSIONALS should produce personnel with understandings and competencies in the education of the severely or profoundly handicapped child throughout his life span, the same professional cannot be expected to handle this entire educational endeavor. Accordingly, those who specialize in early intervention need to exhibit competencies in systematic instruction, teaching basic life skills, team participation and management, parent training and counseling, and community coordination—all with a focus on specific competency development that will enable them to apply these skills to working with infants and toddlers and their families.

Among the competencies required to develop program options for very young children and their families are:¹²⁶

Precise assessment and diagnostic skills.

Curriculum development for individual infants and small children.

Classroom management and intervention strategies.

Maintenance checks and ongoing assessment in the agency setting or in the home.

Program consultation.

Home visits.

Parent training and conferencing.

Referrals.

Involvement with other agencies.

Collaboration in the establishment of parent meetings and parent task forces.

Program evaluation.

Longitudinal research.

Parents as Early Interventionists

Parent training is the key to infant programs.

Longitudinal Research

Professionals should keep

long-range developmental

profiles of their students.

Professional Preparation

Some of our trainees will specialize in early intervention strategies.

"Until we are able to point to a well established system of public education for the handicapped child from the moment when his handicap is identified, we cannot rest content." 127

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Prevocational and Vocational Education

Beyond the Ordinary

"A leading priority is continuous planning with Developmental Disabilities Councils, vocational rehabilitation and vocational education agencies. We have come to see that, with the severely and profoundly handicapped, we must have the long-term consideration that the services we offer can continue through a lifetime. The span we have in education, through age 21, doesn't give us enough time to help these people to move independently in the community, even though the community may be a relatively simplified one. They will still need continuous planning and coordination. They can often outlive their parents, their primary source of supervision, and be in the community with the need for continuing coordinating services. I think there is a lot to be said about this, and it is uncharted territory."¹²⁸

Employment of the Severely Handicapped

It is no easy matter to place them in jobs.

PUBLIC LAW 93-112, The Rehabilitation Act of 1973, allocated increased funding for vocational habilitation programs for the severely handicapped, and this training is being offered largely by state and local rehabilitation agencies. However, public education has a responsibility for preparing these students with the prevocational, vocational, domestic maintenance, and community living skills they will need to enter these programs, and to help them to learn the social skills requisite to success in training and working.

The use of behavioral technology in vocational and prevocational training has shown that severely handicapped individuals can perform complex manual tasks, such as putting together a drill machine,¹²⁹ assembling bicycle brakes,¹³⁰ assembling circuit boards,¹³¹ packing and storing merchandise,¹³² and accomplishing various workshop tasks.¹³³ Under appropriate conditions, these individuals should be able to master many work tasks that would make them employable or at least productive in a workshop setting, and many should be able to perform with a gradually diminishing amount of supervision.

"The use of task analysis in training complex assemblies has been extremely effective with moderately and severely retarded learners. In teaching tasks involving 15 and 24 piece bicycle brake assemblies, printed electronic circuit boards, and other relatively difficult tasks, only a small percentage of the severely handicapped individuals trained . . . failed to reach criteria of skill acquisition. (This is) a dramatic indication that expectancies for the severely handicapped have been far too low. Severely and profoundly retarded blind individuals successfully learned and completed the 15-piece bicycle brake task. Apparently, the technology for teaching competitive work skill is on the way."¹³⁴

The actual employment of the severely handicapped remains a problem, however. Few studies have shown that they can reach competitive production rates, and, even when they are well prepared and capable, it is no easy matter to place them in jobs. Solutions to this problem will require intensive work between school, rehabilitation agency, and community, and may also require that amenable employers be subsidized.

"On the other hand, persons attempting to generate longitudinal developmental services for severely handicapped citizens cannot wait for a more favorable employment climate' before they design educational services that contribute to the development of marketable vocational skills. . . Persons working with severely handicapped students are responsible for developing the maximum number of vocational skills and employment opportunities, however remote competitive employment appears at any given point in developmental space for any given student. If educators can provide severely handicapped students with marketable work skills, who in turn can demonstrate on-the-job success, it follows that more and more people will eventually develop higher and higher levels of productive expectation."¹³⁵

Lifetime Education

We need a longitudinal educational plan that begins at birth and ends in old age. CONTINUING EDUCATION, PROGRAMMING, AND MANAGEMENT for the severely or profoundly handicapped individual past the age of 21 and throughout his adult life emerges as a crucial priority for service delivery, and one that is as yet not legislated. Service delivery of this scope should rightfully absorb public education and community for some time to come, toward the goal of a longitudinal educational plan that begins at birth and ends in old age.

"We have a fairly good investment in our severely handicapped individual to the age

of 21. Often, when formal schooling is over, we not only lose the time and human investment that we have in that individual but we lose the individual for all practical purposes as being a semi-independent or independent member of society. And that is a serious concern."¹³⁶

Adult education would encompass not only vocational training and counseling, but also community self-help skills, domestic maintenance, and sex education. When one considers the applicability of these services to a wide range of individuals within the community, including the mildly handicapped and even the non-handicapped, the practicality of these provisions becomes clear.

"Right now, I'm dealing with one chunk of a person's life. We fail to consider what will happen to this person when he leaves school. Will he go to a job? Will he be in a workshop? Or will he not be able to do any work? We need to start thinking about what happens when he's no longer in our classes."¹³⁷

CERTAIN TRAINEES WILL SPECIALIZE in prevocational, vocational, and adult education, but "all trainees should have basic information on vocational education if they are to understand issues affecting longitudinal functioning of the individuals with whom they are working. Those advocating the integration of the severely and profoundly handicapped into the community cannot afford complacency in regard to the actual situations they will face in the future. The pinpointing of prevocational skills is a continuing need, as is effort to identify and create job placements which may endure in a continually changing technological society."¹³⁸

Skill in teaching prevocational and vocational skills to the severely handicapped will also reguire knowledge and performance competencies similar to the following:¹³⁹

- · Understanding of jobs and work settings for which individual students are qualified.
- Skill in training the student to adapt to the social environment of the work setting, in terms of fellow workers, supervision, and special contingencies of the employer.
- Ability to train basic job skills and prerequisites, including:
 - Basic physical and sensory-motor skills
 - Basic language skills
 - Basic academic skills
 - Basic machine and tool skills
 - Basic hygiene skills
- Ability to train supportive skills, including:
 - Transportation
 - Work preparation
 - Basic money management
 - Time telling and time judgement
 - Health code requirements
 - Informed consent and legal requirements

If the public, parents, and the handicapped themselves cannot see any possibility of independent or semi-independent living at the end of the vocational program for these individuals, the concept of deinstitutionalization will be greatly undermined. It is very much a responsibility of the public schools to provide these programs, and to provide continuing education for handicapped adults so that they may succeed in confronting the problems of independent living.

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Toward the Development of Standards and Criteria for Professional Preparation

The Responsibilities of the Professional

Beyond the Ordinary

The practicing professional and the trainee have a unique set of responsibilities to students and to parents. The professional must be proficient not only in the competencies expected of the educator or ancillary professional, but also in behavioral technology and systematic instruction, the teaching of basic life skills, interdisciplinary teamwork, diverse work with parents, and coordination of programs across communities. Many must also be prepared to intervene with these children from birth, and many others must be expert in prevocational and vocational education.

WE ARE IN THE EARLY STAGES OF RESEARCH, DEVELOPMENT, AND DISSEMINATION in our work with the severely and profoundly handicapped. Thus, we would be presumptuous if we assumed that we could specify all of the competencies that a professional might need in order to work effectively with these individuals. At this point in the evolution of our educational philosophy and procedural framework, we do not know all that we need to know about this population, nor do we know all that we will eventually understand about teaching them and integrating them into our communities.

This, however, is not to suggest that we cannot begin to conceive and promote the standards necessary to providing the best possible services to the severely and profoundly handicapped. On the contrary, there are a number of factors that make this the best possible time to begin a flexible, long-range program of quality control.

First of all, no person nor profession can ever lay claim to knowing everything there is to know. To make such an assumption would be to stifle the striving for excellence. In asserting that we know some things but not others, we confirm the need to continue to build, but we also recognize the good evidence and experience that support our current work. If we waited to develop standards and criteria until we felt that we knew everything, many generations of severely and profoundly handicapped children, as well as our profession, would be poorly served.

Second, research and development activities to date have yielded considerable evidence regarding a number of competency areas that combine to enhance the life and learning potential of the severely or profoundly handicapped person. We have most assuredly isolated the fundamentals. In order to build on them and refine them, we have to guarantee that we can implement these basic and essential principles with a maximum of skill.

Third, the period of evolution and development is most opportune for devising prototypes for the future. In all areas of endeavor, even in the rise and fall of civilizations, there is a time most favorable for charting direction. Those realms of human activity that have reached a zenith tend to become institutional and static in nature. Those which are evolving tend to be highly creative, capable of innovation, flexible. The difference is that between complacency and aspiration.

For each significant human endeavor, there has been a golden age. For those of us concerned with the severely and profoundly handicapped, this is ours.

THE SINGLE MOST IMPORTANT PREREQUISITE for all professionals working with the severely and profoundly handicapped is the belief that all individuals can learn, and that their rate of learning is not a justifiable basis for judging the worthwhileness of an individual nor the importance of teaching him. If the professional or trainee has any question regarding the worth of an individual because he is severely or profoundly handicapped, it will be difficult for him to respond productively to his students. There must be a shared belief that the education of these people is very worthwhile indeed—that, for example, a movement from 2 to 4 responses is just as much a 100-percent gain as is the movement from 50 to 100 responses.

The professional and the trainee must innately believe in the value of the severely and profoundly handicapped and in the importance of teaching them. They have only to measure accurately to witness the gains these individuals can make and to trust the importance of this teaching.

The various ways by which professionals establish relationships with their pupils are difficult, if not impossible, to measure. They can be seen only in outcome data on the performance of each child. The most positive of teaching-learning relationships are based on belief in the child's capacity to grow, and are gained through knowledge and experience in such depth that the professional re-

The Best Time to Develop Standards and Criteria

For each significant human endeavor, there has been a golden age.

Prerequisites to Competence

The professional must believe implicitly in the work he is doing, and his procedures must become second nature. ponse appears to come naturally.

The professional must be confident that his training experiences have been so extensive and intensive that his skills are not a matter of chance or of trial and error, but have become second nature to him.

Self-Evaluation

The professional will be concerned with the adequacy of his knowledge and performance. IF THE PROFESSIONAL OR TRAINEE IS COMMITTED to the education of the severely and profoundly handicapped, it follows that he will be concerned that his own knowledge and performance will be adequate to the task he has undertaken.

We now recognize that the educator of the severely and profoundly handicapped must have highly specialized skills in applying behavioral principles, in establishing instructional conditions, and in employing measurement procedures. Equally important is the systematic instructional process, which provides the orderly progression and intensity that is crucial to the education of the severely and profoundly handicapped.

Moreover, the professional must regard the teaching of basic life skills as an important educational task. He must view such endeavors as toilet training and the teaching of feeding skills not as activities that detract from the dignity of the educator, but, rather, as learning tasks that will enhance the dignity of the handicapped person.

More significant than the educator has ever before imagined has been the concept of comprehensive management, a classroom-based interdisciplinary approach to instruction. Individuals from various disciplines, with the high-level and sophisticated coordination of the educator, can serve to develop a comprehensive interdisciplinary management plan, which is the most effective approach to the education of the severely and profoundly handicapped.

Parallel to this is the most comprehensive parent-professional involvement that has ever been devised in public education, and which is intended to guarantee continuity of instruction and the maximum contribution and participation of parents in the education of their handicapped children. Thus, parents may gain understandings that will serve them in dealing with the problems their children present and in working to resolve problems and deficits they experience in their communities.

Concern with community services and resources must also be the work of the educator, as he strives to prepare his severely and profoundly handicapped students for life outside of institutions. Community intervention and environmental determinism must be among the roles of the professional who carries out his full responsibility to the individuals he serves.

Last, all professionals need basic understandings in terms of early intervention and prevocational and vocational education in order that they may most effectively teach those students who have or have not progressed through early childhood education, and who need instruction that will lead smoothly to the prevocational level. In addition, many trainees should be prepared for specific careers in early intervention, while others should specialize in prevocational and vocational education.

The professional should look introspectively at his own competencies within each of the broad areas required for the education of the severely and profoundly handicapped, evaluate them, and decide whether or not he has sufficient knowledge, expertise, and skill in all of the competencies of:

Behavioral technology and systematic instruction

- The teaching of basic life skills
- Interdisciplinary and transdisciplinary teamwork
- Parent-professional relationships
- Community coordination
- Early intervention
- Prevocational and vocational education

In his own self-evaluation, the professional will judge himself to be adequately or inadequately skilled in the various areas and competency components. Even if his skills are superior in all areas, the responsible professional will work to remain current with new developments in the education of the severely and profoundly handicapped.

The professional should re-enter training to upgrade those skills that he finds wanting in himself. Moreover, he should keep himself informed on the state of the art, and should return for further training when he needs new skills to implement new practices found to be effective with the severely and profoundly handicapped. This is an extremely important responsibility in this evolving area of special education.

In evaluating his skills, the professional must also be thoughtful in attempting to determine whether any lack of competency development might be a result of inadequacies in the program in which he was trained. The professional should remain in contact with those who have trained him, and when appropriate, offer them constructive advice on how the training program might be expanded or improved to offer continually better preparation for professionals.

Participation in Research and Development

The professional will use his work to help others provide services for the severely and profoundly handicapped. FINALLY, THE PROFESSIONAL HAS THE RESPONSIBILITY OF SHARING his expertise and his understanding of the severely and profoundly handicapped. His intention will be to inform fellow professionals, school administrators, and the community of his program and of the success of his students, as well as to assist others in understanding these children.

The professional should carry out public relations and dissemination activities that will generate the interest of others in the severely and profoundly handicapped, that will provide an instructive basis for others to work with these children, and that will add to the body of knowledge in this area of special education.

The full responsibility of the professional is thus circular: to assure himself that he is competent, to determine and contribute to the development of new competencies for himself and for the field, and to pass on to others those skills and understandings that will help them to advance the opportunities of the severely and profoundly handicapped. These responsibilities comprise distinct possibilities for professional growth and leadership. The responsibilities are actual and the possibilities are real. This is indeed an opportune time for the professional to chart directions.