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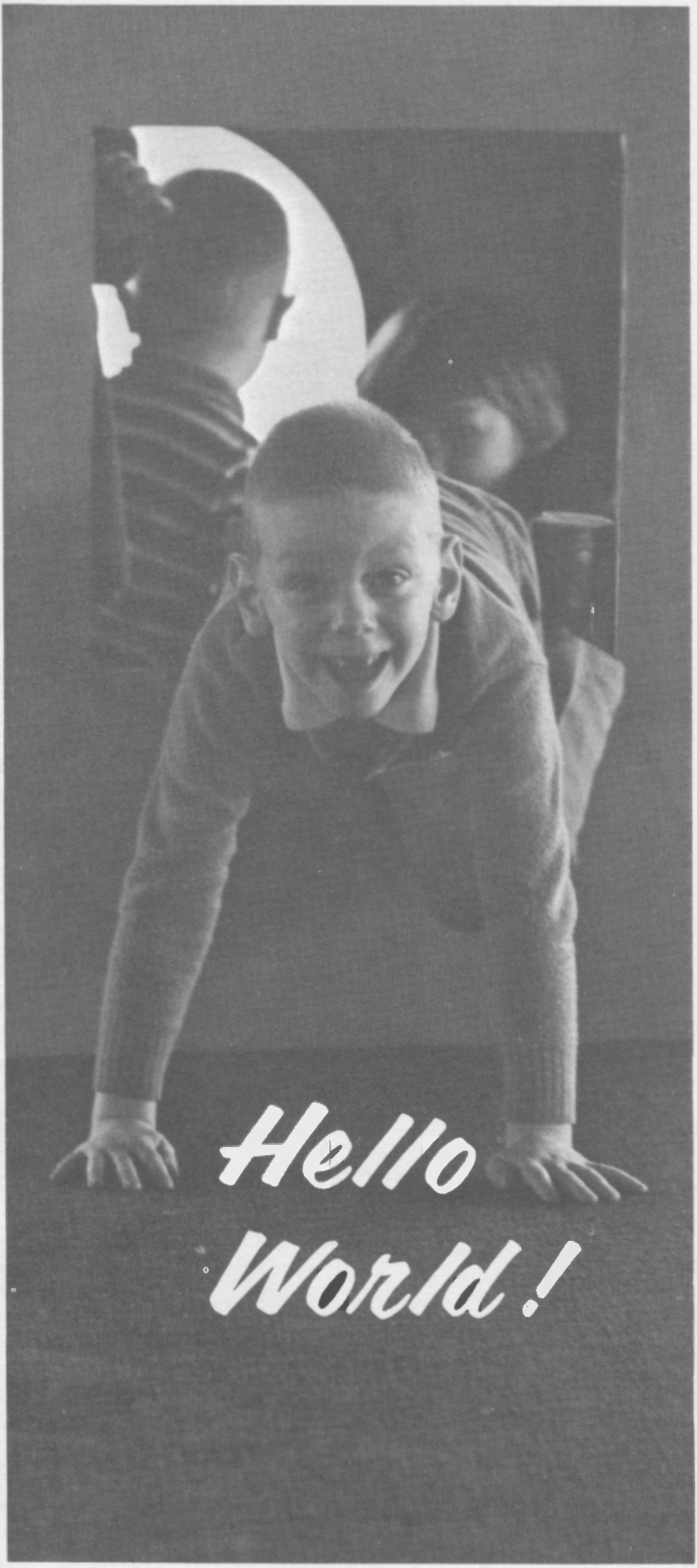
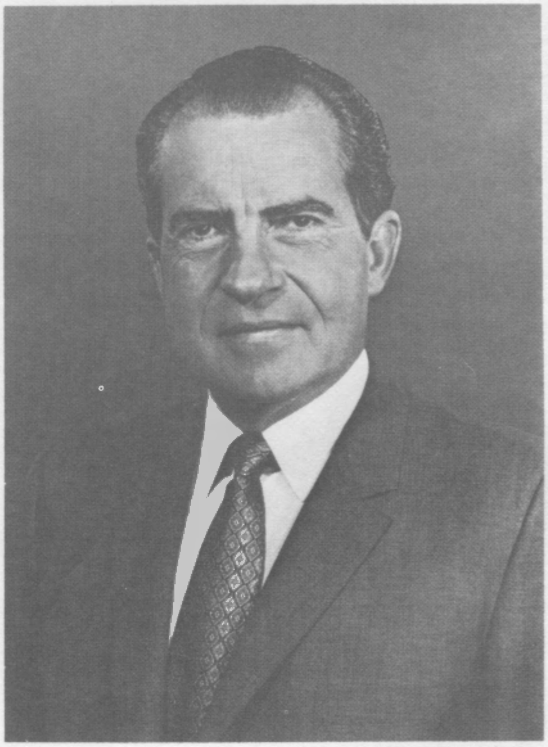


Hello World!

THE PRESIDENT'S COMMITTEE
on MENTAL RETARDATION
presents this pamphlet in the hope that it will further an understanding of the mentally retarded, and by so doing, will ease the way for them to become a part of the world in which we all live.

The Committee is composed of 21 citizen members and 3 ex-officio members appointed by the President of the United States. . . .
. . . to advise him on what is being done for the mentally retarded;
. . . to recommend Federal action where needed;
. . . to promote coordination and cooperation among public and private agencies;
. . . to stimulate individual and group action;
. . . and to promote public understanding of the mentally retarded.



Remember how it feels to be called on in school when you haven't done your homework?

That's the way Tommy feels now. He's the eight-year-old standing by the blackboard with the faded T-shirt hanging out over his blue jeans.

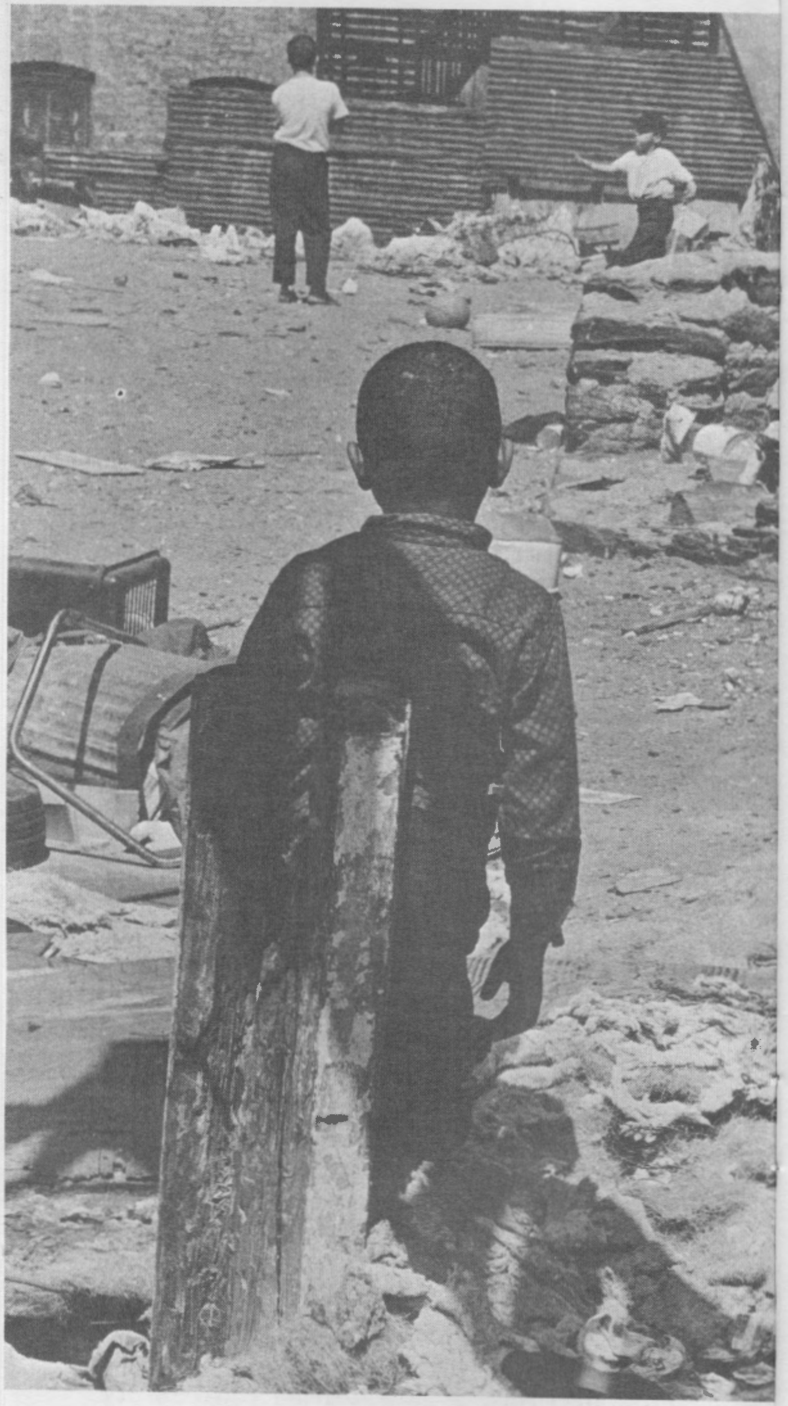
His teacher has asked him to add 46 and 24. She may as well have asked him to solve a problem in nuclear physics. It's true that he didn't do his homework, but if you can't read, what's the point in looking at a book?

Yesterday, Tommy was called down for not knowing his address. In the last two years he has moved from his mother's to his grandmother's, and now to his aunt's.

No one has told him the address.

He had been excited about starting school and learning all the things big children know. But the teacher had no more time to give him than anyone else ever had. And it was almost as noisy and crowded there as it was at home, where there were nine people living in two small rooms.

Each month Tommy drops further and further behind in his schoolwork. Now he is no longer just a slow learner; his ability



to learn has become limited. How long it will remain limited depends on the kind of help he receives.

Tommy is mentally retarded.

In the most important growing period of his life, between birth and five years, when he was learning to talk and becoming aware of the world around him, there was no one who could afford to give him more than the bare physical necessities.

No one could provide him with the luxuries of fondling, talking to him, reading to him, or stimulating his mind and emotions. His early years were his big opportunity for learning. And he missed the opportunity.

Without early, personalized special education, the effort to catch up will become progressively more difficult and futile. Year after year he will probably be given a "social promotion," until he drops out of school at around 15, if he follows the usual pattern. By then he will be in the tenth grade, though he may still be reading on second grade level.

Chances are that his mounting frustration will find expression in behavior problems, and for the rest of his life he will remain emotionally and socially a young adolescent, his potential for a productive maturity lost.

Some gifted teacher or other adult with time and love enough to provide the special attention he needs might yet give him the proper motivation at the teachable moment to spark his mental motor into high gear.

But it will have to be soon—and sustained. Time is running out for Tommy's teachable moments.

Essentially, he is a normal person whose learning capacity has become limited because of the mental and physical hardships of poverty.

Tommy represents the majority of all the retarded persons in the United States.

★ ★ ★

The rest are retarded—mentally deficient—because of some inborn defect, an accident, or a certain disease at an early age. Rich and poor alike can be affected by these forms of mental retardation.

The mentally retarded learn more slowly than others, and are limited in what they can learn. That's all. They are children and adults with the same human needs that we all have—only more so.

Their mental and social handicaps may be mild, moderate, severe, or profound.

The retarded don't need less education because they are retarded; they need more and better education geared more to their individual capabilities than the average, in both academic and social skills. Even the most profoundly retarded can benefit from early training. The earlier the education or training begins, the greater the chances for success.

In fact, many children like Tommy might never have become retarded if they had been given the opportunity for healthy human development in their early years.

Less than a generation ago, many of the experts held that intelligence was fixed at birth. Only a few disputed the theory.

The excitement surging in the field today springs from living proof that mental ability can grow when nourished with human warmth and stimulation. Minds can also deteriorate from neglect.

Since we know now that human potential is determined not by nature alone, but also by each individual's response to his environment, it follows that an improved environment can change the course of life. It is nature *and* nurture that shape human lives—a fact that makes all the difference in current attitudes and actions toward the retarded.

It is this new knowledge—this expectancy of success—that sparks the present concerted national effort of layman and professional, government and private enterprise.

Expanded teacher training programs, new methods in education and training of the retarded, Head Start and other early enrichment projects, revised job training, behavioral and biomedical research, diagnostic and evaluation clinics and new treatment centers are all geared to this new understanding, this change in basic concepts of who the mentally retarded are and what they can do.

Although it will take long and continued effort for the new concepts, services and on-the-spot help to reach all those who need it, many are already benefiting.

* * *

Richard is one of them. Unlike Tommy, whose retardation was caused by his environment, Richard was born with his handicap.

He was slow as a baby—slow to smile, to sit up, to crawl, to feed himself, to be toilet trained.

His parents took him to a mental retardation clinic attached to a nearby university where a team of professionals diagnosed him as mildly retarded—cause unknown, "an accident of nature."

He is now in a special education class with nine others of comparable age and ability, each learning at his own pace.

Richard is the one with the crewcut, writing the word GO, and coloring it green. The class is learning to read signs. They will learn arithmetic similarly planned to serve a practical purpose in life—how to measure wood to make a footstool, how much change you get back when you give the bus driver a dollar.

When Richard was about three, his mother, with the help of the local chapter of the National Asssociation for Retarded Children, organized a pre-school nursery with the parents of other retarded children in the community. She found them through a letter to the editor printed in the local newspaper, and through public service announcements on the local radio station. A nearby church gave them the use of their parish hall for the five-day a week classes.

The parents also worked together to encourage the school board to increase the number and quality of special education classes in the area. Funds for classrooms and teachers' salaries come from local, state and federal sources.

His special education will continue to expand his horizon until his apparent limits are reached. He may then "graduate" into more specialized job training, though from the beginning, his education will be designed to help him become a productive, self-supporting citizen. However, when he has to make an important decision or when a crisis arises, throughout his life he will need help to guide him.

Otherwise, for Richard, all systems are GO.

Less than ten years ago there would have been no clinic, little knowledge of the added benefits of the early socialization and introduction to education of the pre-school nursery, and few special education classes. Those in the field were seldom aware of the potential for learning that the retarded have when given the opportunity.

* * *

The more seriously retarded—representing a minority of the total—present different kinds of problems. Because there are physical causes of mental deficiency, and because there are usually added physical defects, they have more need for medical care than the mildly affected. They, too, however, can be considerably helped by early education and training.

Under other circumstances, that winsome little blond girl swimming in the pool with her sister may have been hidden at home—or left to vegetate in a custodial institution.

Her name is Jennie, and she is moderately retarded.

Her eyes slant a little; her nose is short; her fingers stubby. She has "Down's Syndrome," more commonly called Mongolism, a condition that occurs in one out of about every 600 or 700 births.

Not all of those with Down's Syndrome are moderately retarded like Jennie. Some are only mildly affected; others seriously handicapped.

She is capable of learning to read and write a little—up to about a normal seven-year-old's level—but she learns very slowly and requires much patient repetition in order to retain it.

Jennie will need some protective care throughout her life. This does not mean that she must be in an institution. Increased day care programs, the additional training now available in public schools, and expanded vocational training opportunities are proving that the majority of the moderately retarded can lead useful and productive lives—outside institutions.

This fact represents a revolutionary change in concept and action in less than a decade. Unfortunately, the change has not yet reached into the lives of all of the retarded, and most communities are still without the programs that make semi-independent living possible for them.

* * *

The smallest number of the mentally retarded—but those requiring the greatest personal care—are the severely and profoundly affected.

Some of the brighter members of this group can be trained to do productive work under immediate supervision—an accomplishment most people had never before thought possible.

Sixteen-year-old Ron, for instance, is now happily engaged in placing light bulbs in paper cartons for an electric company that contracted the job to a sheltered workshop.

No light bulbs ever received more tender handling.

The workshop is supported by the local vocational rehabilitation office, in partnership with the local association for retarded children.

In the evenings, Ron returns to the state school where he lives, traveling by a bus provided by the men's group of a church.

He makes enough to provide him with some spending money, and last year a local civic organization took the workshop employees on a Christmas shopping trip. For the first time in his 16 years he was able to buy his parents a Christmas present with his own money. It was the proudest day of his life.

Ron has only partial vision, blurred speech, cerebral palsy, and a very low I.Q. Despite these massive handicaps, he has at last found a purpose in life.

Without the help he has received, Ron might have sat day after day after day on a long bare bench, staring at the long gray walls of a back ward.

Just as thousands like him are still doing.

* * *

The profoundly retarded require a great deal of care and training. For centuries it was thought that all that could be done was to feed them and try to keep them clean. It requires dedicated and constant effort for the nurses and attendants of many understaffed institutions to fulfill even these minimum human requirements.

"There were wards with the completely helpless who cannot turn themselves over

in bed, much less feed themselves; wards with poor tormented souls constantly on the move, as if on a never-ending search for a peace they would never find; wards with quiet little old ladies who from time to time would come back from the private worlds they had occupied for twenty years. . ."

"And finally—and most important—there were the children. . ."

That is a description of a hospital for the severely and profoundly retarded in the words of a state legislator after his first visit to such an institution—"a chastening experience on a bright blue, cold day."

But even here, there is hope, and dramatic change for a fortunate few.

Betsy now dresses and undresses herself, feeds herself and goes to the toilet alone. Not very remarkable for a ten-year-old. But Betsy is profoundly retarded. Seven weeks earlier she could do none of these things.

Because the staff had faith that she was capable of benefiting from training, she was chosen for a special experiment in behavior modification. With infinite patience, step by step, an attendant trained her to feed herself, undress, dress, and go to the toilet, with rewards for the most microscopic accomplishment in each phase of the training.

This promising technique, based on rewards for desired behavior, is being introduced into several institutions for the retarded not just as a pilot study, but as an ongoing part of the total program.

Ward attendants and nurses are seeing many of their charges become changed, socialized human beings. Many more are capable of achieving these goals.

But what hope is there for those much worse off than Betsy? Children like Harry, restrained in his crib for self-protection, his body wracked with convulsions coming at the rate of one every three minutes, twenty-four hours a day.

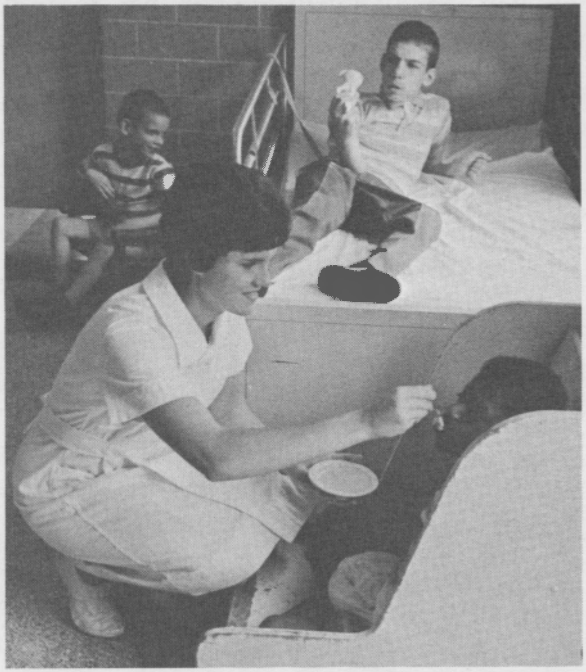
Modern science has not been able to find the answer, and medicine hasn't worked for this child.

But something else is working. A foster grandmother. In fact, a team of foster grandmothers and grandfathers who come into the hospital on four-hour shifts around the clock to take him out of his restraints and hold him, rock him, talk comfortingly to him—and love him.

The convulsions have ceased.

For the first time he is responding to people. Time will tell how far his progress will go. There is hope for others like him.

There are other signs of progress on the institutional scene. Rehabilitation services are starting to move in—and are moving out some who have been patients for 20 years or more. These patients need a great deal of help and supervision, social and job training, but the success is more than worth the effort—and results in substantial savings after the initial investment.



Some go through a period of living in a half-way house and then entering the "outside world." Others work by day in sheltered workshops, business or industry and return to the institution at night. Still others are moving into boarding homes set up specifically for the adult working retarded person, who joins a family of others like himself, with a "mother and father" in charge.

Now they can become producers as well as consumers—and individuals who have found their human dignity.

PREVENTION

The kind of mental retardation that has a physical cause is being attacked on the medical front. Large investments in biomedical research are paying off.

If you are in the child-bearing years, take advantage of the findings, and protect yourself and your children with these measures:

- Guard against rubella (3-day German measles) that can be severely damaging to the fetus when contracted by the mother during early months of pregnancy. Check with your physician regarding immunization.

- Have your children vaccinated against the 10-day measles, a disease that can cause brain inflammation and resulting retardation.

- Insure against results of untreated kidney or bladder infections, thyroid disease and diabetes by being under medical care throughout pregnancy. These diseases often have few or no symptoms, but can cause abnormalities in the baby.

- If genetic counseling is available in your community take advantage of it before conception, especially if there is any abnormality in either parent's family, or if you have had a defective child.

- Protect against x-rays and other radiation exposure for both mother and father before conception, with special precautions for the mother during pregnancy.

- Avoid all drugs during pregnancy except those your doctor prescribes. Certain drugs may cause deformities, and some otherwise harmless drugs in combination with others can result in defects.

- If blood tests at any time indicate venereal disease for mother or father, get treatment immediately.

- Have prenatal tests to discover any incompatible blood factors, and take advantage of the latest treatment available.

- Eat a balanced diet throughout life.

- Have your baby checked for inborn chemical errors immediately after birth. Some can be corrected.

Among other known causes of defects are: Problems caused by prematurity and birth injury; certain infections and viruses, prolonged high fever, inadequate diet and physical injury during pregnancy.

The nine months of gestation and the first three to four years are the most crucial in our entire lifetime.

Good nutrition and health care are vital. But a whole person is one whose mind and emotions as well as his body have been richly nourished.

In the first 30 months, when the child is normally learning to talk, the tone is set for later learning and emotional experience. In that most impressionable period, individuals are patterning their response to life as they perceive it through their senses and through the immeasurable relationship with another human being.

This bond cannot be defined, but it is expressed in a thousand ways—holding the baby close, cuddling, talking, smiling, rocking, playing, perhaps singing or cooing to him.

Simple and obvious? For many, yes. For others, not so obvious. Or perhaps not so simple. The struggle for survival among the poor can often crowd out all other considerations, leaving little time or room for individual attention.

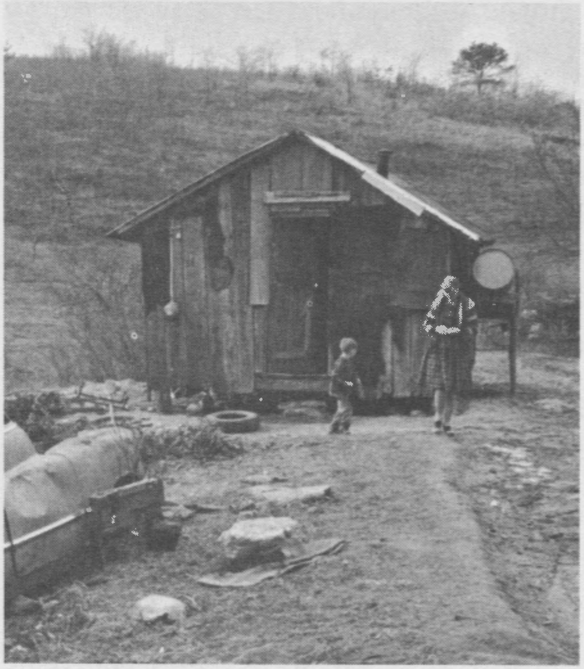
The kind of mental retardation that is caused by deprivation is widespread in poverty areas. It runs in families only in the same way in which crowding, malnutrition, ignorance and unemployment run in families.

Those affected are not all in city slums. They are in the hills and hollows of Appalachia, too, and in Louisiana bayous, in sharecroppers' shacks in Oklahoma, in migrant work camps in California, on Montana Indian reservations, and in disadvantaged homes across the nation.

There is a greatly increased danger of pregnancy complications among the poor, a higher incidence of prematurity and problems at the time of birth, such as breathing difficulties, convulsions and circulation disorders.

These troubles, in turn, very often lead to mental retardation, and varieties of physical defects and weaknesses.

Government and private programs which encourage economic development, improved



education, job training, equal opportunity, better housing, rehabilitation, maternal and child care are all related parts of the combined attempt to prevent mental retardation so widespread among the poor.

TO THE PARENTS

. . . of a retarded child.

The first big hurdle is getting over the initial shock of being told that your child is retarded. There is no need for shame or guilt. These emotions drive parents into either rejection or over-protectiveness, and both can often be more emotionally damaging to a child than the retardation.

Mentally retarded children have been born into families in all walks of life—from the richest home to the poorest slum dwelling.

"Shopping around" for a physician to revise the diagnosis is usually futile. However, rather than determine your child's future on the basis of one opinion, it is advisable to have a team of professionals examine him. His hearing, vision and neurological system need to be tested, in addition to his intelligence.

The most thorough professional teamwork is most often found at a clinic attached to a university, or a community diagnostic and treatment center. If there is neither in your area, ask your doctor to consult with specialists to confirm the diagnosis.

Then if the final diagnosis is positive, accept it—as a challenge, not as a problem. And know that you are not alone.

Investigate all of the health and education services for the retarded offered in the community. If adequate help is not available, join with other parents to start action. This

Mrs. Hubert Humphrey with her granddaughter, Vicky Solomonson, who is mentally retarded.

is the way many such community services began.

If you are the parent of *a retarded adult,* you are probably concerned about his future. What will happen when you can no longer care for him?

As yet, there is no easy answer.

Some states are now building group homes, often called hostels, for dependent, retarded adults.

The best long-range solution is concerted citizen action. There is a need for foster parents, special group living facilities, and a life-long guarantee of sheltered living conditions in each community for those unable to lead independent lives.

VOLUNTEERS

Volunteers are needed to:

- transport the retarded to and from clinics, preschool programs, day care centers, sheltered workshops, recreational activities;
- help them develop through sports and recreational programs;
- work as aides in residential homes for the retarded;
- help in day care centers, clinics, preschool nurseries, special education classrooms, private tutoring, sheltered workshops, offices, labs;
- relieve mothers of retarded children by sitting with them or taking them on outings;
- help the retarded find jobs in the community.

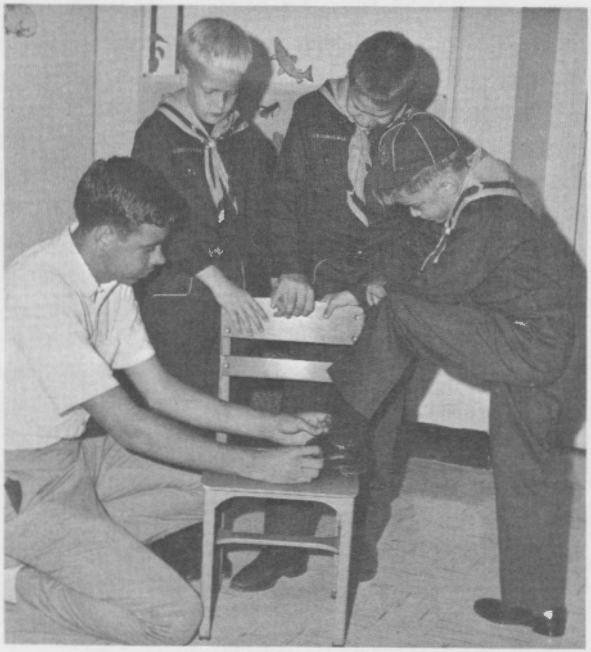
Among those already doing volunteer work with the retarded are local chapters of the Association for Retarded Children, Civitans, Junior Chamber of Commerce, 4-H Clubs, the American Red Cross, churches, synagogues, and other civic and fraternal organizations. If there are no such activities in your area, the Association for Retarded Children will help you start them.

Volunteers *under 21* can join the fast-growing numbers of young people working together with great success to help the mentally retarded live fuller, more enjoyable lives. Get in touch with YOUTH–NARC, 2709 Avenue E East, Arlington, Texas 76011 .

Young people across the country are taking an active—and most effective—role in changing the lives of the retarded through recreational activities, sports, tutoring, fund raising, and drives to inform the public about mental retardation, as well as bringing new life into institutions and "disturbing dusty old ways of thinking," as one hospital administrator put it.

CAREERS

Careers for professional and supportive personnel in mental retardation and related fields



cover a wide range, including special education, psychology, sociology, medicine, and rehabilitation, to name a few.

There are new careers also opening up in mental retardation for junior college and high school graduates, neighborhood leaders, students and retired men and women.

Retired men and women across the country are becoming Foster Grandparents to the retarded with very gratifying results on both sides. They are paid on an hourly rate for about four hours a day.

The best job description of what is required comes from a mildly retarded girl who had a foster grandmother:

"They don't have to be smart, only answer questions like why dogs hate cats, and how come God isn't married. They don't talk baby talk like visitors do, because it is hard to understand. When they read to us they don't skip, or mind if it is the same story again. Everybody should try to have one, especially if you don't have television, because grandmas are the only grownups who have got time."

CONCERNED CITIZENS

If every concerned citizen or group of citizens joined forces with those already engaged in helping the mentally retarded, all of the retarded could lead fuller and more productive lives—and a great many might never become retarded at all.

These are the most important things to do:

In All Areas

Support appropriate legislation on the local, state and national level.

In Education

1. Urge your local school system to provide early childhood education, especially for deprived children.

2. Work to improve teacher attitudes toward children of the slums, and more imaginative educational techniques.

3. Campaign for more and higher quality special education and vocational training classes, with specially trained teachers, and flexible programs to allow children to move freely between academic and vocational programs, as their abilities and interests change.

4. Encourage early identification of learning problems and help for those who need it.

In Maternal and Child Care

1. Urge your family physician, your health department, or local medical group or hospital, to help set up prenatal clinics for all mothers.

2. Urge your hospital to give tests shortly after birth, to discover in time conditions which can cause mental retardation.

3. Ask your hospital, family physician or local medical group to assist in setting up programs in maternal and infant care to help prevent mental retardation.

4. Call or write your local association for retarded children to discover if your state is providing good maternity care and medical and psychological examinations of infants. Then write your legislator and other government officials to support these programs.

5. Organize groups to provide transportation to clinics for under-privileged mothers, or to supervise nurseries where they can take their children while they attend the clinics.

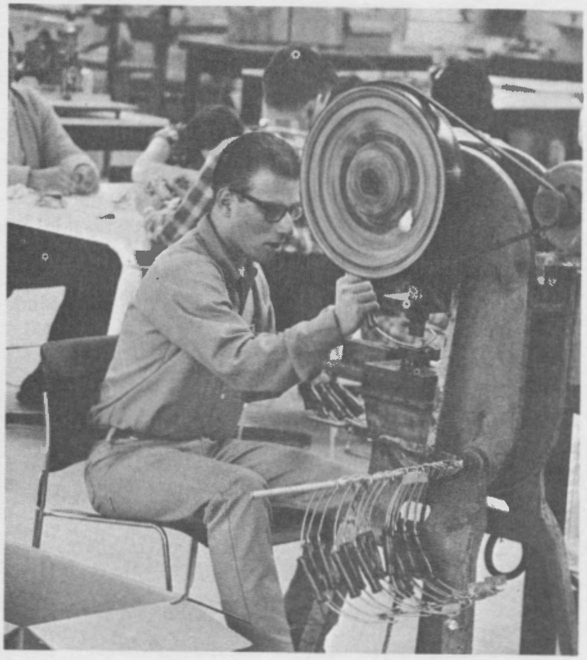
EMPLOYERS

The shirt you are wearing may have been laundered and packaged by a mentally retarded worker.

Your child's favorite toy was probably made by a mentally retarded employee.

The wiring on your television set, the meal you enjoyed on your plane flight, the new upholstery on your sofa—all these things the mentally retarded could have had a hand in accomplishing. For these are but a few of the industries successfully using retarded workers.

In fact, this pamphlet may have reached you with the help of a mentally retarded person employed by the Post Office—one of



thousands working in the U.S. Government.

Employers are learning that it isn't charity to hire the mentally retarded. It's good business.

They are happy doing the monotonous but necessary chores that are often the cause of a high rate of job turnover, frequent absences and frustration—problems that eat into the managerial budget.

When properly trained for a job they feel competent to do, they make fewer job changes, have a lower absence rate, are more punctual, and are generally more conscientious than the average worker.

The mentally retarded, however, are not all alike. Although the majority prefer routine, repetitive jobs, there are many with special skills who are producing genuine works of art, etching on glass, painting, sculpture, industrial and fashion design.

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The best place to start in helping the retarded is with YOU. Whether or not you work with them as a volunteer or in a career, whether you hire or fire them, if you accept them as fellow human beings, their battle is half won.

They need respect—not pity, nor overprotection, nor babying. Though they also need your financial support for education and training, treatment and care, they need you even more. No amount of money or trained manpower can substitute for the most needed commodity of all—and the most successful—a person who cares. The rewards are great.

★ ★ ★

The Committee expresses its appreciation to the following for the use of their photographs:

- Gracewood State School, Atlanta, Georgia
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- National Association for Retarded Children
- David Warren
- Jim Wells

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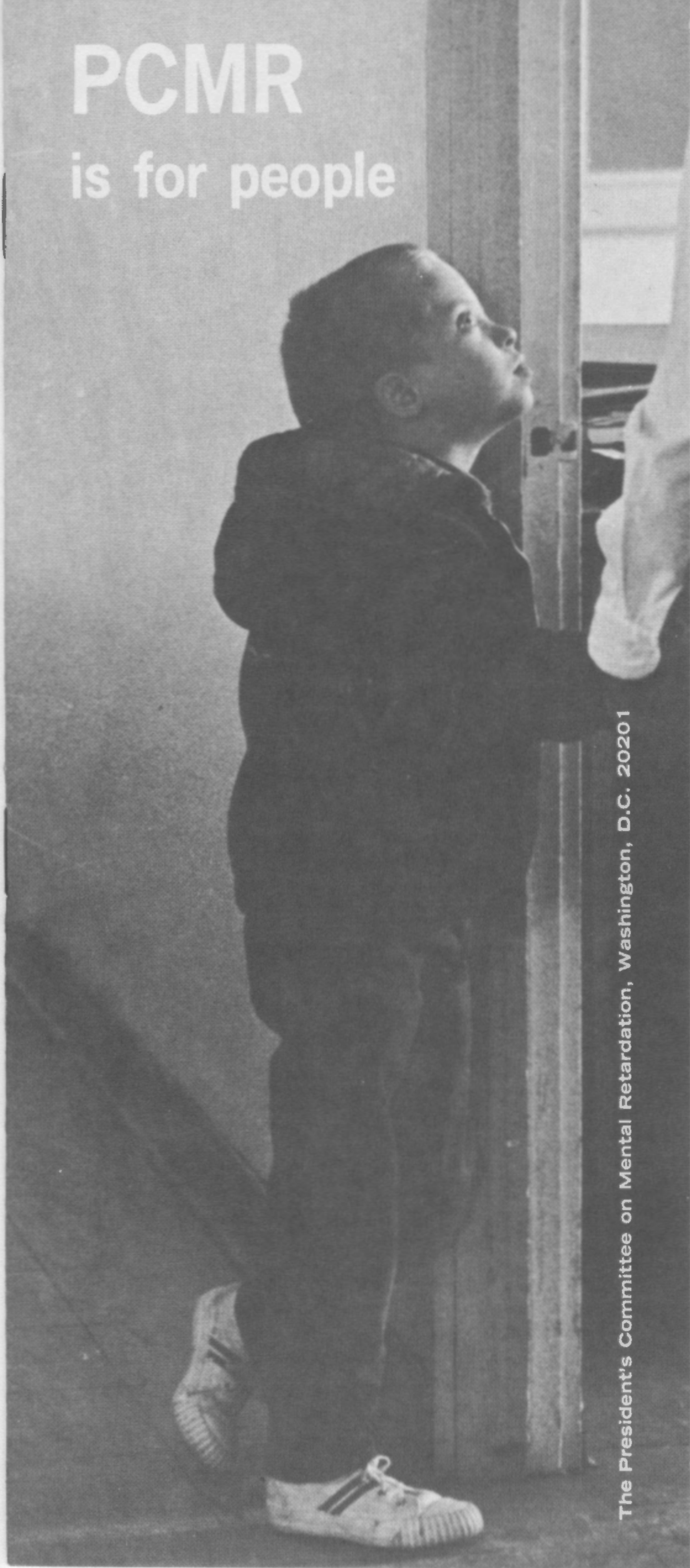
National Association for
Retarded Children
2709 Avenue E East,
Arlington, Texas 76011

Asociacion pro Ninos Retardados de
Puerto Rico
G.P.O. Box 1904, San Juan,
Puerto Rico 00936

Canadian Association for the
Mentally Retarded
Kinsmen Bldg., York Univ. Campus,
Downsview, Ontario

The President's Committee on
Mental Retardation
Washington, D.C. 20201

PCMR
is for people



The President's Committee on Mental Retardation, Washington, D.C. 20201

"The important thing is to integrate the retarded as much as possible into normal activities and services rather than separate them . . .

. . . In this particular field you can do so much to change the life of an individual, to make his life better."

PRESIDENT RICHARD NIXON
to PCMR Members at the
White House, January 19, 1970

DHEW Publication No. (OS) 72–21

The PCMR Mission

Six million Americans, it is estimated, are mentally retarded in varying degrees.

For them and their families, this condition can bring great tragedy.

For the nation, its toll is staggering in lost productivity and cost of special care.

To focus the full efforts of government and citizens on this problem, the **President's Committee on Mental Retardation (PCMR)** was established in 1966.

The committee is a group of prominent citizens named by the President to assist him in translating his concern for the retarded into effective measures of

- Research and Manpower Development
- Prevention
- Service
- Information

The Committee is chaired by the Secretary of Health, Education, and Welfare. The Secretary of Labor and the Director of the Office of Economic Opportunity also serve. Twenty-one citizens are appointed to three-year terms, with one-third of the appointments expiring each year.

The citizen members undertake their Committee duties in addition to their normal occupations as physicians, educators, attorneys, businessmen, etc. To assist them and provide continuity of operations, a small professional staff functions at Washington headquarters, and a number of consultants are retained to provide expertise in specialized fields.

The President Orders . . .

The Executive Order establishing the Committee assigned it three tasks:

1 To advise and assist the President on
   a evaluation of the adequacy of the national effort to combat mental retardation
   b coordination of Federal activities in the field
   c liaison between Federal activities and those of other public and private agencies
   d development of public information to reduce the incidence of MR and ameliorate its effects.
2 To mobilize professional and general public support for MR activities.
3 To report to the President at least annually.

To Meet These Needs

Committee activities carrying out these assignments include:

- **Issue-oriented work conferences of leaders in the various fields having an impact on MR.**

Example: The March 1971 conference to take a fresh look at the whole process of placing children in special education programs for the mentally retarded.

- **Publications highlighting areas where action is needed.**

Example: "Residential Services For The Mentally Retarded: An Action Policy Proposal."

- **Collaboration with other Federal agencies in developing action programs.**

Example: With the President's Committee on Employment of the Handicapped, formulated a 39-point action program on habilitation and employment of the mentally retarded.

- **Campaigns to increase public awareness of mental retardation needs.**

Example: Through the cooperation of The Advertising Council, many magazines, radio and TV stations donated $40 million in free space and time for public service messages from PCMR.

- **Sponsorship of studies on fundamental issues in mental retardation.**

Example: A biologist has been assembling all available knowledge on the relationship of malnutrition to retardation.

- **Convening state and local officials and professional groups to consider special needs of the retarded.**

Example: A Law and Ethics work group of PCMR is planning regional conferences of law enforcement officers and members of the bar on the rights of the retarded when they come into contact with "the law."

- **Developing recommendations to the President for new programs which can prevent or ameliorate retardation.**

Example: The Committee formulated a proposal for a research institute that would explore the little understood learning process in terms of both the biological and behavioral forces, and their relationship. The President adopted (and adapted) this proposal as a key feature of his education message.

And For Tomorrow

PCMR has launched a "new thrust" program, which emphasizes the human ecology aspects of retardation. With mounting evidence that a high percentage of cases labeled mental retardation stems from environmental causes, the Committee seeks to mobilize all available resources of research and manpower for an attack on those causes. The attack will be multi-faceted, dealing with such questions as:

- How can we make available to prospective parents the information and services that will give them the best chance to produce normal children?

The answers will require exploration of vaccination and other measures to prevent infections of the mother which can cause retardation in the child; of nutritional and other pre-natal care that will help prevent retardation; of new genetic techniques, such as prediction of defects by examination of the amniotic fluid surrounding the fetus.

- How can we improve the quality of life during the first few years so that "retardation" will not develop?

We must seek answers in such directions as enriching the child's experience with new stimuli (e.g., Head Start programs); guarding his physical well-being (e.g., the Health Start concept of the Office of Child Development); and making possible an adequate nutritional level (e.g., the Family Assistance Plan).

- How can we keep those who start school with some mental handicap from falling further and further behind until they may develop emotional and behavioral as well as educational problems?

Answers may lie in finding better techniques of measuring ability than I.Q. tests without regard for adaptive behavior or cultural or language background; in providing special education classes for the half of the nation's school districts now without any; and in the improvement of our total education system through application of those innovative methods which have worked best in controlled tests.

- How can we provide an environment in which the mildly or moderately retarded can live in the community as productive members?

Here we must collect and make widely known the best models of new techniques in group homes, recreational programs, job-finding, and counseling service on personal problems.

- How can we mobilize Federal agencies for a coordinated attack on mental retardation?

PCMR has begun a systematic exploration of the varied Federal resources which can be brought to bear. If, for example, new types of living facilities are needed to keep the retarded in their home communities, can the Department of Housing and Urban Development help?

- Can private agencies not specifically concerned with MR make a contribution?

Voluntaryism is a major factor in American life, and PCMR plans to seek broader participation in MR activities by national voluntary or professional organizations. The aim is to provide a fuller life for the retarded through sports, camping, recreational and other programs.

How You Can Help

The job of combating mental retardation cannot be done by government alone.
As a good citizen, you can:

JOIN WITH OTHERS in your area to promote services and better understanding for the mentally retarded.
Contact your local association for retarded children, Civitan Club, Junior Chamber of Commerce, public school special education department, community recreation department, or community volunteer office.

BRING COMMITTEE RECOMMENDATIONS to the attention of public and private agencies for appropriate consideration.

STIMULATE INVOLVEMENT of area professional groups—medical society, bar association, etc.—in special mental retardation projects related to their professional concerns.

BECOME A TEACHER OF THE RETARDED. Contact your local college or university for information.

YOU CAN HELP—IN SO MANY WAYS.

U.S. GOVERNMENT PRINTING OFFICE: 1972 O—460-240

ORDER BLANK

Please send me the publications of the President's Committee on Mental Retardation checked below, to address on other side.

☐ **HELLO WORLD. Popularly written general information booklet, with retarded individuals illustrating levels and kinds of retardation, causes, means of prevention and aid.**

☐ **TO YOUR FUTURE WITH LOVE. For young people seeking meaningful volunteer and career opportunities. Many experiences are told by volunteers in their own words.**

☐ **THESE, TOO, MUST BE EQUAL. Describes America's needs in habilitation and employment of the mentally retarded, and lists proposals for action.**

☐ **RESIDENTIAL SERVICES FOR THE MENTALLY RETARDED: AN ACTION POLICY PROPOSAL. A proposed statement on residential services for public and professional review.**

☐ **MR 71: ENTERING THE ERA OF HUMAN ECOLOGY. A report on the interrelated genetic and environmental factors that cause mental retardation, with indications of what PCMR is doing about such problems as lead poisoning, genetic damage, and legal rights, among others.**

☐ **MANPOWER AND MENTAL RETARDATION—AN EXPLORATION OF THE ISSUES. Proceedings of a joint United States-Canada Conference: 1970.**

☐ **A VERY SPECIAL CHILD. Report of a conference on placement of children in special education programs for the mentally retarded, with recommendations on restructuring testing process.**

☐ **INFORMATION OFFICE NEWS CLIPPING SERVICE. Topical clippings from the mental retardation field nationwide.**

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The President's Committee on Mental Retardation
Washington, D.C. 20201

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The President's Committee on Mental Retardation
Washington, D.C. 20201

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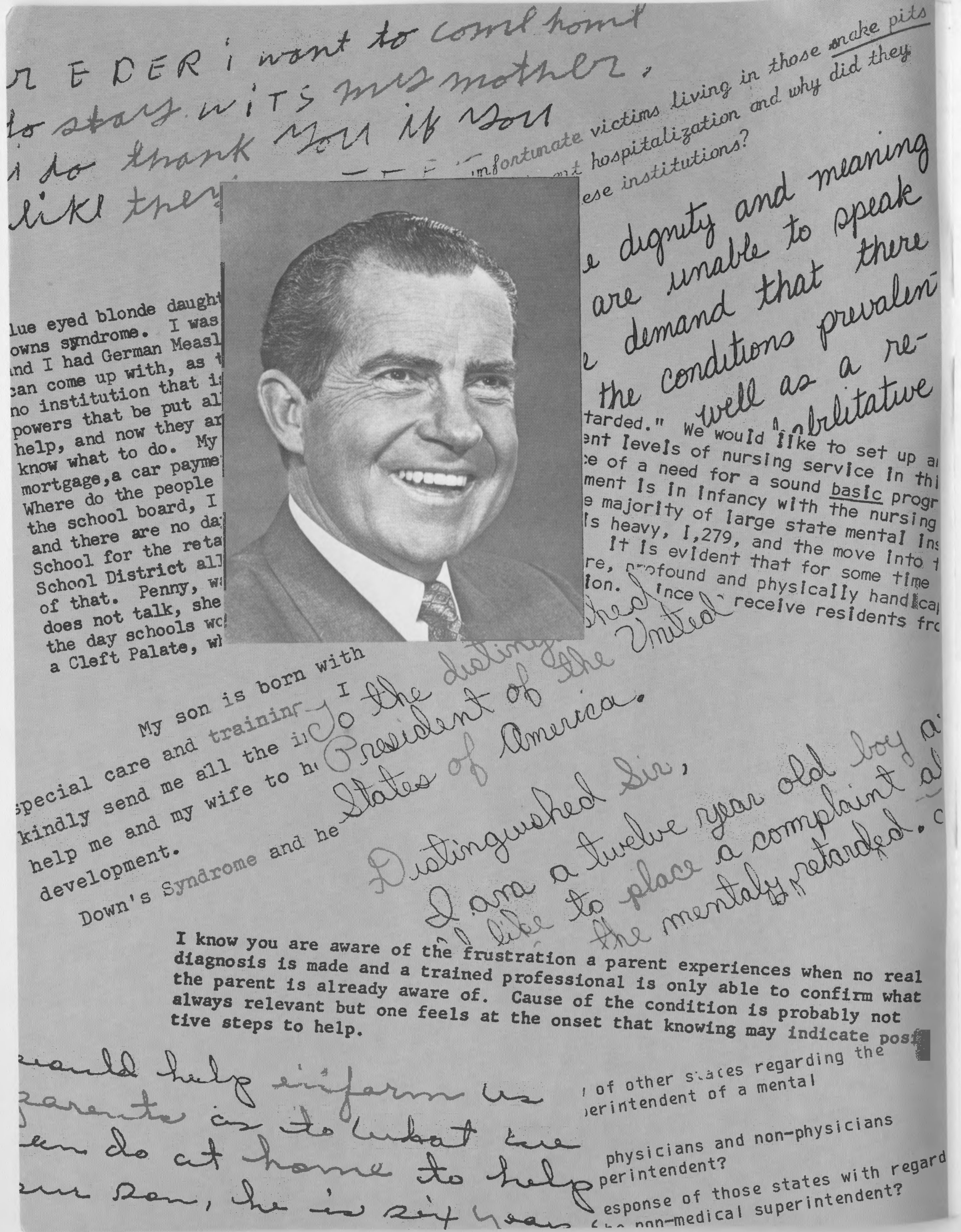
mr 72

ISLANDS OF EXCELLENCE

Report of the President's Committee on Mental Retardation



r EDER i want to come home
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My son is born with
special care and training I
kindly send me all the i
help me and my wife to h
development.
Down's Syndrome and he

To the distinguished
President of the United
States of America.

Distinguished Sir,

I am a twelve year old boy a
like to place a complaint a
the mentaly retarded.

I know you are aware of the frustration a parent experiences when no real diagnosis is made and a trained professional is only able to confirm what the parent is already aware of. Cause of the condition is probably not always relevant but one feels at the onset that knowing may indicate positive steps to help.

would help inform us
parents as to what we
can do at home to help
our son, he is six years

of other states regarding the
perintendent of a mental

physicians and non-physicians
perintendent?

esponse of those states with regard
non-medical superintendent?

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
pcmr

The President's Committee on Mental Retardation, Washington, D.C. 20201

The President
The White House
Washington, D. C.

My dear Mr. President:

It is my pleasure to transmit to you the sixth annual report of the President's Committee on Mental Retardation. In doing so, I pay tribute to the leadership of Elliot L. Richardson as Chairman during the past two years.

Two major national goals, outlined by you in meeting with the Committee, form the theme of this report:

- To reduce by half the occurrence of mental retardation in the United States before the end of this century:
- To enable one-third of the more than 200,000 retarded persons in public institutions to return to useful lives in the community.

The following report, MR 72, Islands of Excellence, presents a number of national, state, regional, and local programs that typify the positive approach to prevention and alleviation of mental retardation.

They are not necessarily the best available--although some are--but each is an example of what can be done throughout the nation. As islands of excellence, they emphasize the point that only a relative few now benefit from current knowledge of human development, biomedical technology, and a respect for human dignity.

One vehicle that promises to expand these benefits is the growing interest in legal rights for the retarded. To further this interest, the President's Committee on Mental Retardation has called a National Legal Rights Conference to be held in the spring.

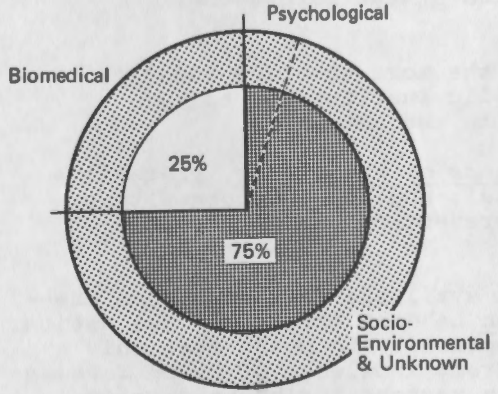
Another means to achieve national impact is the potential uncovered by the Federal agency review that the Committee conducted at your request. The review has revealed untapped resources in departments throughout the Federal Government, requiring only coordination and application to retardation to be effective in this field.

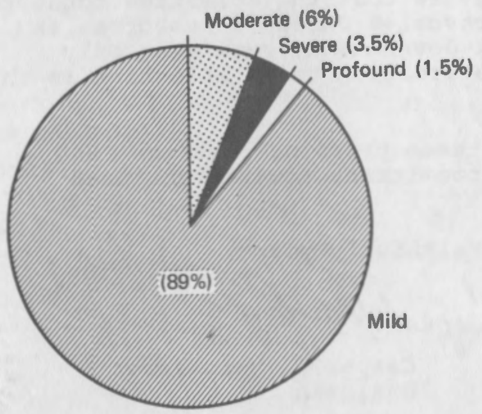
We appreciate your leadership in these pressing problems, and look forward to your support and commitment toward continued progress.

Faithfully yours,

Caspar W. Weinberger

Caspar W. Weinberger
Chairman


MENTAL RETARDATION BY CAUSE


CLASSIFICATION OF THE MENTALLY RETARDED POPULATION

Contents

TOWARD A LIFE OF QUALITY

EASING THE BURDEN

INTO THE COMMUNITY

The President's Committee on Mental Retardation
Washington, D.C. 20201

DEW Publication No. (OS) 73–7

THE increasing emphasis on State, regional and local responsibility in planning, funding and provision of services makes it imperative for those in the field to be informed of what is NOW being done well for a few, and should be available to all.

Included in this report are programs that are representative models in prevention and treatment of mental retardation. There are many others equally deserving of recognition. The main point, however, is that services of such high quality are reaching only a small percentage of the population.

TODAY we have the biomedical technology and the knowledge of human development to begin to approach the President's goal of reducing by half the occurrence of both organic and functional retardation.

Thousands of children may escape becoming statistics in future reports on mental retardation because their minds were stimulated early enough to provide them with a firm base for learning (pp. 7, 18). Others will be born mentally and physically sound because of preventive measures taken during their mother's pregnancy and their infancy (pp. 8, 11, 15).

The efforts toward prevention described in these pages, however, are not sufficient. For the most part, we fail to communicate, to finance and to apply the biomedical technology and the information on human development we now have. Too many universities, hospitals, classrooms and social agencies are teaching and practicing long outmoded theories.

TODAY we know how to ease the burden of mental retardation for those who are affected.

There is substantial evidence from the report on treatment of severely and multi-handicapped children (p. 26) that there are very few—if any—"hopeless cases." Helping them takes adequate staffing by trained professionals and paraprofessionals. And the desire to help them. We no longer have the excuse of not knowing how.

The responsibility does not end with diagnosis and evaluation. It begins there. Inestimable suffering, human waste and public cost could be saved by early evaluation, diagnosis and treatment, *followed by community services for each child who is potentially handicapped* (pp. 11, 15, 22, 31).

Given the right services at the right time, most such children could become productive adults, leading lives of dignity.

Yet a survey of State education agencies completed in 1971 by the National Association for Retarded Children found that not more than 60 percent of retarded children are being served in *any* State. One State is currently meeting the educational needs of only 15 percent of retarded school-age children.

TODAY we know how to meet the President's goal of successfully returning to the community at least one-third of the more than 200,000 retarded children and adults now in public institutions.

Programs in Connecticut (p. 37), Nebraska (p. 42), Wisconsin (p. 43), Pennsylvania (pp. 46, 47) are showing the way to normal living for the retarded. Participants overwhelmingly prefer them to the inhuman warehouses that are so deplorably prevalent. And the net cost of normal living to the taxpayer can be less.

Most of the examples included in this report are not only models worthy of duplication (and capable of being duplicated), but are also reflections of major national trends, harbingers of the future that all may someday enjoy.

Among those broad trends:

- An increasing awareness of the fact that $1.00 spent for prevention is worth $1,000 spent for warehousing or wasted lives.
- Growing appreciation of the need for parent education and enrichment programs in early childhood based on human development concepts.
- New approaches to education, extending the "learning years" both earlier and later than the rigid "school years," with no time limits, no rejections, no categorizations, and no labels.
- Concentration on the learning process itself, with an emerging change in definition of learning disabilities that encompasses all learning problems, with varying degrees of competence considered.
- Restructuring of medical training and practice, with interdisciplinary emphasis, and teamwork of many professionals and ancillary personnel in treating the whole person within his environment.
- Growing recognition of the rights of retarded individuals, as evidenced by the myriad court cases regarding their civil rights.
- Recognition that consumer action can often achieve results before court action becomes necessary.
- Moves toward community agencies sharing the responsibility to provide more normal living conditions for retarded children and adults, with residential institutions providing back-up services, if needed.

These trends can be accelerated only if professional training is brought up to date with what is actually taking place in many hospitals, schools, institutions, and group homes.

Despite the fact, for instance, that education in the classroom is moving away from the categorical approach, very few regular classroom teachers are given training in teaching the handicapped children coming into integrated classrooms.

Although there are exemplary cases of cross-pollinization in higher education between the department of human development and regular or special education, many universities still lack the integrated approach. In an attempt to compensate for this lack, some elementary schools are now reeducating their teachers in developmental concepts, through in-service training.

"We know the priorities," said the head of a large State university's education department. "We need the resources to fit them to the priorities. Meanwhile, we have to answer the needs of those on our doorstep."

Another problem in education involves decision-makers in State departments of education. There is an emerging development of in-service training programs for the professionals already employed in these departments, to bring them up to date with what is often already happening out in the field—or could be happening if they were aware of the possibilities.

Arthur Tress

In the medical field, obstetricians and pediatricians, to name just two disciplines, are learning more on the front lines than in medical schools how their responsibilities interrelate and overlap. And many of the more progressive medical centers are joining the social worker and public health nurse with the medical team.

"We know the priorities. We need the resources."

In residential care, also, the gaps between theory and reality are becoming apparent.

A young psychologist in a progressive State school bemoans the fact that the training he received in higher education was far behind what was being done in the innovative institution.

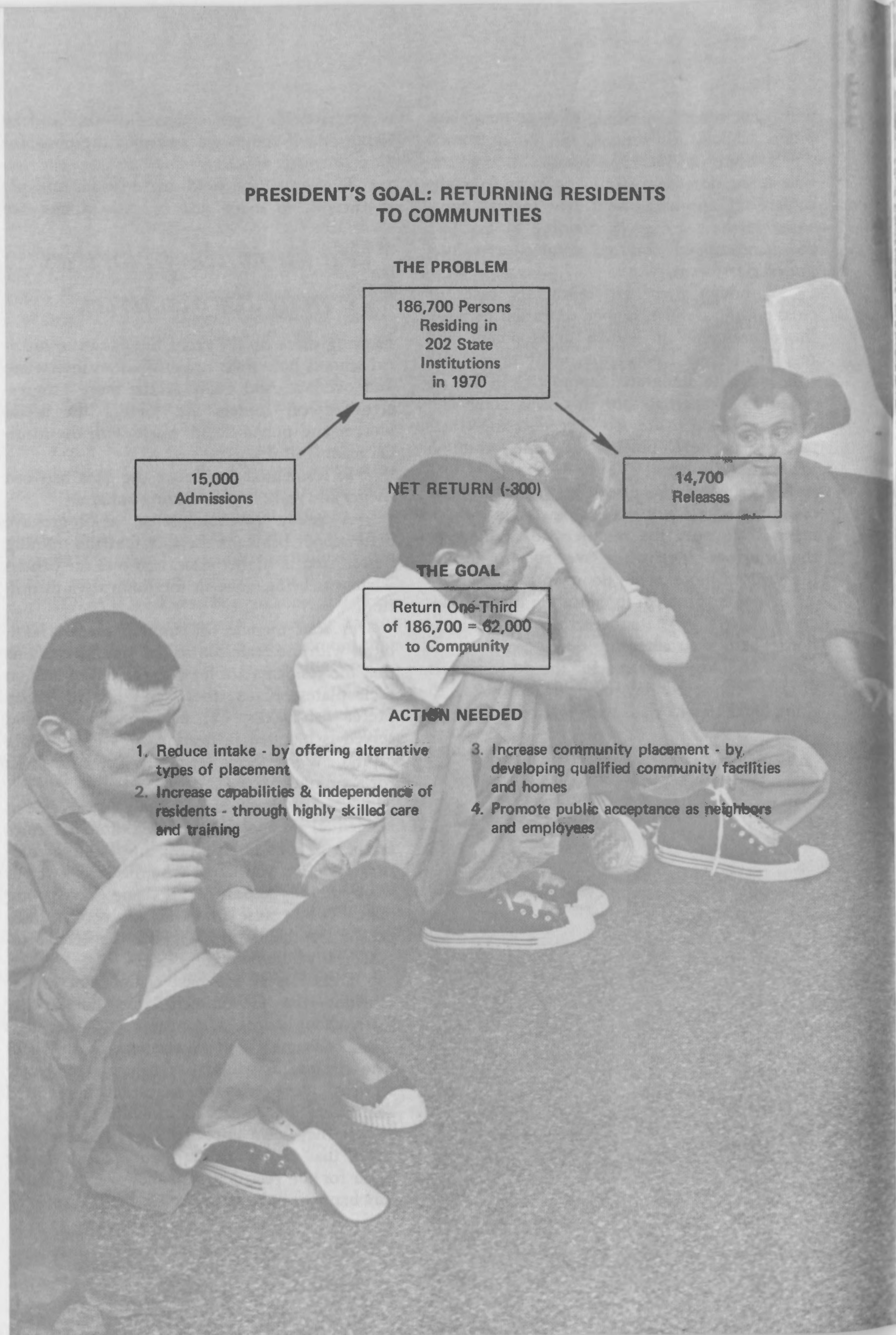
A staff member of another State school, bitter with the State-controlled system, explains that the residents are leaving the baked fish on their plates because they don't like it. "They prefer fish sticks, but every ounce of food served is planned in headquarters in the State capital. We've been trying to get fish sticks for six months now."

The newer generation drawn to service in residential care complains of outmoded rules and regulations imposed by out-of-date administrators. "Do you know why the girls want to work in the laundry?" asks one such young man. "It's because that's the only place they get to see the boys. They don't even eat together. It's inhuman!"

Direction in the past came from higher echelons—the Government, the universities, State school boards, administrators. Today, it is often consumers and newcomers to the field who are leading the way, pressuring for better services, more relevant education, integrated health care, and respect for individual rights.

If they seem impatient, it is because they *know* that the world can be made a better place for the retarded, and they want to make this happen, not "someday" but NOW.

PRESIDENT'S GOAL: RETURNING RESIDENTS TO COMMUNITIES



THE PROBLEM

186,700 Persons Residing in 202 State Institutions in 1970

15,000 Admissions

NET RETURN (-300)

14,700 Releases

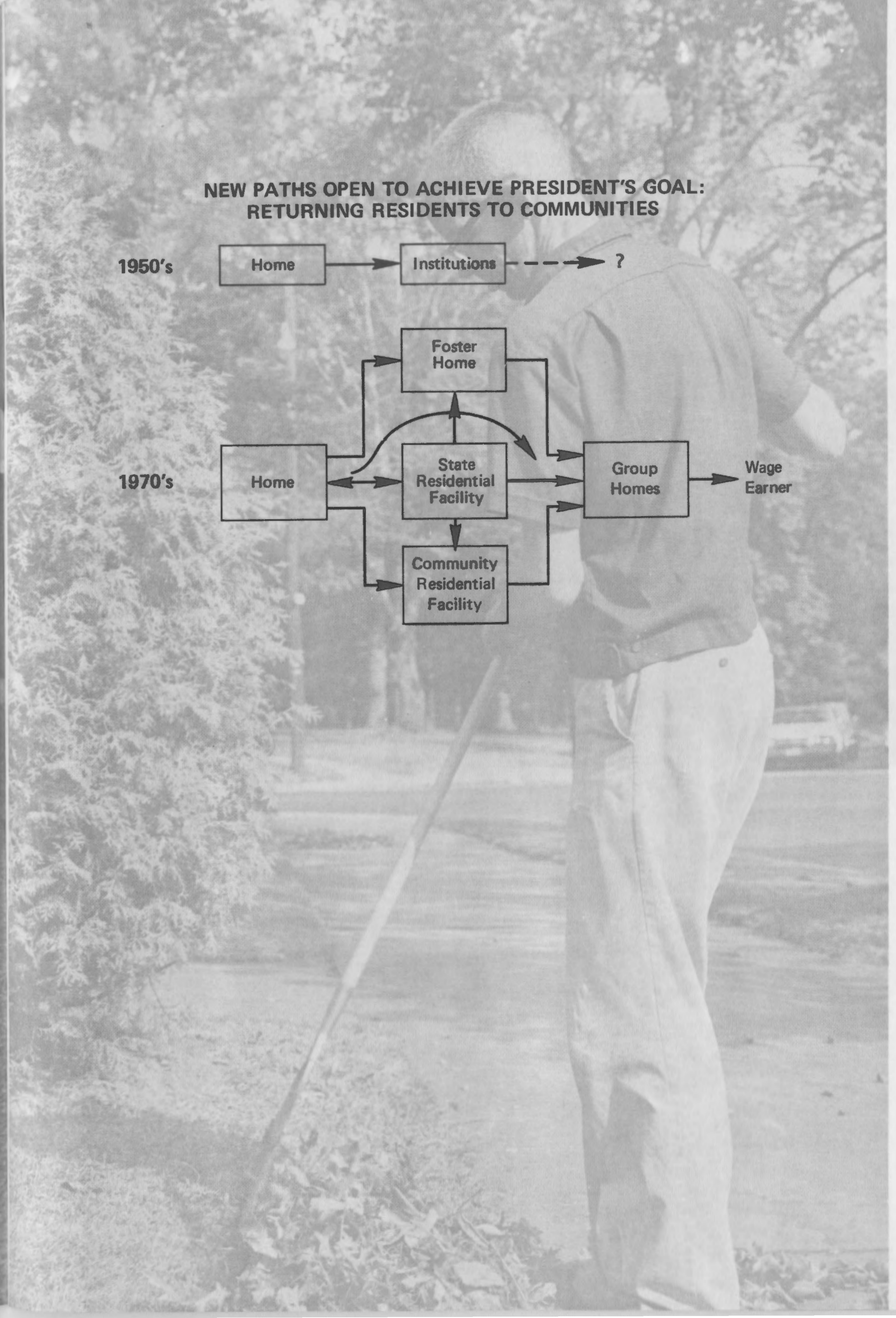
THE GOAL

Return One-Third of 186,700 = 62,000 to Community

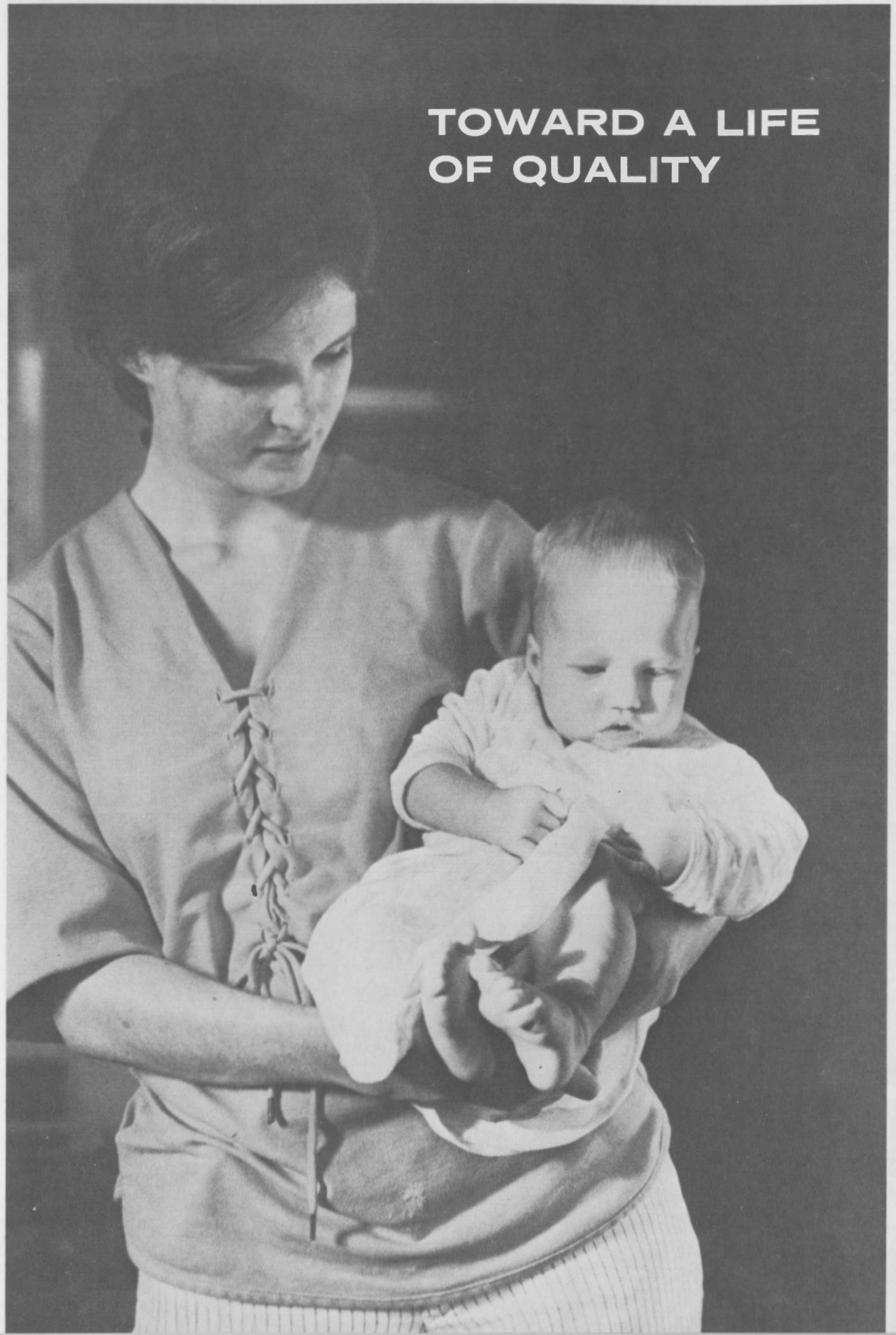
ACTION NEEDED

1. Reduce intake - by offering alternative types of placement
2. Increase capabilities & independence of residents - through highly skilled care and training
3. Increase community placement - by developing qualified community facilities and homes
4. Promote public acceptance as neighbors and employees

NEW PATHS OPEN TO ACHIEVE PRESIDENT'S GOAL: RETURNING RESIDENTS TO COMMUNITIES



TOWARD A LIFE OF QUALITY



Education for Parenthood

Where do you start to prevent mental retardation?

A program just launched is starting at the beginning of one aspect of the problem, with education for parenthood.

Although a substantial number of babies are born retarded because of biomedical causes, a far greater number become functionally retarded because they have been deprived of basic needs during early childhood development.

Late in 1972, HEW's Office of Education and the Office of Child Development jointly initiated a major program aimed at teaching teenage boys and girls how to become good parents potentially capable of raising children who are mentally, socially, emotionally, and physically healthy.

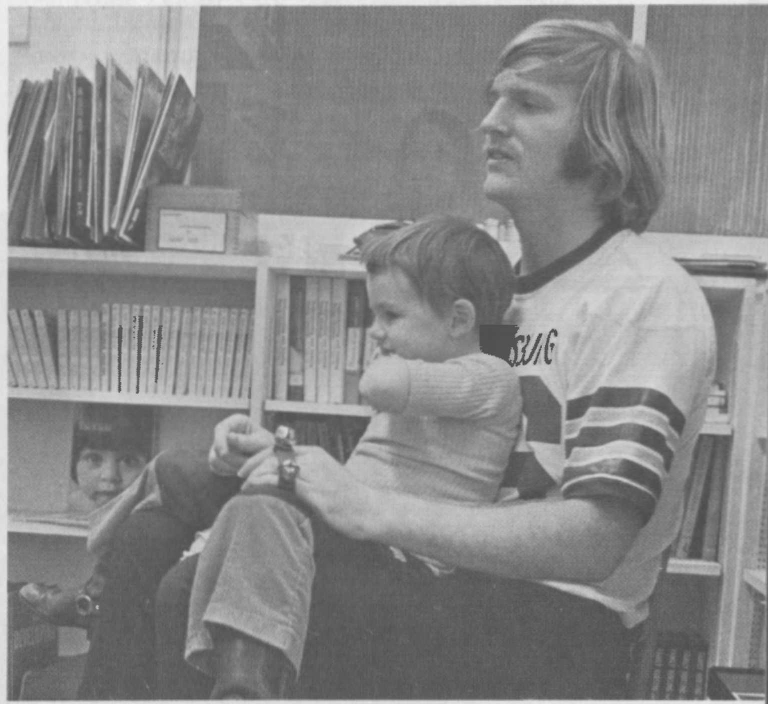
The Education for Parenthood program will begin with a large-scale plan involving several hundred school districts as well as national voluntary organizations serving youth.

The program attempts to increase prospective parents' knowledge of child growth and development; of the social, emotional and physical needs of children; and the role of parents in successful child rearing.

The Education Development Center of Cambridge, Mass., was awarded a grant to develop a curriculum for parenthood education. The curriculum combines both classroom instruction in child development and practical experience in working with young children at day care centers, Head Start programs and kindergartens.

National statistics point up the need for such education.

According to the Metropolitan Life Insurance Company, approximately 12,000 girls under age 15 gave birth in the United States in 1971—a 23.6 percent increase over the 1968 figures. This is the highest percentage increase of any age group. The next highest percentage increase over 1968 figures is in the 15-19 year-old group, who gave birth to 629,000 babies in 1971, a 6.3 percent increase.



The deprivation that so often leads to functional retardation begins just after birth. Pre-parenthood education may be one remedy that can be applied before it's too late to make up the deficit.

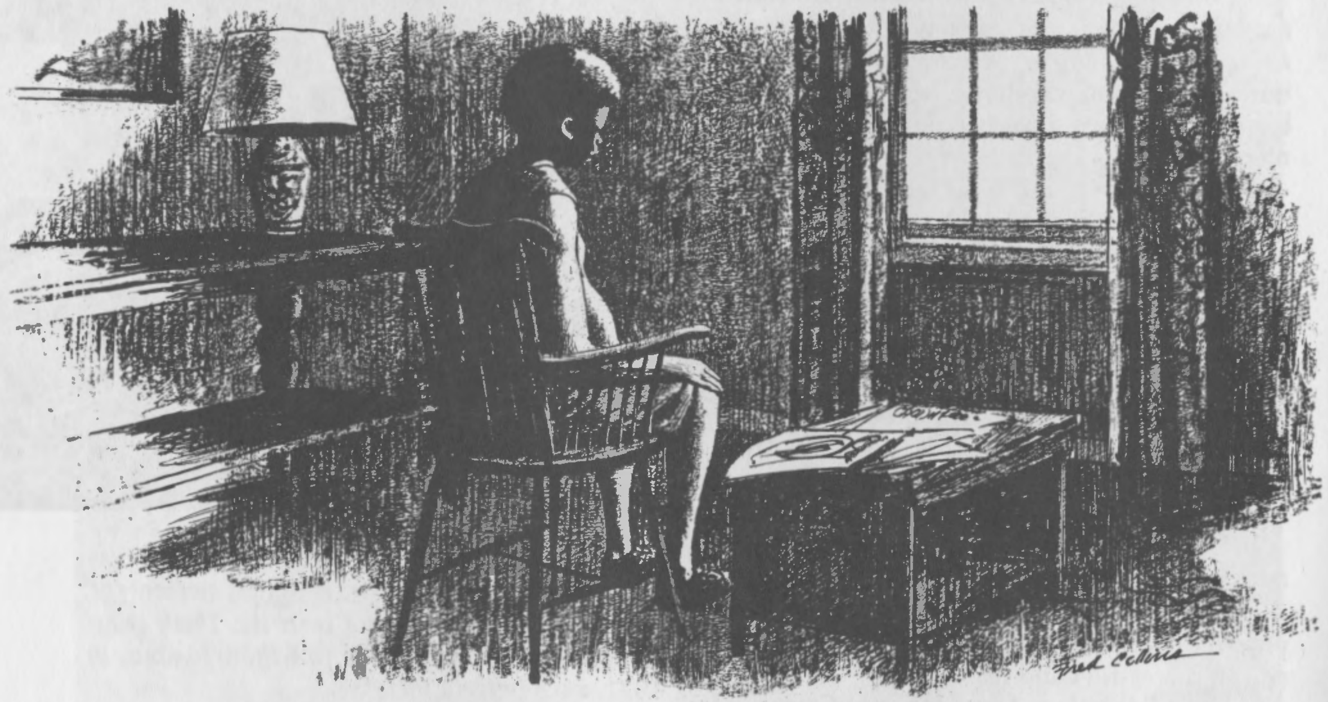
For further information, write:

Education for Parenthood
Office of Education
U.S. Department of
Health, Education, and Welfare
400 Maryland Avenue, S.W.
Washington, D.C. 20202

The Mother Is Just a Child

The frightened girl waiting to see an obstetrician at Grady Memorial Hospital in Atlanta is just 16. She is jobless, unmarried, malnourished, and pregnant with her first child. She has never used any form of contraception.

The probability is high that she will deliver prematurely, and that her baby will have a mental, physical, and/or emotional handicap.



She is the prototype of the obstetrical patient most commonly seen at Grady, which serves the indigent population of Fulton and DeKalb Counties. The two counties include metropolitan Atlanta. A large percentage of the residents of Fulton and DeKalb have recently moved in from rural areas.

Over 50 percent of Grady's obstetrical patients are under 21, reflecting the consistent, nationwide trend toward teen-age mothers.

This 16-year-old mother-to-be typifies obstetrical patients at medical centers serving those who cannot afford private care throughout the country. At Grady, she is Black; her color changes in Appalachia, the Southwest and other parts of the country, but not her lifestyle nor the outcome of her pregnancies.

The magnitude of the problem of adolescent pregnancy continues to increase. The highest percentage increase in live births by age of mother, comparing 1968 figures with 1971, appeared in the 12 to 19 age group.

Teenage mothers—under 17—produce a disproportionate number of low birthweight (under 5½ lbs) babies. Low birthweight carries an increased risk of mental retardation and is the most important single factor in infant mortality.

The adolescent's own growth requires adequate amounts of calories, protein and calcium.

> *"The cycle of poverty, ignorance, maternal malnutrition and low birthweight infants must be broken. If we could make sure that infants, children and pregnant mothers receive adequate nutrition, we could interrupt this cycle and remodel our future."*
>
> **—Charles U. Lowe, Scientific Director**
> **National Institute of Child Health**
> **and Human Development, NIH.**

But the pregnant adolescent has serious extra nutritional needs for the child developing within her.

Studies on the nutritional status and food habits of adolescents, pregnant and non-pregnant, frequently indicate inadequate and bizarre diets, with especially low intake of iron, calcium, vitamins A and C.

Poverty compounds the adolescent dietary problems. Adolescent pregnancy raises the problem to national significance.

Of all women who deliver at Grady, 98 percent request—and receive—information on contraception for the future.

Perhaps as a consequence, the number of multiple pregnancies is sharply declining. This is true at Grady and nationwide. However, those at risk for producing handicapped children, and least prepared for motherhood—16 year old, jobless, unwed, malnourished girls—are increasing their reproductivity.

The 16-year-old girl in Atlanta will receive expert medical attention from the Grady Maternal and Infant Care Project, including screening for rubella, sickle cell anemia, venereal disease, and other infections. Available to her if she needs them will be such services as psychiatry, medical specialties dealing with maternal and fetal care, nutritional education and social services, including family planning. She will also have access to consultation and resources of Emory University Medical Center, with which Grady is affiliated.

If typical, she is not interested in attending "birth control clinics" following the birth of her child. So Grady has established a teenage "interconceptual care" clinic, which provides peer group meetings, a case worker to aid with problems, routine contact with school personnel, and health services, as well as birth control and health information. Meetings are relatively well attended.

Total health care—not just during pregnancy—is available to her and her baby.

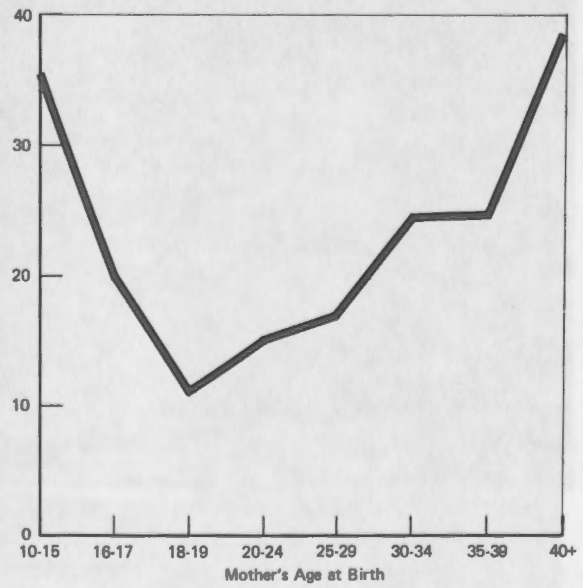
She is more fortunate than her cousin, whose day-laborer husband does not qualify for welfare, but whose salary cannot begin to cover health insurance or good health care. They, like millions in the low-middle income brackets, are too poor for private care, too rich for Medicaid, and too young for Medicare.

For further information, write:

Maternal and Infant Care Project
Parklawn Building
Fishers Lane
Rockville, Maryland 20852

Maternal and Infant Care Project
Grady Memorial Hospital
Atlanta, Georgia 30303

CHILDREN NEUROLOGICALLY ABNORMAL AT ONE YEAR BY AGE OF MOTHER (WHITE)



Source: Collaborative Perinatal Study of National Inst. of Neurological Diseases and Stroke

"The goal is not survival; it is intact survival"

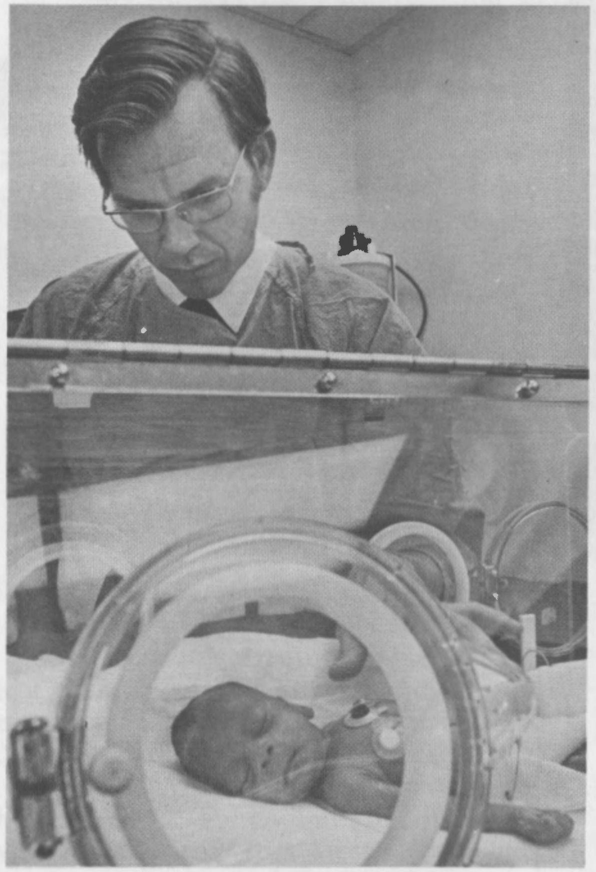
Modern technology is responsible for saving the lives of many premature and high-risk infants through the new intensive care units for newborns, spreading in a network across the country.

But modern technology is not enough.

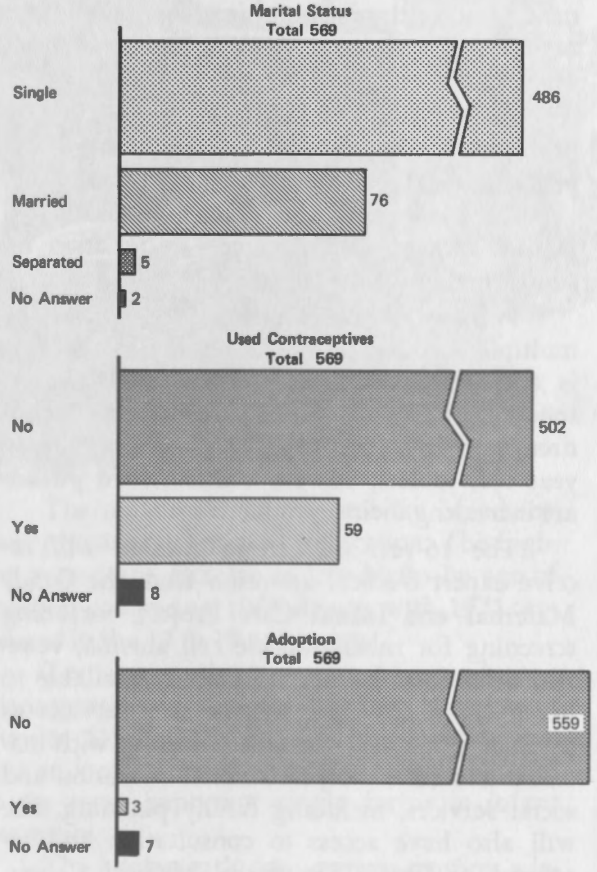
Even though a large percentage of these babies survive, many may emerge with serious mental defects.

Funding for intensive care programs staffed by highly trained neonatologists *on 24-hour duty* is an urgent necessity.

Deeply concerned by the facts, one physician states the problem in these terms: "The goal is not survival, it is *intact* survival."

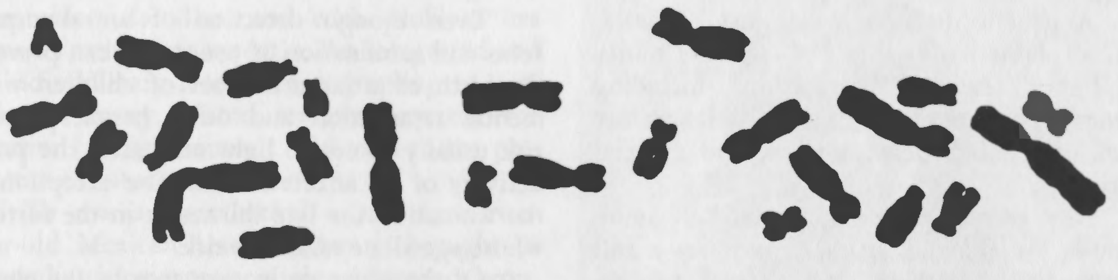


MAJOR CHARACTERISTICS OF PATIENTS SERVED AT GRADY MEMORIAL HOSPITAL INTERCONCEPTUAL CARE CLINIC



Source: Progress Report, Grady Memorial Hospital Maternal and Infant Care Project, 1971-72

From Chromosomes to Family Care



The flow and interchange of staff among the services of the Los Angeles County—University of Southern California's Medical Center make it difficult to know where one service stops and another starts.

That's the point.

The continuity of specialized care that the clients receive cannot be captured in any organizational chart because of the close interaction among the staff, and the coordination of services.

The Genetic Center's team works closely with the Department of Obstetrics and Gynecology, their Family Planning Division, and the entire Pediatrics Department, especially the intensive care unit for newborns. And the clinic for developmental problems of infants and children is an integral part of the entire network of services.

Social workers and public health nurses are often the bonding agents for linking the medical, social and educational services.

Since the Genetic Division is most immediately concerned with prevention of mental re-

tardation and other handicaps, it invites closer inspection.

"A genetic division is not just a laboratory," explains its director. "We have a multidisciplinary team of physicians, including genetics post-graduate fellows, laboratory technicians, public health nurses, and a social worker.

"Any genetic program involved in amniocentesis for prenatal diagnosis requires a full team to do the back-up work necessary in genetic evaluation and counseling," she adds. (Amniocentesis is a procedure in which a small amount of amniotic fluid surrounding the fetus is removed. Examination of the cultured amniotic cells may indicate whether the fetus has a chromosomal or biochemical defect detectable by present laboratory tests.)

In the past two years, about one out of every 20 pregnant women seen by the Genetic Center's staff were found to be carrying a fetus with chromosomal or biochemical abnormalities, and the couple in each case decided to terminate the pregnancies.

Couples are first evaluated by physicians of the Genetic Division to determine the genetic risk involved in the pregnancy. If they choose to have amniocentesis, a thoroughly trained obstetrician performs the procedure.

It takes two to three weeks for the amniotic cells to grow in culture and be analyzed for evidence of the fetus' normal or abnormal chromosomes. A fine art now, the technique is constantly being refined to improve the reading of the microscopic genetic message captured on the slide.

In the weeks awaiting the outcome of the tests the couple very much needs the psychological support of the professional team.

Although by far the largest number of the patients are found to be carrying fetuses showing no evidence of genetic disorders, anxiety is high among all until results are known.

For those found to be carrying an abnormal fetus, there is further team counseling, as the prospective parents decide if the pregnancy is to be terminated or not.

The risks of having a fetus affected by certain genetic disorders in future pregnancies may be known before conception. In some cases the carrier state for genetic disorders such as Tay-Sachs disease can now be determined.

Even though detection of an abnormal fetus and termination of pregnancy can prevent the birth of a large number of children with mental retardation and other handicaps, the risk usually comes to light only after the prior delivery of an affected child. The exception is the woman in the late thirties or in the forties, whose age alone raises the risk.

Of the pregnant women seen by the physicians of the Genetic Division since 1970, about two-thirds had a previously affected child, such as one with Down's syndrome (mongolism) or a biochemical abnormality. About one-third of the women were over 35 years of age.

The majority of the amniocentesis referrals to USC's Genetic Center are from private physicians. A large number of the Center's patients had previously used the service.

> *"No medical practitioner can be excused now for not knowing the nature of genetic diseases, the special diagnostic techniques applicable to them, the identification of carriers, the means of reducing the deleterious effects in many of them, and means by which their incidence in future generations can be reduced."*
>
> —George W. Beadle, Ph.D.
> Nobel Laureate in Genetics
> Former President, U. of Chicago

A very small proportion of requests for amniocentesis are from people in the lower socio-economic groups, even though it is reasonable to assume that these groups include a large number of high-risk mothers and even though no patient is ever turned away for inability to pay.

The Medical Center of USC has become acutely aware that there are few, if any, single-problem families, and each problem has several facets. Consequently, the integrated and multidisciplinary teams are attempting to provide the many related services required for effective family treatment, and vital to the prevention of future problems.

To use a hypothetical example, a two-year-old Mexican-American boy is brought to the pediatric emergency clinic with severe bronchitis. After treatment for the acute problem, the medical staff completely evaluates him and confirms their observation that the child has Down's syndrome and is seriously delayed in development, in addition to being undernourished.

An interview with the mother discloses the fact that she is 37 years old, about three months pregnant and not under a doctor's care. Another child in the family, a five-year-old girl, is found to be relatively healthy but somewhat below normal mental development for her age.

Assisted by a pediatric social worker, the mother receives a thorough obstetrical examination. She then becomes a patient in the obstetrical service of the hospital and will be delivered there.

Because of the younger child's chromosomal abnormality expressed in Down's syndrome, and the mother's age, the risk that

Marcia Kay Keegan

Of 3,500 patients seen in a two-week period last year at the Emergency Pediatric Clinic of Los Angeles County—U.S.C. Medical Center, 70 percent were Mexican-American, and 40 percent of these spoke no English.

"Have you ever faced a mother with a desperately ill baby in her arms at 2 o'clock in the morning, and found that she speaks no English and there is no Spanish-speaking interpreter available?" asks a pediatrician at the clinic.

He was echoing the frustration felt by a number of people attempting to serve the Spanish-speaking population which has increased dramatically in the last few years, especially in the Atlantic and Pacific coastal cities. There are frequent complaints that budgets in medical, social and educational services often ignore the pressing need for translators.

she is carrying another affected child is increased. So the pediatric social worker, who is also part of the Genetic Division's team, discusses the situation with the mother, who is then evaluated and counseled by a physician in the Genetics Division.

An amniocentesis to detect fetal chromosomal abnormalities is offered, and the parents decide that they wish this procedure. While awaiting the results of the growth of the amniotic cell culture, the public health nurse attached to the genetic team counsels the parents and tries to allay anxiety. She is available at all times to give very personalized service.

Meanwhile, the social worker locates a Headstart class in the community that has an opening—not an easy task—for the five-year-old girl whose development is below normal. The hope is that this program may give her the added mental and social stimulation needed to prepare her for a regular first grade class in public school. If not, she may require special education.

For the two-year-old with Down's syndrome, a medical and nutritional team goes to work on his physical needs, while the public health nurse counsels the family on his care and feeding. Soon the social worker will begin the search for a pre-school program for handicapped children in the community. The child will remain under the guidance of the Medical Center's team as long as he needs such help.

While the search for community services for the children of this family has been going on, the laboratory technicians have analyzed the amniotic cell culture and found no abnormalities.

This mother's pregnancy will be followed closely by the obstetrical team, and should continue to term without problems. If any develop for her or the baby, highly specialized medical help is available in the Medical Center.

She will be provided family planning services if she wishes, as well as genetic counseling if there are future pregnancies.

All of these services for the family are within easy walking distance of one another. The social worker or public health nurse is there to aid in moving from one service to another with ease.

For further information, write:

Genetics Division
Los Angeles County—U.S.C. Medical Center
1200 North State Street
Los Angeles, California 90033

California's plan for the development of a regional service system for the retarded throughout the State is now operational.

The State is setting up a network of comprehensive medical and educational facilities designed to supply a complete range of services for an estimated 200,000 retarded individuals.

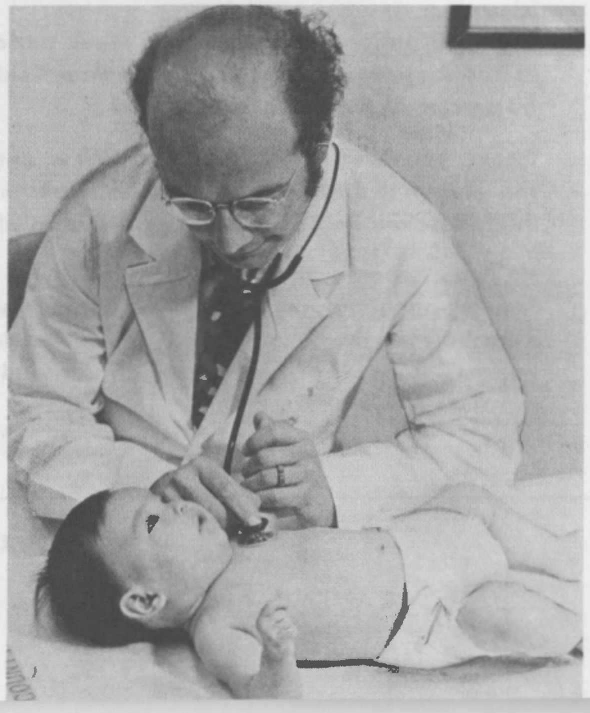
Regional centers offer a total management plan, including diagnosis and continued counseling. They are designed to guide parents to educational, training, and recreational programs, or to find foster homes or out-of-home placement for children whose parents cannot care for them.

"If we had more funds for early childhood centers and short-term care," says a California social worker, "there would be much less need for full-time residential facilities."

With adequate financing to assure equitable distribution of regional center services, the California system promises to be a plan for other States to follow.

For further information, write:

Bureau of Mental Retardation
State Department of Public Health
Berkeley, California 94764



Nurse-Midwives Show the Way

In 1969 the infant mortality rate in rural Holmes County, Mississippi was 39.1 per thousand. Less than three years later, it was down to approximately 21 per thousand. In that same area, the neonatal mortality rate in 1969 was 23.4 per 1,000 live births. In 1971 it was 8.5.

Although such dramatic progress is in part due to teamwork in maternal and infant care among the University of Mississippi Medical Center, the State Board of Health, local physicians and other community health professionals, the *key* addition in that period was the nurse-midwife of the County Health Improvement Project (CHIP), which started in '69.

The Project started with demonstration programs in education and service in Jackson, Mississippi and surrounding area, and a program in rural service in Holmes County, which is a mainly low-income—or no income—area.

CHIP is now going into two more rural Delta counties, with an additional program in Vicksburg.

The first step was to break down the prejudice against midwives. The educational program at the medical center, however, was training not just midwives, but Registered Nurses as professional midwives under the supervision of physicians. When this point was illustrated, progress was smoother. Since the project started, 25 have been graduated from the 12-month training program at the University of Mississippi and are now practicing in the State. Forty nurse-midwives are currently working in Mississippi.

"We are concerned with the quality of life as well as physical well-being."

They are now gearing to train 20 nurse-midwife students twice a year, for a total of 40 annually. Graduates of the program will be placed in six southeastern states: Florida, Georgia, South Carolina, Alabama, Mississippi and Louisiana.

Basically, the nurse-midwives are being trained in an organized approach to total maternal and child care. They are prepared to handle normal prenatal care, delivery of the baby in the hospital (hospital delivery is required), and follow-up of the mother and baby at least through the first year.

Working with community health aides trained at the University of Mississippi, the nurse-midwives follow the mother and newborn child intensively at home the first month after delivery.

Instead of the usual 6-week checkup for new mothers, the CHIP mother has her checkup at the end of four weeks at the University Medical Center or health department clinic. During this time, the nurse-midwife counsels her on family planning, and starts her on whatever family planning method she has chosen.

The baby gets a 6-week examination by the nurse-midwife, and is seen at home at 3, 6, 9, and 12 months. The nurse-midwife is available by phone at all times.

The people in Holmes County generally are farmers without much money, so CHIP has arranged to have the Department of Agriculture's Food Supplement program come into Holmes. In addition, since the well water supply is often contaminated, the babies under this program get a prepared formula that does not require dilution.

One of the criteria for nurse-midwifery care is that the pregnant woman be essentially normal, with a prospect of an uncomplicated pregnancy. The high-risk patient is cared for by a physician. From the beginning, and through each stage of care, if any problem is detected in mother or child, the nurse-midwife immediately consults with an obstetrician or pediatrician.

In addition to the routine tests and immunizations for the child, the nurse-midwives check the hemoglobin level, nutritional status, and developmental level.

"We are concerned with the quality of life, as well as physical well-being," says the nurse in charge of the program. "So we see that the infants get early stimulation, and we counsel the mother on child-rearing practices as well as nutrition and health education."

"In some respects, the ghetto child is better off than the rural youngster, for he at least gets some medical care, while the rural child may have none at all."

—Jay H. Arena, M.D.
Past President, American
Academy of Pediatrics

They use developmental tests on children, and use them as a teaching tool for the mother, also.

If there is a developmental lag, there is an immediate referral for remedial measures. And in this total care project, a number of cases of potential mental retardation have been found and checked before progressing further. Some of the babies, for example, have been born with hyperbilirubinemia (jaundice). These children have been treated immediately, and are now normal. If untreated, the result could be mental retardation.

Another benefit from the program comes from having the Holmes County mother deliver in the hospital. CHIP has Maternal and Child Health Service funding for the hospitalization if the family is not on Medicaid or any other Federal aid program. (In other Mississippi counties, if the family can't afford hospital costs for delivery, the baby is often born at home.)

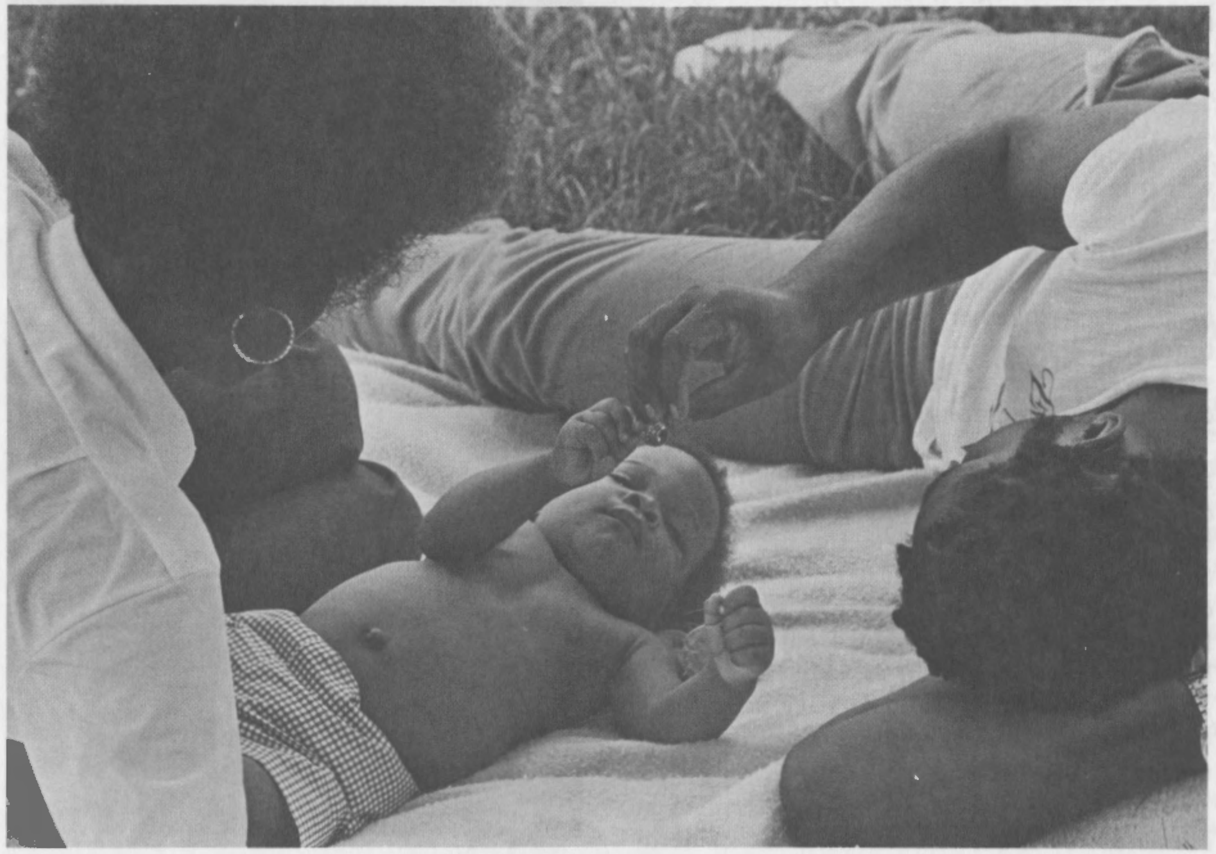
Problems the nurse-midwife detects in the newborn are referred to local physicians or specialists available at the University of Mississippi Medical Center, a service not available in home deliveries. The personalized, first-rate medical care the nurse-midwife can give is proving valuable not only for mothers and children but also for physicians who are then freed to give more time to difficult cases.

Funding for CHIP comes mainly from HEW grants and private foundations, with a very small amount in State money. "Much of my time is spent looking for money," says the project's director.

Because this successful project in the Delta was a product of Mississippi minds at work, it is known affectionately as the "Made-in-Mississippi Health Care Plan."

For further information, write:

Public Information Office
University of Mississippi Medical Center
2500 N. State Street
Jackson, Mississippi 39216



Home Is Where the Teaching Is

Home Start is so commonplace, so full of the old-fashioned virtues—parental care, family solidarity, order in the home—that it seems almost pretentious to call it a program.

Home Start is a mother in Cleveland, Ohio talking with her young child as she peels potatoes for dinner.

A grandmother in Gloucester, Massachusetts who takes care of her working daughter's pre-school children, marching around the living room with them, beating pans with wooden spoons.

A father in Logan, Utah reading a story to the children after he tucks them in bed.

A Parkersburg, West Virginia family sitting down to dinner together every night at six-thirty.

That's Home Start.

There's something old, something new, something borrowed and something that rings very true about the whole concept.

The something old, of course, is the premise that child-rearing belongs in the home. And a home with some order in it, with healthy meals eaten together, and a reasonable bedtime. And conversation. Not just commands issued over the din of the TV, but give and take conversation. Questions and answers.

The "new" is twofold: (1) the relatively recent knowledge gained from the "growth sciences" that such deceptively simple child-rearing practices are essential to the healthy mental, physical and emotional development of the child, and (2) the realization that such matters have somehow gotten crowded out of modern homes—poor and affluent as well—and can no longer be taken for granted. They need to be taught. Home Start is beginning with the disadvantaged.

The something borrowed—and applied in Home Start—is the undeniable evidence accumulating from human development studies throughout the world that a child's mind and emotions develop in stages, in much the same way as his body develops. There is a time schedule for each building block of growth, varying somewhat with each individual child. But if a block is missing, the whole structure is apt to collapse.

The "growth sciences" owe their origin to the Swiss psychologist, Jean Piaget, who was the first to describe how children construct their mental model of the world in cumulative stages. His studies started with mentally retarded children.

The child's environment, he holds, is the key to how well and how rapidly the mental model is built. The greater the child's variety of experience, the greater will be his ability to handle an even wider variety of experiences.

Then by combining, or re-combining what he has learned before, he can build on that base to proceed to new methods of learning, coping, reasoning.

The concept, adapted by Home Start, is not narrowly defined as "education," but is concerned with the development of the child as a whole person, with the parents as the natural teachers, the home as the natural setting. Neither is its goal emergency *treatment* for children deprived of essential building blocks in their development; it is *prevention* of the mental and emotional handicaps suffered when the cornerstone of the foundation is missing.

(The centers-based developmental day-care programs have a similar goal, but are designed mainly for young children whose mothers must work or go on welfare.)

The valiant "treatment" efforts of tutoring programs and other compensatory projects to help disadvantaged children "catch up" to the competence of more advantaged children, have opened the nation's eyes to the importance of early childhood, and the desperate need for help of many of our children.

But such programs are not achieving the results they had hoped for, possibly because they may have come too late in the natural schedule of child development.

Competence is a cumulative thing.

These compensatory programs, and the much-maligned schools, may be building on a house of sand, developmentally speaking.

Home Start could turn out to be the supplier of the missing cornerstone, not supplanting the other programs, but laying the foundations on which they can later build.

Home Start was born in the Office of Child Development of HEW, in March 1972. Stated purpose of the home-based program is to focus on enhancing the quality of children's lives by building upon existing strengths and assisting parents in their role as the first and most important educators of their own children.

It is serving approximately 3,000 children roughly between the ages of 3 and 5. Benefits of the program, however, extend to both younger and older children in the home.

The 16 cities with Home Start programs, as of the time this report was written, are: Gloucester, Mass.; Binghamton, N.Y.; Parkersburg, W.Va.; Franklin, N.C.; Huntsville, Ala.; Harrogate, Tenn.; Cleveland, Ohio; Fort Defiance, Ariz. (serving Indian families); Houston, Tex.; Dardanelle, Ark.; Wichita, Kans.; Logan, Utah; Reno, Nev.; Fairbanks, Alaska; Laredo, Tex. (serving migrant families); and San Diego, Calif. There is at least one Home Start program for each of the ten HEW Regions.

Home Start is a Head Start demonstration program, serving children in the same age range and economic categories as those served by the center-based Head Start.

Some communities, such as Binghamton, N.Y., already had projects similar to Home Start, so Home Start joined forces with the existing project.

Each city involved has a continuing inservice staff training plan for the home visitors. They are generally para-professional women from the neighborhood in which they will be working. Most are mothers familiar with the community and its resources.

Usually traveling in teams, they average about 12 families apiece whom they visit at least once a week, bringing simple educational materials and child-rearing ideas with them.

"I never thought of myself as a teacher before."

Often they find their families by simply walking through lower-income neighborhoods and knocking on doors. They explain the program, invite the family to participate, and if the family accepts, they are in. The home visitors become family friends. Each city's program serves a minimum of 80 families.

The mothers seem uniformly enthusiastic after the initial apprehension or distrust wears off. For the first time, many feel, there is an ally to help them in their difficult and confusing role as mothers. One of the purposes is to help them enjoy raising their children.

"I used to get rather short-tempered with my children," said one Home Start mother, whose five children range from 5 months to 8 years. "When they'd ask a question, I'd just give them something to get them out of the way. Now I try to answer them very sincerely. We talk—a lot—and I think things are much better than they used to be."

Home Start does not try to change a family's lifestyle, but to build self-confidence and give them the skills that are needed for a more productive life.

The visitors also try to help low-income parents bring some order into their lives, suggesting set times for meals, a consistent bedtime for children, and certain places for their toys and clothes.

Parents in the programs frequently get together to discuss mutual problems, and sometimes to hear talks about child-rearing. Some make toys and games for the children.

Mothers are made aware that the most common household objects can be learning tools. They also receive booklets with suggestions for activities appropriate to certain ages, educational games, and simple tests of learning skills. "I never thought of myself as a teacher before," one mother commented proudly. "I thought only the schools did that."

There are games to teach conceptual thinking,—organizing and categorizing things, done with such readily available items as laundry, groceries, kitchen utensils.

Parents are encouraged to praise good behavior, to explain cause and effect, to offer choices in order to foster independent thinking, and to be consistent in discipline whenever possible.

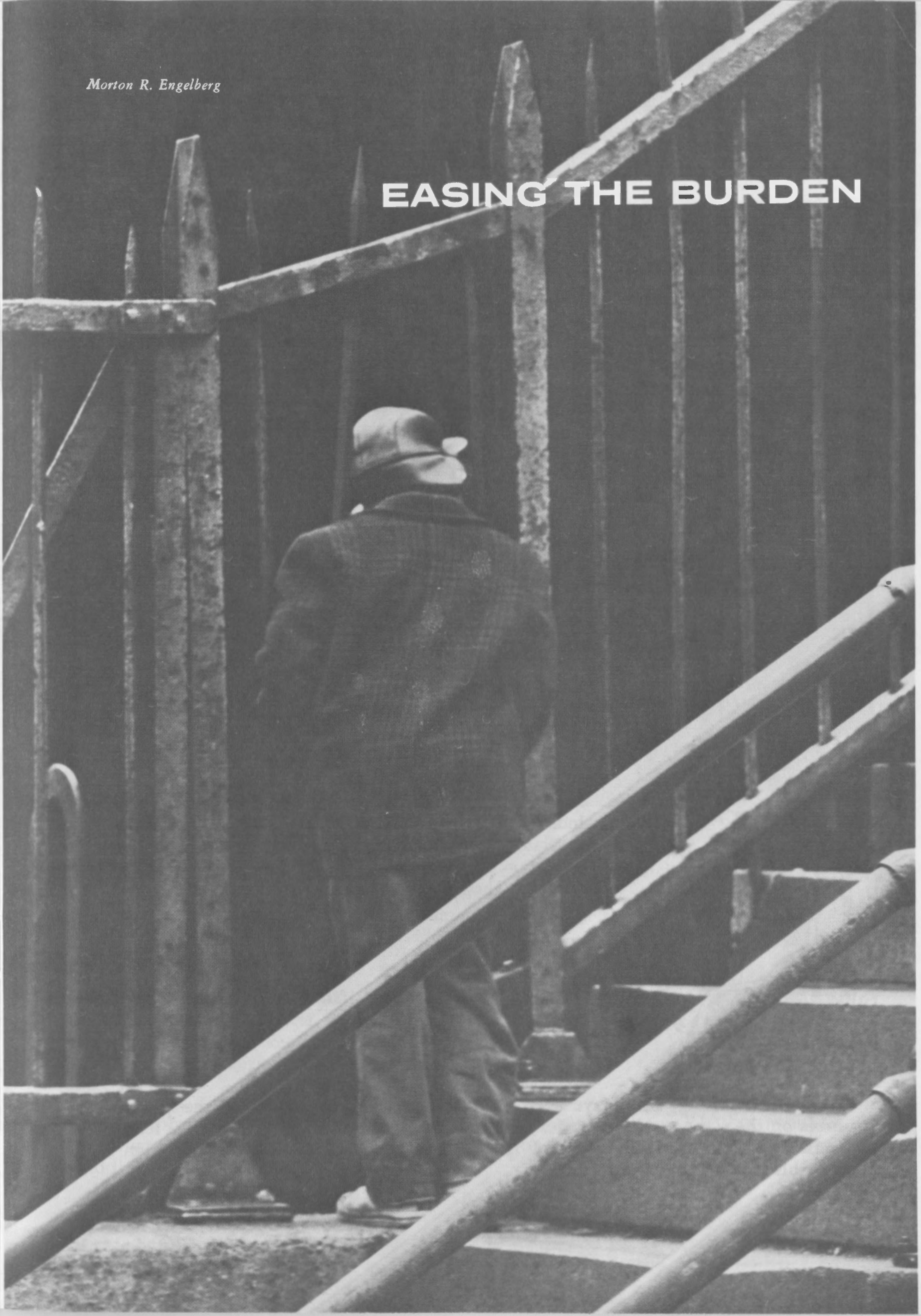
It's too early to predict long range effects, but at short range, it looks good. Many comments testify to the program's success so far: "I used to take my problems to a beer joint. Home Start brought me out of myself, to get a good look at what I could do for my kids."

One shy, young mother offered: "Without Home Start I would crawl back into my hole."

For further information, write:

Director, Home Start
Office of Child Development
P. O. Box 1182
Washington, D. C. 20013

EASING THE BURDEN



Morton R. Engelberg

Retarded People Have Rights, Too

The legal rights of the mentally retarded have been long ignored. Parents and agencies have had to beg for services and funding, and even then, succeeded only when their patience outlasted that of the dispenser of the largesse.

Suddenly, the scene has changed. Cases are being brought to court, on behalf of the mentally retarded, asserting the *right* to education, (including protection against assignment based on unfair labeling) the *right* to treatment, and the *right* to be free from involuntary servitude. (See *MR 71*)

A deluge of such cases is flooding the courts. They may mark the beginning of a new national attitude toward people who are mentally retarded.

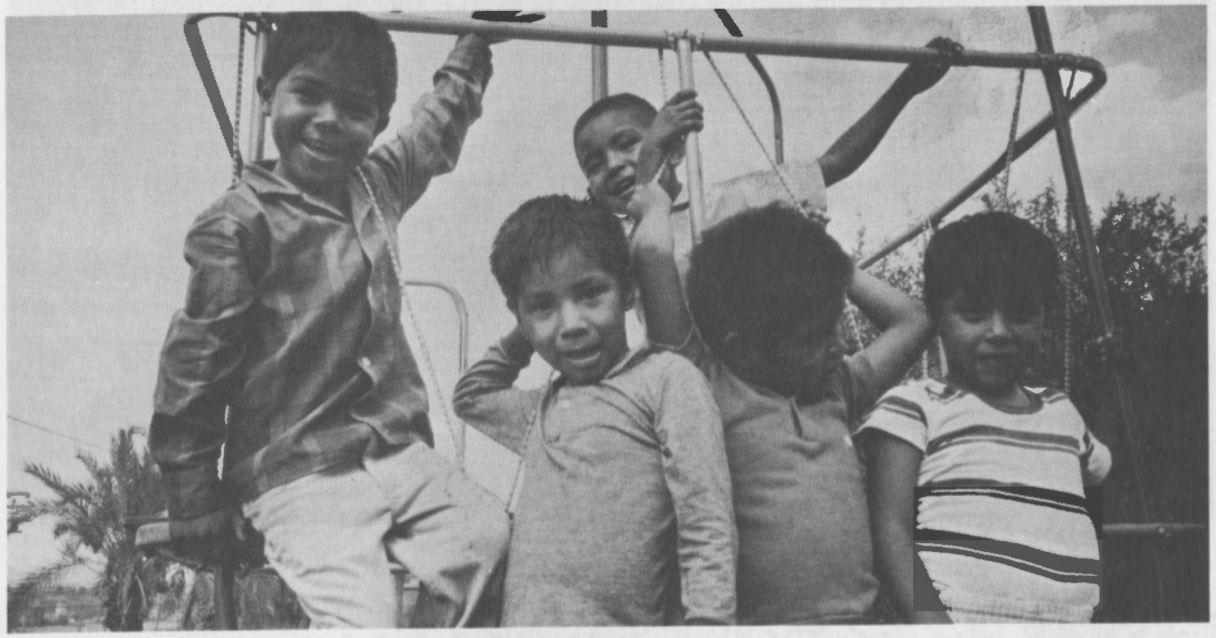
- Henry is 11 years old. He is brain damaged, and termed trainable. He is also physically handicapped, and in a wheel chair. The school district in which he lives has a program for mentally handicapped children, but Henry is called "too handicapped" to be eligible.

- Katherine lives on an Indian reservation. She had spinal meningitis at 18 months and has been retarded since that time. The State says her education is the responsibility of the Federal government, since she is Indian, and lives on Federal property. Neither Interior Dept.'s Bureau of Indian Affairs nor HEW's Indian Health Service has a program to suit her needs. She could go to the closest institution, over 300 miles away, but her parents want her at home. There are no community services for her on the reservation.

- Alice is 7. She can't talk, and has been called "untestable" with the available testing materials.

As of this writing, suits have been brought against seven states and the District of Columbia on the right to education for all children, regardless of handicap. In at least one suit—Mills vs. Board of Education of the District of Columbia—a court decision has affirmed this right.

- Petey is Black, 6 years old. He lives in a crowded tenement in a northern city. When Petey was tested in school he was given a set of blocks to assemble, among other items. The blocks have pictures of freight cars on them, and he was to arrange them so that the engine went in front, freight cars in the middle, caboose at the end. How can you tell where the caboose belongs if you have never seen a train? He failed the test.

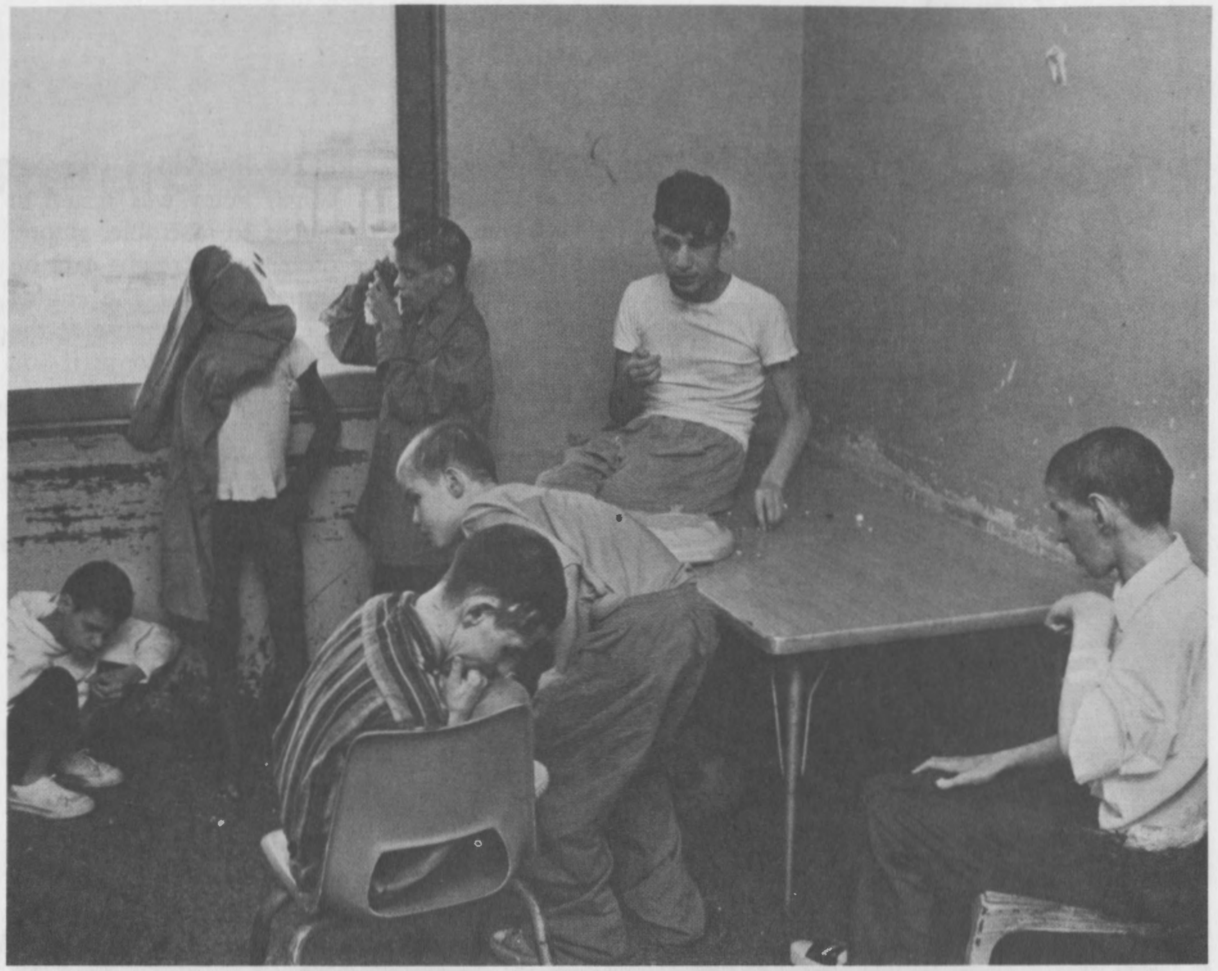


Paul Conklin

- Roberto arrived in this country three months ago from Mexico. He is 8. The family speaks no English. The person who administered his IQ tests spoke no Spanish. None of the team who devised the test had ever been to Mexico. He failed the test.

- Clarissa is the 7-year-old child of a white, destitute family living in an isolated, mountain shack in Appalachia. Clarissa didn't know that she was supposed to match a medieval suit of armor with a lance. She failed the test.

California, Massachusetts, and Louisiana have been sued for labeling members of minority groups and others as mentally retarded on the basis of tests geared to a white, middle-class background.



"The seclusion rooms are small cells with locked doors, barred windows, and are just large enough for one bed and a mattress on the floor. Residents are locked in these rooms without supervision and frequently for long periods of time.

"One resident who was recently observed in a seclusion room had been there as long as the ward attendant had been assigned to that ward, which was six years. Physical restraints, including straight jackets, nylon stockings, rags as well as rope are often used without physician's orders. One young girl was observed in a straight jacket, tied to a wooden bench. It was explained that she sucked her fingers and had been so restrained for nine years." *

In Alabama, Georgia, Illinois, Massachusetts and New York there is court action on right to treatment for mentally retarded in State institutions.

"Approximately 500 residents work at Partlow [State School], mainly in maintenance, without compensation. Many residents also work without pay in the direct care of severely and profoundly retarded residents. They have received no prior training for these tasks.

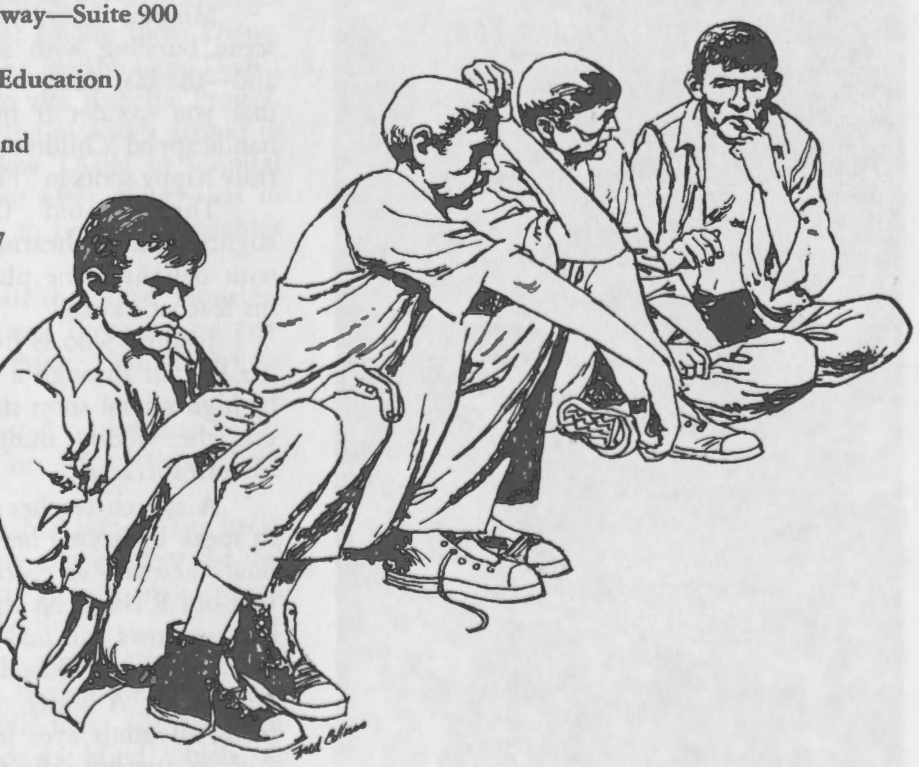
"In fact, a work assignment to a severely or profoundly retarded ward is often used as a means of punishment. There is no written policy protecting working residents. Many have been at their present job assignments for 20 to 30 years and some for over 40 years. They work without supervision, often under dangerous conditions, and many work in excess of 60 hours a week." *

In five states suits have been filed on the issues of peonage: The right of institution residents to be free from involuntary servitude, and, if they work in the operation of the institution, to receive minimum wages, social security, and other working benefits.

For further information, write:

Council for Exceptional Children
Governmental Affairs Office
1411 Jefferson Davis Highway—Suite 900
Arlington, Virginia 22202
(Information on Right to Education)

National Center for Law and
the Handicapped, Inc.
1235 No. Eddy Street
South Bend, Indiana 46617



* Source: Testimony before the U.S. Federal District Court for the Northern District of Alabama, relative to Partlow State School—Wyatt vs. Stickney.

The Multi-handicapped Child

The elevator, when it works, creaks its way up the rusted cage to the seventh floor. You are anxiously aware of being within the walls of New York City's ancient public hospital, Bellevue.

Your destination is the unique Rubella Project's pre-school, an educational laboratory for children with multiple handicaps—deafness, blindness, mental retardation, in varying degrees. Many have all three conditions, and more. Recalling other settings featuring similar children, you fight the urge to run away.

Minutes later, you are caught up in a scene bursting with such hope, such vitality, and—the last thing you would expect—humor, that you wonder if the Pre-school for Multi-handicapped Children may not be one of the truly happy spots in "Fun City."

Three-year-old Gerardo, thick glasses slightly askew, hearing aid in place, shrieks with delight as he plunges down a slide into his teacher's arms.

Juanita, who is five, and blind, is guiding her teacher through a multi-sensory maze built by high school shop students, feeling the flowers, the woolly things, the rough and the smooth surfaces.

A speech teacher is helping a child learn to speak by having her blow soap bubbles. One floats across the room, and hits blond two-year-old Richard on the nose. His teacher lifts her eyebrows and makes a face in mock astonishment. For a second he does nothing. Then he laughs. A gusty, two-year-old laugh that turns all adult eyes in the room toward him with excitement. His teacher hugs him to her, and he begins bouncing up and down in her arms, still crowing with pleasure at his accomplishment.

Across the room, the mothers put down their coffee cups and—even though three speak only Spanish, two speak only English, and Richard's mother speaks only Romanian—they somehow communicate their mutual pleasure in this feat.

It is the first time Richard has ever laughed.

When his mother was pregnant, she had rubella. Richard seemed to be normal at birth, but it soon began to be apparent that something was wrong. He did not respond as a normal child should. No eye contact, no smiles, coos, laughter, nor even much crying. The tentative diagnosis was autism, with possible deafness.

No one knows yet if he is deaf or not. Now, four months after entering the pre-school program, he is tolerating the earphones that test his response to sounds. He is making firm eye-to-eye contact. And he is making the happy, human sound of laughter.

Sharing in the Event of Richard's Laughter is a beautiful, young-looking Puerto Rican mother of eight children, among them Diana.

In April of 1972, she had brought Diana, then 10, in her arms to the Rubella Project. For the five years since the mother's arrival in New York she had taken Diana to hospital after hospital, and clinic after clinic—ten in all—seeking a program to help her daughter learn something.

The answers were all the same: Hopeless case. Nothing can be done. There are no programs for this kind of thing. You can try to get her in an institution.

But her mother insisted on keeping her at home. And persisted in her efforts to get help for her child.

For ten years Diana had lain on her back, unable to sit up. The only nourishment she did not reject was milk with an egg in it, which she drank from a baby's bottle.

Finally, at a children's evaluation project, Diana was diagnosed as having the one condition she did not have—blindness. She was then referred to a program for the blind, which, on finding she was not blind, referred her to the Rubella Project because it serves an an evaluation unit for the region's deaf-blind center.

After an intensive evaluation at the Rubella Project it was found that Diana has congenital rubella with the following manifestations: Severe hearing loss, failure to thrive, chronic brain syndrome with severe mental retardation, behavior disorder with autistic features, and an impulse disorder. These conditions were compounded by malnutrition and anemia. Her "blindness" was profound apathy.


Diana

Because her problems were so severe and complex, Diana was hospitalized for ongoing and simultaneous evaluation and treatment. She was force-fed to counter the malnutrition and anemia, and given medicine to control the impulsivity (despite her weakness, she would throw whatever came within reach, including equipment used to film her progress).

At the same time, an interdisciplinary team of doctors, nurses, educators and social workers—and her mother—worked together. In a few weeks Diana was eating ravenously. She was sitting up and slowly beginning to observe the world around her, amplified by a hearing aid, and sharpened by her growing perceptivity.

Strengthened and supported by the team, her mother was becoming her most effective therapist.

Within a few months, Diana was walking with relative ease. Although still severely retarded, she takes part in the pre-school program, responds even with humor, and has learned many self-help skills.

The point of the story, however, is not so much Diana's success, but the failure of the service system at all levels.

How much of her degeneration over a period of ten years was caused by professional and societal neglect? The team at the Rubella Project believe that with early diagnosis and treatment she may have been far less retarded than she is—with a chance for significantly more independence than she can ever achieve now, and at much less cost.

How different would her life have been if she had had a hearing aid at the age of one instead of ten?

What effect would proper diet from infancy have had on brain development and physical skills?

How different would have been the life of her parents and brothers and sisters if they had not had to wait ten years in hopelessness and helplessness?

There are literally thousands like Diana on the back wards of State institutions all over the country. *If such dramatic improvement can be evidenced in a few months in a severely, multi-handicapped child after ten years of professional neglect, how much suffering, human waste and public cost could be saved by an early evaluation, diagnosis and treatment followed by community services for each potentially handicapped child?*

During investigations which began a decade ago and contributed to progress toward prevention of rubella birth defects by vaccination, the Rubella Project expanded its mission to focus also on early detection and treatment, family training to handle the problem, and placement in appropriate community services.

When a child is brought in, a physician interviews the parents and gives the child a thorough physical, bringing in whatever specialists are required. Since this is a medical center-based program, there are specialists in all fields available.

At the same time, in the examining room, a member of the educational team evaluates the child, eliminating the need for further referral procedures and the all too frequent gap between medical diagnosis and educational management.

From then on, for a period of several months, the integrated medical, social service and educational management team develops a program for the child and his family.

A child is eligible if he has at least two of the following conditions: auditory impairment, both peripheral and central; visual impairment; brain dysfunction; mental retardation; physical impairment and behavior disorder.

The project is no longer limited to children affected by rubella.

Staff includes a teacher of the deaf, a teacher of the mentally retarded, an assistant teacher, a social worker, an occupational therapist, two health aides and several graduate and undergraduate students in these fields. These are in addition to the project's traditional medical personnel, which includes 28 specialties.

The Rubella Project is a component of the Department of Pediatrics, New York University Medical Center—Bellevue Hospital Center. Funds come from Federal, State and local governmental agencies and private donations.

As a laboratory to explore new methods and technology in treating multi-sensory deprivation, the pre-school recognizes that *diagnosis cannot be separated from treatment, and treatment cannot be separated from the home environment if there is to be the necessary impact on the lifestyle of the multi-handicapped child.*

So there are home visits and personal involvement in the home life of the child. At the same time, the parents—more often the mother—learn techniques under direct supervision, and are deeply involved in the treatment.

The project becomes "home base" for the family, and the children return at least once a year for checkups on their educational and social progress as well as medical condition.

Where do they go after the pre-school? There are too few community placement possibilities for them. And what becomes of those unknown thousands of similar multi-handicapped children for whom there is no such thorough pre-school?

Deaf children feeding their turtle

Like the hospitals and clinics and private physicians from whom Diana's mother sought help in vain, the vast majority of professionals are choosing to run away from the problem, or ignore it.

Hopes rise, justifiably, with that creaky old elevator to the Rubella Project. There is treatment there that helps. Then what?

For further information, write:

Rubella Project
New York University Medical Center
550 First Avenue
New York, New York 10016

In response to growing pressure on the States for treatment of the deaf-blind-retarded child, a handsome, ultra-modern regional residential facility, Frampton Hall, has recently opened at the N.Y. Institute for Education of the Blind in the Bronx, N.Y. The building was paid for by private funds. Program funding comes from the Deaf-Blind Centers and Services of Bureau of Education for the Handicapped and the regions served. It is one of ten deaf-blind regional centers.

Frampton Hall receives patients from a region that covers New York, Pennsylvania, Delaware, New Jersey, Puerto Rico and the Virgin Islands. The facility provides care for about 75 children between the ages of 3½ and 21.

Frampton Hall cannot handle severely emotionally disturbed children, severely crippled, those with a mental age measurable in weeks, or those whose families cannot take part in the training or be able to follow through.

Applicants have a thorough pediatric workup at the Bellevue Rubella Project, which may take two days to a week. While waiting, there is an apartment at Frampton Hall for the mother and child.

Once admitted, the child has the advantage of being in what is perhaps the most advanced therapeutic milieu of its kind, with every architectural and decorative detail designed for the instruction, safety and comfort of deaf-blind retarded children. There are no more than four children to each bedroom, and living quarters are in units close to private, specially equipped bathrooms.

But Frampton Hall is no protective, padded cell. The children are taken out frequently, not just to walk through the spacious grounds of the Institute, but on field trips to shopping centers, the zoo, public parks and playgrounds, and wherever else they can find opportunities to sharpen their senses. With few exceptions, the children go home on weekends. If their home is too far, the staff seeks out some change for them whenever possible.

Although the highly trained staff is responsible for training them in basic requirements of physical needs, there is also much activity in classrooms—baking, doing puzzles, making collages, dancing, marching, and introducing them to pleasures of childhood that other children learn naturally.

There are plans for a pre-vocational program in housekeeping and simulated workshops in the future.

The whole program is designed to prevent institutionalization. Yet, even after their training at Frampton Hall is completed—where else can they go? For some, the newly created National Center for Deaf-Blind Youth and Adults will provide the answer. But for many others there is no place.

"We all wonder," said a teacher, "what will happen to them after they leave here. They will always need a great deal of help. But who will give it to them?"

For further information, write:

N.Y. Institute for the Education of the Blind
999 Pelham Parkway
Bronx, New York 10469

Center for Services
for Deaf-Blind Children
Bureau of Education for the Handicapped
ROB #3
7th and D Streets, S.W.
Washington, D.C. 20202

Texas Removes the Label

If you are interested in EMRs, TMRs, MBIs or other such labels, don't go to Texas. If you are looking for the usual special education classrooms, proudly displayed, you will find few in Texas.

However, if you care about *children* and their individual, special needs, take a look at Texas.

Something special is happening to special education there. And what is happening may well be a preview of a new era in education in general. The new concept of comprehensive, personalized education for individual needs is called Plan A.

The primary goal in this child-centered plan is to provide each handicapped child in the state with an education suited to his ability to learn. Specialists are available to give the special help required to the child as well as to the teacher.

By deemphasizing labeling and isolation in self-contained classrooms, and by focusing on the learning needs of each child rather than on the handicap, Texas is giving an increasing proportion of its handicapped children the opportunity to move into the mainstream of education—and of life.

Contrary to fears that handicapped children would drown in this mainstream, they are being taught to swim.

"They used to bring these kids in here and tell me, 'this one's got an I.Q. of 55. This one's MBI.' I don't want to know what their I.Q. is or what they can't do. All I care about is what they can do."

The speaker was a muscular shop teacher

in North East San Antonio's Roosevelt High School. He was standing by, unconcerned, as a group of students, most of them handicapped, expertly handled makeshift levers and ramps to load onto a truck the 7 x 9 foot house they had built. The scaled-down red and white building, a highly professional construction job, was to be the Christmas toy collection headquarters for a local radio station.

Across town, at Alamo Heights Junior School, a resource teacher was working in a "resource room" with four students who had reading problems. Later one would go to math class, two to social studies, and the fourth to shop, where he is learning on lawnmowers, tractors and auto engines, to be an expert mechanic. The school does a brisk business in lawnmower repair. In the old system, all would have been labeled mentally retarded and isolated in a special education self-contained unit.

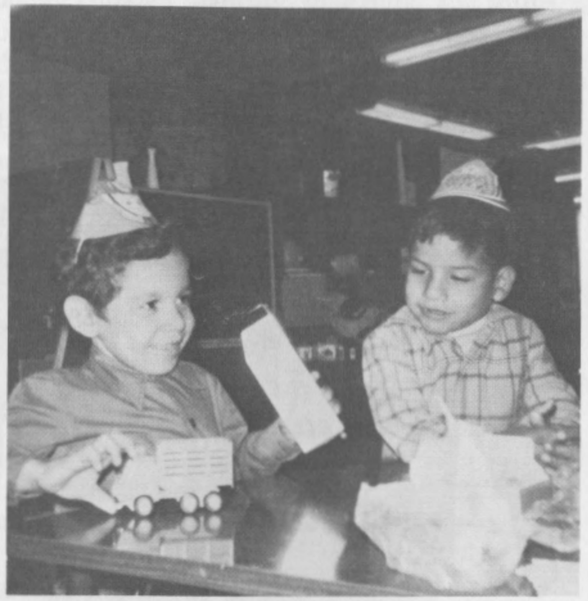
The same system of integration was taking place with children in classrooms through the school. Those with special needs were receiving personalized help, then returning to art, music, physical education, shop, or regular classrooms.

"We still have to match the child carefully with the regular teacher, the principal explained. "Those who may discourage or squash the child's initiative don't get these children."

Until higher education catches up with the changes in elementary and secondary education, a great deal of the success of a comprehensive system depends on the understanding of the principal and administrative staff, and the individual teacher's attitude and instincts, in addition to teaching techniques.

Directors of Special Education are discovering that principals trained in primary and early childhood education generally are more realistic toward children with varying special needs than are those coming from other education fields. The latter seem more oriented toward rigid, chronological criteria for grade placement.

Technique and instinct both are apparent in Victoria Plaza Elementary School, where trained residents of Victoria Plaza, a model housing unit for aged persons, across the street, regularly take part in the school's program, and supply an extra dimension of care for the children.



Integrated regular classrooms and resource rooms buzz with teacher-child dialogues:

"Tell me why you chose that picture, Robert." Probing into the learning process.

"Let's break up this ball of clay. Now, with all these pieces, do we have *more* than we had before? Or less? Or the same amount?" Developing concepts of conservation of matter.

"Would you like to make some figures with the clay?" Creativity.

Piaget all the way.

The newest educational techniques are most obvious, however, in the early childhood education programs. At Edgewood's Cardenas Early Childhood Center, children from three to five years are given highly specialized attention. Although most are handicapped mentally or physically and are predominantly Mexican-American, there is a mixture of children from several cultures and with a wide range of IQs.

Brilliantly colored, and carpeted throughout, the demonstration school is alive with the joy of children discovering the world and themselves. But it is ordered exuberance.

In one learning area of a large room, a group marches around in a circle, beating out a ragged rhythm with whatever can be turned into a percussion instrument. One child has thick glasses, two or three have hearing aids, one a brace on her leg, and a few are marching to the rhythm of a very distant drum. With them are a teacher assistant and a Spanish-speaking volunteer, who is young and male.

Over in a "learning well," two carpeted steps down, a little girl sits with a teacher who is giving her individual instruction. In several intimate, quiet rooms, small groups of children are working with teachers who are specialists in specific fields, such as speech therapy, or emotional disturbance.

Around a table in another corner there is a social event—a party. A mother sits a little apart, observing over a cup of coffee. She is a member of the parents' group, PIENSA, an integral part of the center's program.

Every few minutes, the action changes, to keep pace with the attention span of these young children.

The scenes at the San Antonio schools are being duplicated in many parts of the State, now that Plan A is expanding to 187 school systems. It is expected to cover the state by 1976, serving the needs of every handicapped child in Texas.

As it grows, the effect it is having in regular primary and secondary education, as well as teacher training, is slowly becoming noticeable, though not fast enough to keep up with Plan A's pace.

It is the early childhood programs, more than any other educational advancements, however, that are moving Texas' special education program out of the column marked perpetuation of mental retardation and into the column of prevention.

Plan A had a nebulous beginning in the late '60s, with the State plan for education of handicapped children, provided for under Title VI of the Elementary and Secondary Education Act of 1965, as amended.

In-depth research on the Texas State Plan, as well as on many other State plans, indicated that special education was not being responsive to the obvious call for massive restructuring of education in general. Instead, the special education plans seemed to be perpetuating the status quo. And the status quo was not working.

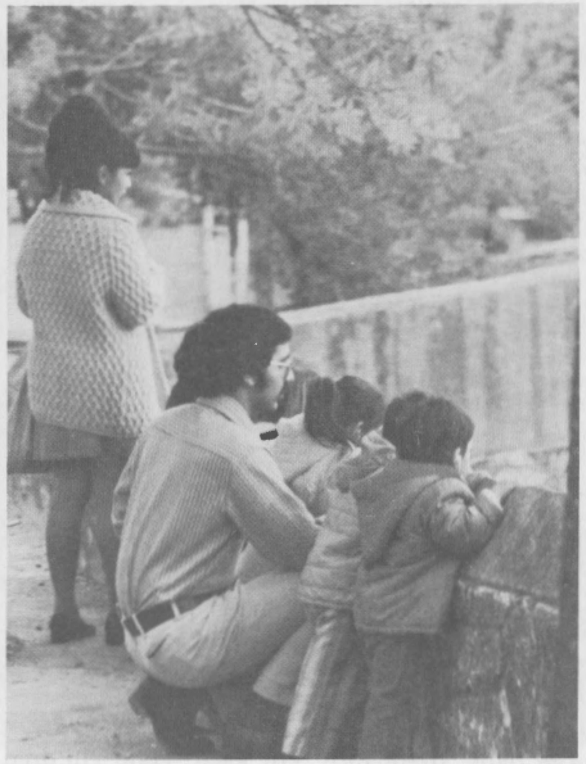
In 1968, for example, less than half of all *known* handicapped children in Texas were participating in the type of special education program they needed. (In one school district, there were 8 *known* multi-handicapped children under 6 years of age. After the Plan A program started, 42 were found.)

More than 40 counties provided no special education for their handicapped children.

Under 6 percent of the school-age population throughout the State were receiving special education services in 1968, while educators estimated that 10-20 percent needed such services. Many, receiving little or no help, dropped out of school.

A disproportionate number of minority children were enrolled in special education. There were unanswered questions concerning the adequacy of the standards by which they were measured.

In addition to these statistics, there was the ever-present label, the stigma, the isolation that perpetuates and accentuates the handicap. And the dehumanization of the category—an EMR, a TMR or some other faceless designation.



Costs were increasing; benefits decreasing. Researchers brought in experts in special education and related fields, distilled their ideas into a report with 17 recommendations for drastic changes in special education.

Major recommendations were:

- Discontinue labeling and categorizing children. (Do not label one child as brain injured, another as emotionally disturbed, a third as mentally retarded, etc.)
- Shift the emphasis from the handicapping condition to the educational needs of each child. (Discontinue emphasizing the fact that a given child is crippled. Instead, assess his individual needs and program his education accordingly.)
- Shift the emphasis from the self-contained special class to mainstream or regular education facilities. Where a handicapped child can achieve, provide him with an education in the regular school program with modifications and support as needed.

The research findings and recommendations, supported by the Texas Education Agency, resulted in legislation that was passed unanimously by both houses of the Texas Legislature in 1969.

With wholehearted support from the State Board of Education and the Commissioner of Education, Plan A began during the 1970-71 school year, with a pilot project in five school systems. In 1972-73 there are 70,000 handicapped Texas children receiving these special services. By 1976, Plan A is expected to serve all of Texas' handicapped children, from 3 to 21 (with infant stimulation programs in many areas).

Case finding is the responsibility of the local school district, and because of the change in funding patterns, it is to the district's financial advantage to get the children in school.

Under Plan A, however, funds are allotted to school districts according to average daily attendance, and exceptional children who spend more than half of their time in regular classes—including art, music, gym, shop, homemaking, etc—are eligible to be counted in average daily attendance. For each 3,000 children in average daily attendance, the school district is allotted 20 professional instructional units, 7 teacher aides, and 3 professional supportive personnel units. For each additional 1,000 pupils there is an additional entitlement.

School districts may form cooperative programs, especially for severely handicapped children. Several have done this. Some regional programs have been established for children who cannot cope with a regular classroom.

Previously, there was little or no assistance to teachers in regular classrooms that included handicapped children. Supportive staff positions were not available, nor was there a possibility of contracting for services.

To assist the regular classroom teacher, specialists are now available, including educational diagnostician, helping teacher, resource teacher, teacher aide, counselor, visiting teacher, speech therapist, teacher of the deaf, blind, and others for special needs.

Funds are available for appraisal of handicapped children, with each child receiving an individual education prescription. Each child is given individual help in this program, rooted in Piaget's theories of cognitive learning.

In addition to the programs in the early childhood centers, there is a homebound program for stimulation of infants and for the bedridden.

The Texas Education Agency's Special Education Department is currently holding a continuing series of institutes to create awareness of the need for curriculum change, and to train teachers and administrators in the application of Piaget's learning theories to curriculum development for exceptional children.

Each participant is responsible for bringing ideas and results of the conference back to the school district, and implementing changes if there are implications for that school district.

Those attending return to their schools and children with a heightened interest in the child as an individual rather than in terms of norms or as a subject to be located within a set of statistics. They are filled with Piaget's commitment to adapt the school to the mind of the child, to adapt teaching techniques to the cognitive structures of the child's thinking process, and to adapt the content of what is taught to that which is relevant rather than traditional.

They learn to replace teacher monologues with dialogues between child and teacher, and between child and materials. Teachers are taught to listen, to teach the child *how* to learn, to stimulate his own activity and to encourage him to direct that activity into meaningful channels.

Strategies for curriculum change are growing out of these progressive concepts, which are based on sound knowledge of human development as it relates to the learning process itself.

While these educational changes are taking place, Plan A classes are being examined in minute detail by Project PRIME (Programmed Re-entry Into Mainstream Education), the largest single study ever undertaken in special education. Findings will give policy makers across the nation firm data on how handicapped children can benefit most from integration into the regular classroom, and to identify strategies and climates in administration and teaching necessary to accomplish this goal.

PRIME is a cooperative venture of the U.S. Office of Education's Bureau of Education for the Handicapped, the Texas Education Agency, local school districts and higher education institutions.

The outcome of this study, combined with the dynamic concept of Plan A, promises an impact that will spread beyond the limits of special education, and far beyond the borders of Texas.

For further information on Plan A, write:

Director of Special Education
Texas Education Agency
201 E. 11th Street
Austin, Texas 78701

For further information on PRIME, write:

PRIME
Bureau of Education for the Handicapped
ROB #3
7th and D Streets, S.W.
Washington, D.C. 20202

Ralph Matthews

INTO THE COMMUNITY

The Open Institution

After a visit to Mansfield you wonder why anyone would want to leave it.

Mansfield Training School, a State residential facility serving eastern Connecticut, is situated in the gently rolling, well clipped countryside, about 30 minutes from Hartford. Two lakes mirror the beauty of the land.

Everything seems open there—the unfenced grounds, unlocked doors, the dormitories, the staff, the snack bar, the director's office, and above all, the faces of the residents.

There is a clothing "store," with attractive window displays and mannequins, where the residents choose their own clothes.

"Why dole clothes out, when they can come in and choose what they like?" asks the superintendent, who has a background in both mental retardation and public administration. *"Besides, they'll have to get used to buying clothes when they leave."*

The snack bar is open morning to night, patronized by staff and residents alike, and staffed by residents.

"We got a little flack on this," he says, *"when we decided to open the staff's snack bar up to the whole place. So we started with the 'high-level' residents only, one day a week. Eventually, they were all coming, any time they wanted to. Nobody gives it a second thought any more. It's all part of the normalization process."*

Next to the snack bar is a "teen club" with a bowling alley and small tables that give it a club atmosphere.

The beauty parlor is as pink and feminine and professional as any on "the outside." Two State-employed beauticians staff it and supervise residents who learn to do each other's hair. Appointments in advance are generally required.

"We used to have a small place where the girls could wash and set their hair but it wasn't very sexy. So we invited the West Hartford Junior Women's Club out here to talk with some of the girls and see the place. We told them we'd need about $7,000 to get a nice shop. We got $15,000."

There's a plaque on the wall in honor of the donors.

Elsewhere on the campus, there's a men's barber shop, complete with all the trimmings.

There's a vocational training work-shop where a worker tells with pride how he thought up the distinctive "Mansfield grooves" in big, chunky candles, and shows how he achieves the effect—with an ingeniously protected blade.

The training school's recreation, physical education and music programs have been used as a model for other institutions. The school band and the blind glee club have entertained thousands and have cut two long-playing records.

At Christmas, there is a big holiday party—one of the many held during the year. Individual neighboring communities, clubs and fraternal organizations, churches, and the news media all join forces in Project FOCUS (Forgotten Ones Christmas You Serve) to give attention and friendship to the 500 "forgotten" residents of Mansfield who never receive visitors and have no family.

"We get a lot of publicity from the newspaper and TV stations for FOCUS, and the response from the public is terrific. There are gifts, and, of course, the party, and contributions from all ages of people. Friendships get started and pretty soon, we've got another volunteer."

FOCUS may have started as a Christmas project, but it now lasts all year round, with fashion shows, plays, concerts, roller skating

and bowling and a dozen other activities that get residents and neighbors together.

"We do anything we can to close the gap between the community and our residents."

The pattern begins to come clear. The clothing store and the beauty parlor and the snack bar and the teen club and FOCUS and all the other attractions of Mansfield are not just for the purpose of making the lives of Mansfield residents more pleasant and more normal. They are also preparation for the life that many will be living in the community.

Whenever possible, the children go to local public schools. And the public schools come to Mansfield, with plays and picnics and athletic events. Over 400 college and 70 high school students volunteer in various programs at Mansfield.

Many of the retarded adults hold jobs in neighboring industries. In turn, the companies' technicians and engineers have helped Mansfield set up training programs for others who will hold similar jobs in the future.

Residents take train rides into nearby cities to visit museums, zoos, parks, fire departments, airports—whatever the community offers that will add to their experiences. Most pay for the outings by saving up tokens earned by working at Mansfield.

In the summer and often on weekends, big groups go out to the rugged and beautiful camp recently acquired. They eat around campfires, hike through the woods, and play in the open field. Many of the residents helped prepare the campsite, which was a wilderness when they got it. Mansfield has even dammed up a stream and made a lake for swimming, boating and fishing.

"Everybody needs a change of scene once in a while."

Throughout Mansfield there is a feeling of constantly changing scenes. Old storage areas ripped apart and being converted into brightly colored learning spaces for multi-handicapped children who need special training. A big, roofed patio being built beside a cottage housing non-ambulatory residents, so that they can be wheeled outside for picnics and fresh air. A bigger and more professional gift shop where the candles and other gift items made at Mansfield are sold to the public.

"We want to get all these old buildings down eventually. We're gradually getting there. Some of these places were built over 50 years ago. They've got to go."

Mostly, though, it's the people who give the place its sense of dynamic movement. Both staff and residents.

A resident in his late 50s proudly shows off his room, furnished homestyle, complete with color TV. He paid for the television and most of the furniture with money he has earned working at Goodwill. "It's a lot better than cows," he says, obviously not a rural type.

Each man has his own room in this section of a large, old building which somehow manages to look like an apartment building. All have outside jobs, but are not quite up to coping with the outside world fulltime.

They get around, though. The bachelor resident manager takes four or five with him on his annual vacation to Florida.

A group of teenagers in the new Kennedy Cottage—a modern, small, ranch-type house on the grounds—discuss their future with excitement as they prepare their own dinner.

Another young adult group, also on their way to the outside, drops by the snack bar and invite some friends to come over to their apartment for coffee in the morning. They have their own quarters in the staff apartment building across the road. They're almost—but not quite yet—completely on their own.

Some won't be going at all. But they're not hidden in drab back wards.

The day room for the most profoundly retarded had been a large, high-ceilinged, barn of a room, gray and forbidding and with years of institutional history permeating its walls.

"We had to do something about it, and lowering the ceiling or remodeling was too expensive. So we called in some of the architectural students from the University of Connecticut across the way, and put it up to them. Now it looks like a pleasant place to live in. And it's designed to get them to move around some."

The gaily-painted room has a four-section partial divider in the center, mounted on a slightly raised and carpeted platform. Action flows around the center area, with each of the four sections offering a slightly different interest. Over each of the four areas is a bright-colored tent, suspended from the ceiling, and hung just low enough to give the room a cozy, more intimate feeling. The cost for the "remodeling" was nominal.

There's a cottage for blind retarded residents, with its own dining room, and private bedrooms, with two or four to a room. Using the same space that had previously been a large dormitory, it has been remodeled into private quarters with funds from the Connecticut Lions Clubs.

The group of blind retarded young people sitting talking in their living room called out to the visiting staff member, "Don't forget to come to our concert next Sunday night."

They are members of a choir that was to sing at a neighboring church, and they had been practicing for the concert for months.

Why would anyone want to leave here?

"Look, it may seem like a country club, but it's still an institution. And an institution is an institution, especially with these huge old buildings we're stuck with. The idea is to get as many as we can into real life, or as close to it as possible."

The staff goes through continuing education to make them more sensitive to their charges.

Throughout the region, there are former Mansfield residents living in group homes, some in boarding homes, a few living independently. Mansfield has leased the homes, and Mansfield staff remains available when needed, in addition to the house parents who are there at all times.

Sometimes, residents still at Mansfield spend weekends at the group homes, as part of the phasing out system.

The homes are in quiet residential areas of neighboring communities, all within walking distance of transportation. There had been some neighborhood apprehension before they moved in, and a few real problems, but all got settled.

"There's no point in moving people from some big, bad institution into some little, bad foster home."

"This is really great," said one man who had been at Mansfield 17 years before being weaned away carefully to the group home. He was working in the kitchen of a rather expensive restaurant, and bragged about the prices on the menu. He was making $89 a week take-home pay. Everyone must be able to pay $25 a week room and board before he or she can enter into the group living arrangement.

A few blocks away from this house was a similar one for young women, and some not so young. They are all working in the community.

Some share apartments in the Hartford apartment house Mansfield leased three years ago. There are 15 units. Those who live there pay for their own apartment and food. The only cost to the State is for social service and housekeeping supervision. This is the final step on the way to living without any supervision or help.

Through Connecticut's system of regional centers for mental retardation services, Mansfield's residents who move out into the community can be sent to any one of the 12 regions and receive the social services available in each region. In other words, the resident can go to another area in the State and be "picked up" to receive their full range of services.

Mansfield now has about 750 in community-based programs. Over the last five years, the resident population has been reduced from 2,100 to about 1,400.

So Mansfield has already surpassed the goal of moving ⅓ of the residents out into community living. What is the next step?

Most of those who have no place to go are severely and profoundly retarded. They usually have several handicaps, and many are bedridden.

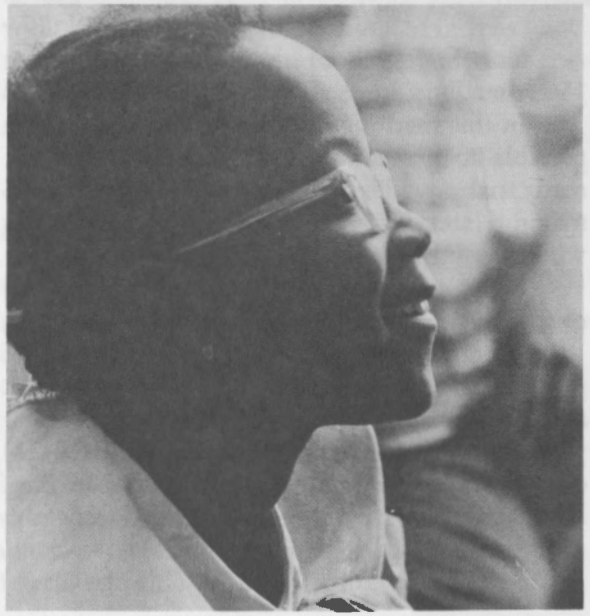
Foster care or nursing homes is possible for many if rigid restrictions can be modified concerning fire regulations, zoning, and similar obstacles to more personalized, private care. With the right kind of community relations, a number of homes would open up to caring for severely handicapped children, for example. Such care is more reasonable and better, generally, than institutional care.

The safeguard against undesirable private care is in the system of licensing. If the State office of mental retardation had the right to license such homes, and the authority to insist on adherence to standards of care, each home would have to adhere to uniform and strict standards.

"There's no point in moving people from some big, bad institution into some little, bad foster home."

For further information, write:

Superintendent
Mansfield State School
Mansfield Depot, Connecticut 06251



The Survey Research Center of the University of Michigan recently did a study of institutions. Among their findings: Those facilities with an educational treatment technology, almost without exception, provided higher levels of care, more balanced programs, and more equalitarian rendering of services to recent versus long-term residents than other facilities did.

Facilities with a medical or psychiatric treatment technology had many residents who actually deserved educational and other therapeutic service, but who received far less than their share of these.

Residents at medically oriented institutions, when matched with those of equal functioning at educational facilities, nevertheless were provided far fewer educational, social, vocational and even certain medical-nursing services than their fellow residents at educational facilities.

These and other structurally-based differences existed despite about equal financial and other resources between the two kinds of facilities.

There Are Choices

NARC

The goal is to move at least one-third of those now in institutions out into the community.

Is the nation moving toward that goal?

Some states have surpassed the one-third figure. Other states still have people who have been waiting as long as nine years to get into State institutions for the retarded, with no alternatives available in the community.

A director of a State institution may report a drop of over 100 in the resident population for the past year. An examination of their destination, however, reveals that close to 50 have been sent to a State mental hospital because of their advanced age and senility. Numerous other residents are being transferred from one State school to another.

One State school that moves out about 150 annually, admits about 140 annually.

In this mad juggling of residents, it is impossible to give any accurate account of how many nationwide are coming in, going out, making lateral transfers, or not moving anywhere.

Many are definitely moving out. Johnny is one of them.

When he was six, Johnny was still in diapers. He was able to say four or five words, and could barely walk. All day long for six years he had stared at the blank walls of a crowded ward of Beatrice State School in Nebraska, where he had been brought shortly after he was born.

Severely retarded, he faced only the bleak prospect of eventually moving into another ward of Beatrice where the residents were older. That was all.

But one day Johnny was taken out of the back ward and into a hostel in Omaha where five other severely retarded youngsters were living.

Johnny now is a lively little boy who goes to special education classes; he talks and sings, goes down the sliding board, dresses himself and, of course, is toilet trained. Five days a week he, along with the others of the "family," are bused to their special classes, physical therapy and recreation programs.

Perhaps more important, he is being introduced to normal living, in a real home, on a real street, and living with a real couple who are taking on the role of parents.

Although at this stage his daily expenses are almost double that of institutional care, the ultimate goal is that he will eventually earn his own living and become a taxpayer instead of a tax-user. He will need supervision and help, however, for the rest of his life.

He has a good chance to reach that goal of earning his own living. After all, Henry made it. And Henry came out of Beatrice when he was 46, after 38 years on the back wards. His records said he was "totally incapable of functioning outside."

Henry, also, moved into a hostel in Omaha, and was given five months of intensive vocational and social training. He has not missed a day of work nor been late once for his job as a dishwasher in an Omaha restaurant.

He was almost late once, but that was during a blizzard. He walked through it and punched in on time.

The effects of the trend toward normalization are being felt not just in Nebraska, but across the country. The newer way exists in pathetic contrast, often in the same State, with the most backward back wards. Funding is spotty, usually a combination of Federal (HEW and HUD), State or regional, and local monies. Occasionally, private funds are available, or housing is provided by churches, unions, civic or fraternal organizations, or foundations. There is no national pattern; only a national trend toward normal living, through the use of hostels, foster homes, group homes, community training centers, day-care, respite care, and other community services.

The answer is not just removal from the institution, but a concerted effort of a variety of community services that can provide good alternatives to institutional living—or a by-pass of the institution altogether.

Wisconsin is planning to put into effect such a system. Standards, licensing and supervision of the community housing program are an integral part of the plan. Training programs

for the "parents" are arranged as much as possible.

One plan is for children under 18; another for adult retarded individuals. All require community resources back-up, and continued supervision by the sponsoring agency.

In the CHILDREN'S living system, the following are planned, and some in operation:

- FOSTER HOMES. Private homes with a family-type care program for less than five children. Full-time.
- GROUP FOSTER HOMES. Family-type homes for five to eight children. Full-time.
- CHILD WELFARE INSTITUTIONS. Facilities within the community for four or more developmentally disabled children who cannot remain in their own or foster homes, and who require specialized training, care and services. May be temporary.
- BOARDING HOMES. Homes for one to four children who temporarily need a place to live while attending a specialized school program—especially rural children. The children go home on weekends and for vacations.
- TEMPORARY CARE HOMES. Short-term, respite care for one to four children to relieve the family, or give emergency housing to children while plans are made for their more permanent living arrangements.

For ADULT living systems, 18 years and over, Wisconsin plans:

- FOSTER HOMES. Private homes with a family-type care program for less than five adults who can tend to their personal needs, and do not need continuing medical nursing services. They may be working and paying a part of their expenses or being trained for employment.
- GROUP FOSTER HOMES. Family-type homes for up to eight retarded adults who need supervision and personalized living. May be short-term or long-term care.
- BOARDING HOMES. Homes for up to eight retarded adults who are capable of independent living and total self-care. Most pay their room and board from earnings. Sometimes placement agencies supplement the cost. Little supervision required.
- RESIDENTIAL CARE INSTITUTION (Type I). Long-term care for a maximum of 50 semi-dependent individuals, most of whom will be able to care for themselves with minimal supervision, but require special social and vocational help. Emphasis on training by specialists in non-medical fields.
- RESIDENTIAL CARE INSTITUTION (Type II). Short-term care in a program resembling a hostel or halfway house for 9 to 30 residents living semi-independently, with social, minimal nursing and community living needs met in the home. Some work or go to training programs in the community.
- NURSING HOME CARE. Three types of licensed nursing care for those who require specialized attention:

  Skilled: for those requiring services of a registered nurse because of severe handicaps.

  Limited: for semi-ambulatory persons with some self-help skills.

  Personal: for ambulatory handicapped persons who require minimal medication and are capable of supervised community activities.

In all nursing home care, State residential facilities make an independent evaluation of licenses, and they must meet the requirements of the State licensing agency.

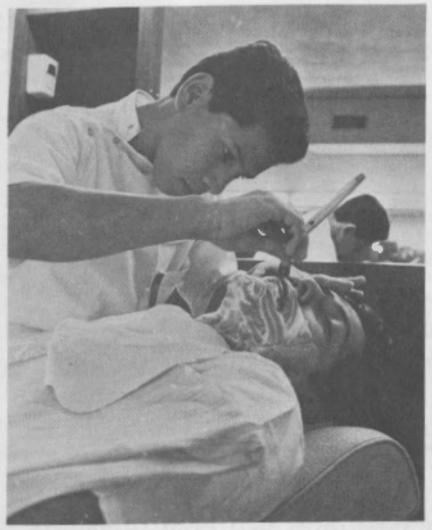
Adequate adult programming for social, educational and recreational needs is possible with proper staffing and funding. The use of trained volunteers is also encouraged.

The Wisconsin plan combines several agencies, including Division of Mental Hygiene and Family Service, Division of Health, Department of Social Service, Department of Industry and Human Relations (for local building, zoning, health and safety requirements) with overall monitoring by the Bureau of Mental Retardation.

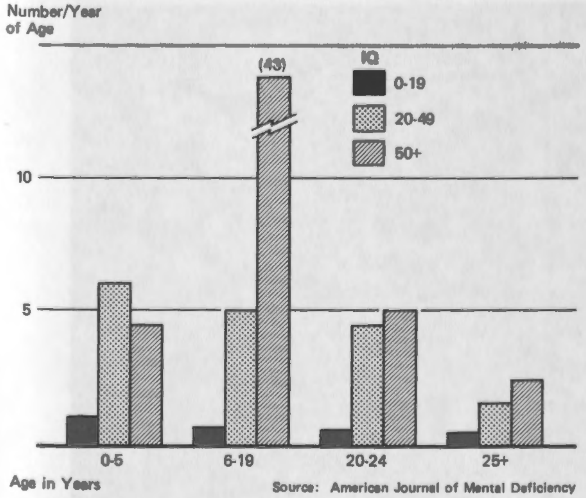
For further information, write:

Eastern Nebraska Community Office
of Retardation
Central Office
116 South 42nd Street
Omaha, Nebraska 68131

Wisconsin Department of Health and
Social Services
Bureau of Mental Retardation
Madison, Wisconsin 53706



ESTIMATES OF NUMBERS OF RETARDED PERSONS PER YEAR OF AGE IN A COMMUNITY OF 100,000



Source: American Journal of Mental Deficiency

Making It on Their Own

Elwyn Institute, a residential facility for the mentally retarded near Philadelphia, chose 65 of its long-term residents to take part in a 4-year research project concerned with independent living.

All were retarded, with an average of 15 years in institutions. Most had been orphaned or abandoned by their families at an early age. The oldest had been in an institution for 49 of his 50 years.

They were given batteries of aptitude tests; classes in personal adjustment, work adjustment, and community adjustment; and a choice of 15 trade training courses. And then they were moved out into halfway houses to introduce them to independent living.

> *"The mentally retarded are people. People do not live in institutions or facilities. People live in houses."*
>
> —**Jens Malling Pedersen**
> **Danish Architect**

Their work record:

More than 90 percent are employed in steady jobs.

Of those who had been in the labor market for four years, more than half had changed jobs—largely to better themselves.

They were more satisfied with their work than with their wages and chances for advancement.

Their social record:

One-third were married, and had a total of ten children—not one of whom is retarded.

All have made some new friends since leaving Elwyn. A few joined bowling clubs.

Most return to Elwyn for annual parties, picnics, and on visiting days. A number came back for help in filling out income tax forms.

Favorite recreation (in order of popularity): TV, radio, visiting friends, going driving, movies.

Their record as residents of the community:

Their savings accounts average between $300 and $500. Most have life insurance, in addition.

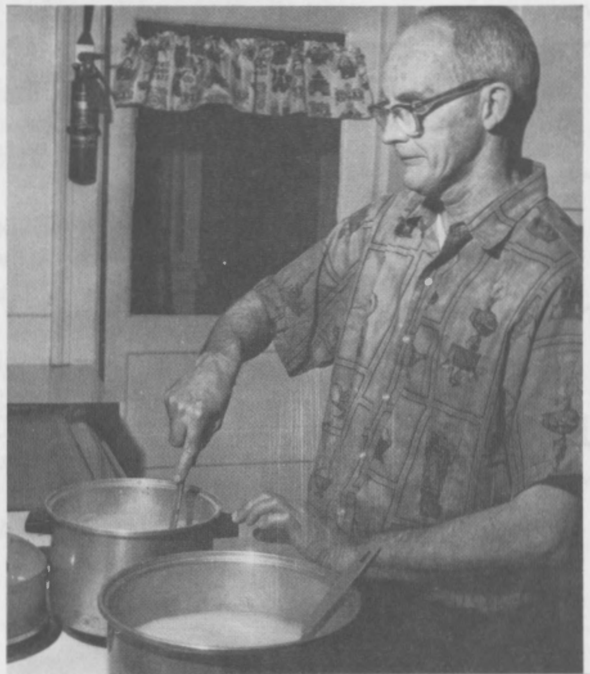
Three had been arrested, but none convicted.

Most lived in rented rooms or small apartments, starting out in furnished quarters, then buying their own furniture when they could afford it.

So they have made it in the community. Nearly all feel they will never need to be in an institution again. And Elwyn agrees.

For further information, write:

Elwyn Institute
111 Elwyn Road
Elwyn, Pennsylvania 19063



Building a Model for the Nation

Back in September of 1964, a group of special education vocational students in Pennsylvania were given the job of cleaning up and renovating an abandoned school bus garage. It was to be used later as a classroom and training facility for senior high school boys.

Within two years they had gone far beyond cleaning up; they had renovated the building and constructed a wood-working shop, an auto body shop and a classroom. The building became a "monument" to the vocational students' ability.

Too much had been gained to stop with that one project, so when a house in the community was about to be condemned, the Director of Special Services of Intermediate Unit One arranged to have it given to the program.

One year later, the expertly renovated building was ready to be used as a home management house for trainable senior high school aged girls. The boys are still responsible for its maintenance.

A more ambitious step followed. With $150,000 of school funds, the students overhauled a two-story building that is now the West Leisenring School for the Handicapped. A bright, cheerful school, it is complete with elevators and ramps for wheel chairs, a physical therapy room and other special purpose spaces. Its estimated value today is nearly six times the cost of renovation.

By now, the vocational students had shown that they could do a job with supervision, and do it well. It was time for the program to grow up to its potential and branch out beyond the limits of the school.

An agreement was made between the program directors and *Concerned of Pennsylvania, Inc.*, a non-profit organization launched by clergymen of three denominations to develop badly needed low-cost housing.

Concerned acquires the homes to be renovated, provides the building materials and leaves the completion date open-ended. The special education class provides students to do the work, instructors to supervise and train them, and hand tools and equipment.

Specialized services beyond the capacity of the students are contracted out by *Concerned.*

Because of the source of free labor, it is possible to cut the selling price of the homes to the cost of materials and contracted services only. And the special education classes are assured a permanent program of on-the-job prevocational training in the building trades.

The group has now progressed to building new pre-fab houses.

To steelworker James Greene and his family, their renovated home in Smock, Pa., is a "dream come true."

The Greens paid $9,500 for their attractive 4-bedroom home, with most of that amount covered by a Farmers Home Administration mortgage.

The new pre-fabs are being sold for $15,500, well below the usual market price. *Concerned* now has applications for 175 would-be purchasers.

Because the construction work has taken the boys considerable distance from their school, they have a trailer for a classroom that goes with them on the construction site. It serves 20 to 25 students.

The industrial arts teacher, who has had several courses in teaching the mentally retarded, and the certified special education teacher assigned to the classroom trailer, work closely with the boys and with each other.

Classes and construction work are done in shifts. If there is any problem on the job involving math, reading, measurements, etc., it can be immediately corrected in the classroom. The curriculum is built around practical aspects of the job.

Visitors to the current construction site will see one group of boys vigorously engaged in such tasks as waterproofing foundations while the other half of the class sits in an adjacent trailer concentrating quietly on their math workbooks. Peering over their shoulders, you'll see such eminently practical problems as:

"A plumber, in connecting a water tank, used six lengths of pipe as follows: 16 inches, 28 inches, 8 inches, 21 inches, 6 inches, 32 inches. How many inches of pipe should he charge to the job?"

Their instructor says he has never had any discipline problems, although this was not true when they were in a more traditional, less relevant academic setting.

All eight of the June graduates from the program found employment, in spite of depressed conditions in this once prosperous coal mining area.

They are living proof of the motto on the wall of their trailer-classroom:

"When the going gets tough, the tough get going."

Despite the attraction of the program, the question inevitably arises: What do the unions think of it? Isn't such work cutting into their territory?

Not at all. The Monongahela Valley Building and Construction Trades Council is not only endorsing the program, but promoting it as an innovative approach to some of America's most urgent problems in both education and housing. Unions are busy with larger-scale projects and welcome the entrance of these young allies into the field.

So, what started as a local, vocational education experiment for a few young men could prove to be the spearhead of a *national* program to provide low-cost housing, vocational education and employment to thousands.

Fruition of such a plan requires the participation of State and local education departments and of several departments of the U.S. Government, including Labor, Commerce, Agriculture, Housing and Urban Development, and Health, Education, and Welfare.

Indeed, the vocational students of the Monongahela Valley are building more than houses; they are building a model program for the rest of the nation.

For further information, write:

Director of Special Education
Intermediate Unit One
1148 Wood Street
California, Pennsylvania 15419

PCMR'S ROLE

The Executive Order establishing the President's Committee on Mental Retardation assigned it three tasks:

1. **To advise and assist the President on**
    - **evaluation of the adequacy of the national effort to combat mental retardation**
    - **coordination of Federal activities in the field**
    - **liaison between Federal activities and those of other public and private agencies**
    - **development of public information to reduce the incidence of MR and ameliorate its effects.**
2. **To mobilize professional and general public support for MR activities.**
3. **To report to the President at least annually.**

HIGHLIGHTS OF PCMR's ACTIVITIES IN 1972

PCMR MEMBERS 1972

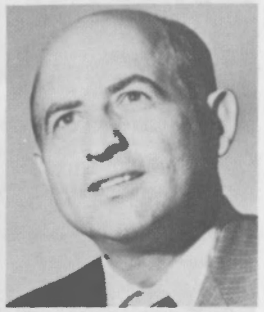
Elliot L. Richardson
Chairman

Clair W. Burgener
Vice Chairman

Marianna Beach

N. Lorraine Beebe

Robert A. Collier



Frank R. DeLuca

Richard J. Elkus

Ralph J. Ferrara

PCMR organized, at the President's request, a full-scale *review of all MR and MR-related programs in the Executive Branch of the Federal Government.* The published report is the first on the total Federal MR effort.

PCMR developed and published a Committee position paper on *lead poisoning,* terming it a preventable cause of mental retardation.

PCMR held a series of meetings on critical issues in mental retardation, focusing on the *return of retarded persons to community life.* Participants: National leaders from parent and professional organizations in the MR field.

PCMR launched a newsletter for the *exchange of information* on public relations activities of agencies involved in MR, with PCMR as clearinghouse.

PCMR maintained an active interest in several *court cases* testing the rights of the retarded to education, treatment, due process, and payment for work. Committee assisted certain plaintiffs in obtaining expert advice and testimony. PCMR plans a *National Legal Rights Conference* in the spring of 1973.

PCMR determined that the President's goal of reducing by half the occurrence of MR could best be met through improved *maternal and infant care.*

PCMR organized *training institutes* in southwestern and midwestern states for leaders in parent and professional MR groups. Institutes covered a wide range of subjects including the latest in preventive measures and community services, presented by experts.

PCMR met with the youth branch of the National Association for Retarded Children to discuss their *volunteer efforts.*

PCMR met with spokesmen for the *health insurance* industry to try and resolve misconceptions of the nature of mental retardation which has caused insurance groups to consider the retarded "uninsurable."

PCMR conducted, in a coordinated effort with several agencies, a definitive conference on *early childhood screening and assessment,* led by foremost authorities in the field. The findings and conclusions will probably have national implications concerning cost-effective screening programs and treatment before the occurrence of irreversible damage.

PCMR expanded its *international* interests, in attempting to identify mental retardation services and programs which might serve American citizens overseas. Participants in a series of meetings included representatives of the State Department, Organization of American States, International League of Societies for the Mentally Handicapped, and Armed Forces agencies.

PCMR served as catalyst in creating the *Indian Education for Health Committee,* whose formation was personally announced by the Secretary of Health, Education, and Welfare (responsible for Indian health), and the Secretary of Interior (responsible for Indian education). The purpose is to coordinate health and education programs on reservations, with an emphasis on mental retardation prevention and improved community services for the retarded.

PCMR studied, endorsed, and disseminated information nationally about an innovative *school*

Donald L. Fox
(Deceased)

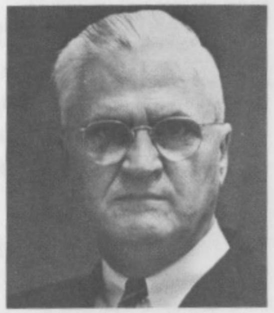
Melvin Heckt

Cecil B. Jacobson, M.D.

James N. Juliana

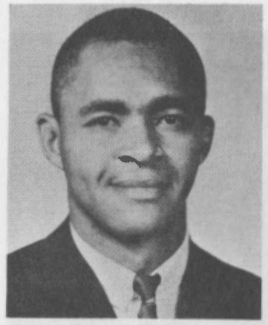
Lawrence A. Kane, Jr.

Aris (Bob) Mallas

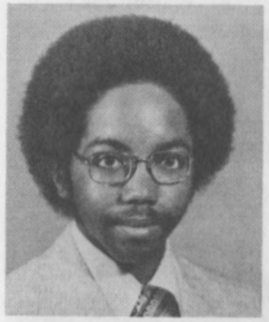


Lloyd E. Rader, Sr.

Louise R. Ravenel



William B. Robertson



Kenneth S. Robinson

Jeannette Rockefeller

The Secretary of Labor, Ex Officio

vocational program in Western Pennsylvania in which retarded youth learn construction skills and related academic subjects by renovating houses for sale to low-income families.

PCMR conferred with the National Association of School Psychologists on alternatives to *IQ tests* in assessing pupils' individual needs.

PCMR held a planning session with representatives of Federal agencies in the mental retardation field to discuss *training of administrators in the delivery of human services* rather than solely for the delivery of services to a specific group.

PCMR issued six new *publications,* bringing the number of reports to 20 at the present time. (A current list is available on request.) Total number of publications distributed in 1972: 259,550. Total number of *inquiries* received and answered in 1972: 42,860.

Caspar W. Weinberger

Will Beth Stephens, Ph.D.

Margaret B. Ulle

Miriam G. Wilson, M.D.

The Director of the Office of Economic Opportunity, Ex Officio

MR 72 RECOMMENDATIONS

We have described in this report models of programs in various parts of the nation. Clearly implied is our recommendation that such programs be adopted or adapted on a wider scale by State and community agencies. More specifically, as to Federal actions, we offer the following recommendations as means of achieving the President's goals in mental retardation:

1. A Mental Retardation Coordination and Liaison Office at the highest administrative level should be established in Federal departments of executive agencies that have not already done so. Through these offices, the departments and agencies should work with the President's Committee on Mental Retardation for a coordinated effort. Similar action should be taken at the regional level, involving Federal, State and local representatives.

2. A plan should be formulated by the involved Federal departments to aid State and local governments in implementing community services as alternatives to institutionalization of mentally retarded persons.

3. Public agencies and private businesses capable of helping retarded persons to find competitive or sheltered employment should reexamine and intensify their efforts to secure far more job placements. A chance to do work according to their highest potential is crucial to a better life for retarded persons.

4. As a prime means of preventing handicaps, efforts should be concentrated on improving maternal and infant care.

5. The Federal Government should make fullest use of existing Federal authority to act on behalf of legal rights of the mentally retarded, and should consider enlarging that authority.

6. Appropriate agencies and organizations should work with PCMR in focusing information and education resources to create greater public awareness of prevention possibilities and a climate of community acceptance for retarded persons.

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Ruth Ann Metzger

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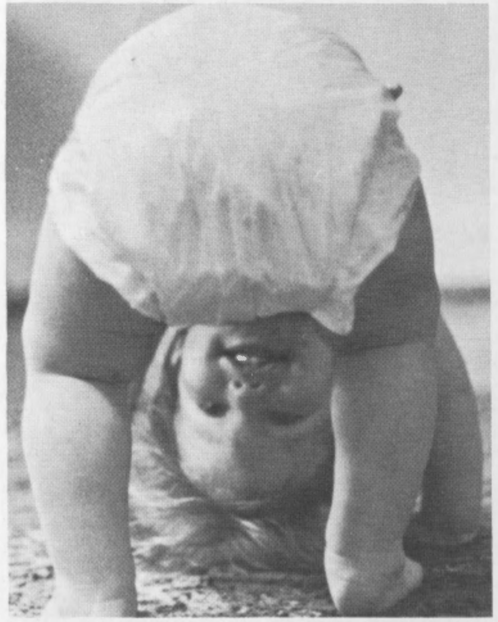
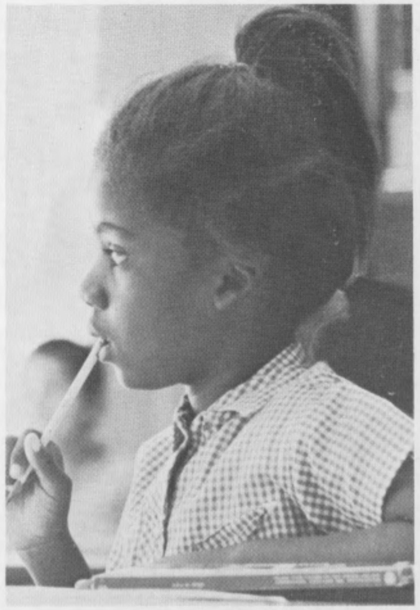
George Tarjan, M.D.
John D. Thompson, M.D.
Thomas A. Tucker
Raymond W. Vowell

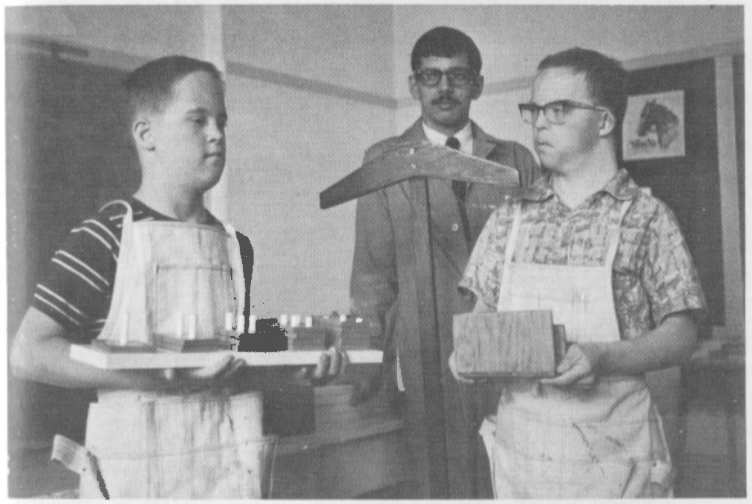
We wish to thank the numerous individuals in all levels of government and the private sector, especially those in voluntary organizations, who have contributed so much toward PCMR's efforts to reach the President's goals of prevention and normalization in the field of mental retardation. We appreciate the commitment of PCMR's consultants and special advisors who have given technical assistance on many projects and special reports. And we wish to pay special tribute to the staff whose experience and dedication have enabled the Committee to carry out its far-ranging program to prevent mental retardation and to ease the burden of those afflicted.

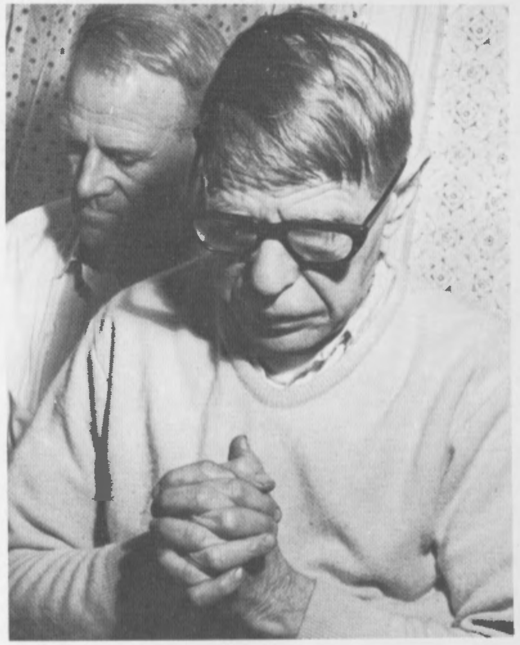
Fred J. Krause
Executive Director

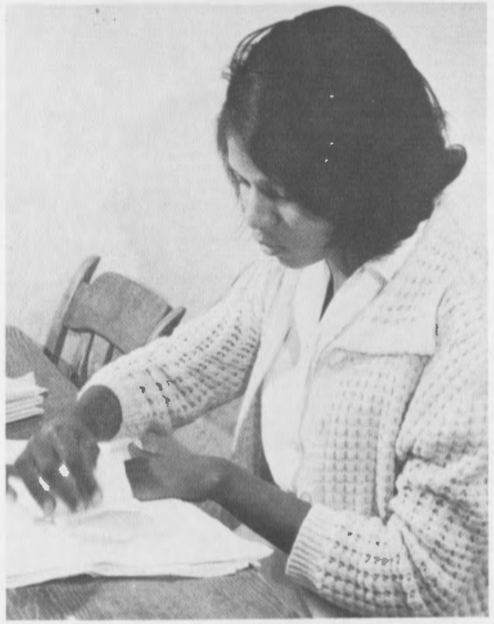
☆ U. S. GOVERNMENT PRINTING OFFICE : 1973 735-726/2118











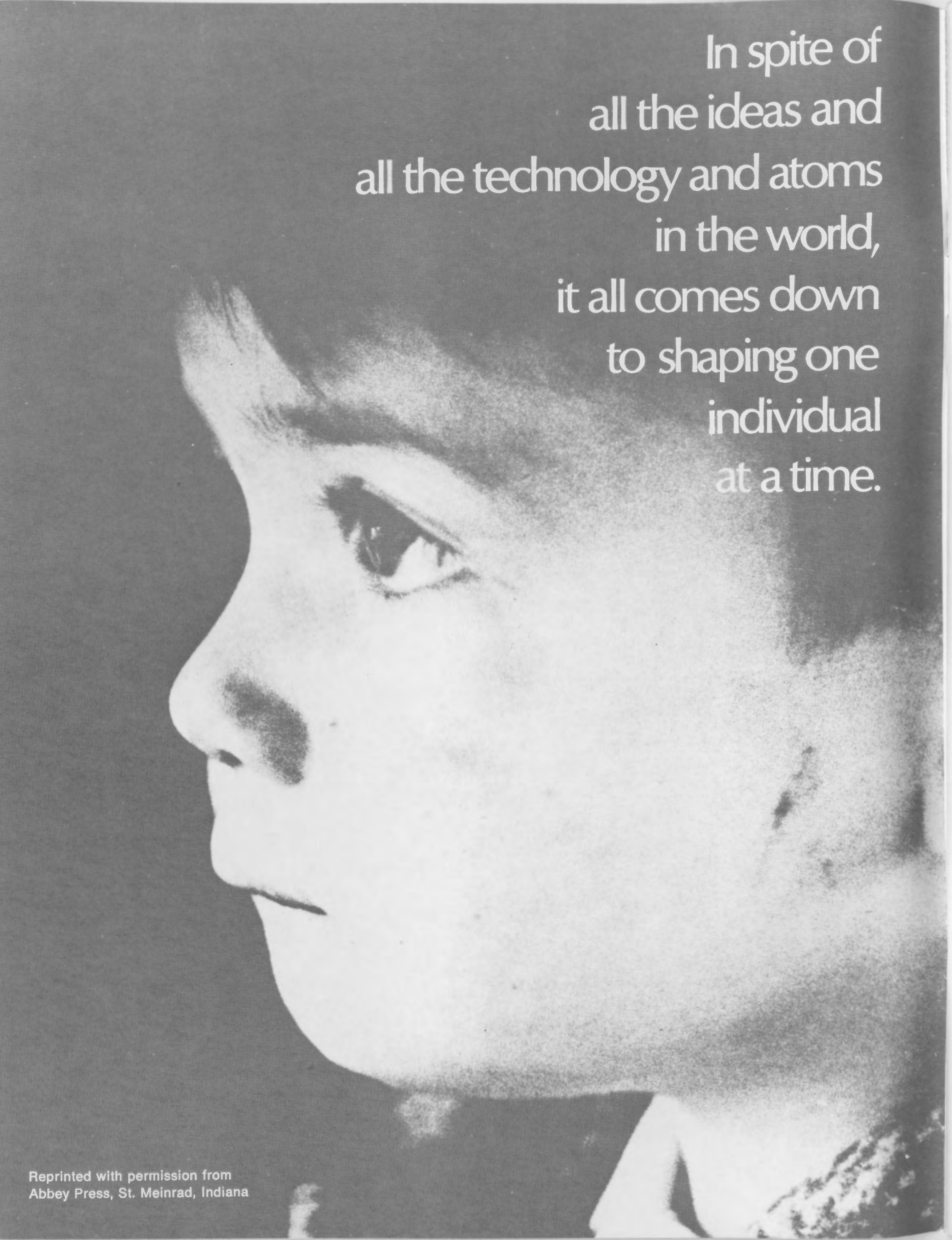
DHEW Publication No. (OS) 73–7

THE PRESIDENT'S COMMITTEE
ON MENTAL RETARDATION
Washington, D.C. 20201

The President's Committee on Mental Retardation
Washington, D.C. 20201

MR 73/ THE GOAL IS FREEDOM

THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
Washington, D. C. 20201



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The President
The White House
Washington, D.C.

Dear Mr. President:

It is a pleasure to present to you the seventh annual report of the President's Committee on Mental Retardation, MR 73: The Goal Is Freedom.

This is a human document, concerning mentally retarded people who might have lived wasted lives had it not been for remedial action that enabled them to develop into contributing members of society, freed from those internal blocks that set them apart.

Some have been able to avoid dependency by early treatment. Some have been brought out of institutions into employment and community living. Others have been saved from retardation by preventive measures.

Both the prevention of mental retardation and the preparation of retarded people for community living are relevant to the goals you have set for the nation.

These achievements have been made possible by the application of modern behavioral and medical science in the prenatal, neonatal, and early childhood periods, in addition to the concept of continuous development for all retarded persons, no matter what the age.

Evaluation of programs can now be based on specific data, with records showing individual progress along a continuum of objectives toward a stated goal for each person. The criterion for evaluation has changed from whether or not the client is being served to how much improvement the client has shown as a result of the service.

We commend these advances to your attention. We ask your support in helping to bring these services to all retarded individuals and to all those at risk of being born retarded.

Faithfully yours,

Caspar W. Weinberger
Caspar W. Weinberger
Chairman

N. Lorraine Beebe
(Mrs.) N. Lorraine Beebe
Vice Chairman

INTRODUCTION

This report is not about "the mentally retarded."

It is about a little boy who failed to thrive because he had been abandoned; a young girl suffering from the emotional effects of 16 years in a State school; a group of "crib cases" who were helped to function as human beings and given their identities; a young woman emerging as an adult after 26 years as a child.

The primary diagnosis for all of these people was mental retardation. The primary problem for each, however, was fear, or social inadequacy, or physical limitations. These internal, personal barriers to freedom were more responsible for keeping them from living meaningful lives than their IQs.

When they were recognized as individuals, each different from the other, each with potential for further development, they were given help based on individualized assessment of their actual needs.

As a result, they did develop, and are still developing as persons, step by step, toward realistic goals.

The expectation of continuing development toward objectives and goals, set on the basis of individual assessments, and measurable on achievement scales, promises to become the guiding principle in the mental retardation field.

Consequently, planning for services is shifting from a program-centered approach to a client-centered one. The criterion for evaluating programs is no longer: How many clients are being served? It is becoming: Are the clients developing as a result of this program?

The President's Committee on Mental Retardation therefore has chosen to base the first section of this report on individual children and adults who have grown and developed as a result of this goal-oriented, personalized concept. Large-scale, long-term results are not yet available, since application of the concept is relatively new.

The report is also concerned with other kinds of programs that can aid in avoiding dependency and promoting optimum development. The main emphasis here is on prevention of the problem. The second section consequently contains material related to research on prevention and early intervention. It is based on presentations given at a four-State Forum held by PCMR in Kansas City, Missouri in the Fall of 1973.

Areas covered include prenatal research into the causes of handicapping conditions, the oldest and at the same time the newest method of transporting a high-risk infant, early childhood programs for handicapped children, and treatment to prevent long-term institutionalization.

One of the methods of communicating such advances is this annual report from the President's Committee on Mental Retardation to the President and to the American people.

Other activities conducted by the Committee in 1973—in the field of legal rights, early childhood intervention, preparation for community living, housing, public information, among numerous others—are covered in the report's third section. All are designed to promote progress in preventive measures, or to create a climate that will enable individuals who are retarded to live as normal a life as possible.

Taken all together, the underlying philosophy of the entire report was expressed over 100 years ago by Thomas Carlyle:

> *"Let each become all that he was created capable of being; expand, if possible, to his full growth, and show himself at length in his own shape and stature, be these what they may."*

DHEW Publication No. (OHD) 74-21001

MR 73

bears witness to the Committee's beliefs that:

- **Mentally retarded people are capable of continuing development.**
- **Corrective measures introduced in early childhood can reduce the severity of the handicap and sometimes reverse its course.**
- **Prenatal and neonatal biomedical intervention can prevent many forms of mental retardation and related handicaps.**

STEP BY STEP TOWARD FREEDOM

"We will let him show us what he can do."

He was like a frightened deer when he arrived at the children's center. A small, wild creature, clawing, biting, kicking everyone within reach, including himself.

At five, he spoke only a few words. Prolonged screams were his principal means of protesting captivity.

Mentally ill?

Mentally retarded?

His last psychological evaluation, when he was four, tentatively gave him an IQ of about 30.

"Forget the diagnosis," said the center's director. "He is a frightened child. We will work with him and see what happens. We will let him show us what he can do. And then we will work with him some more."

Bryan is seven now, a sociable, outgoing little boy who is the pride of his foster family. Aggressiveness has turned into leadership; he often plays teacher to his class.

Soon he will graduate from the center's program to a special education class in public school. Later, he may be able to move into a regular class. No one knows yet. After all, he has traveled so far in the last few years. . . .

At least it appears that he is headed for a self-sufficient life. Two years ago he was headed for a lifetime in an institution.

Bryan is one of an increasing number of retarded individuals who are being helped to develop toward personal freedom and functional independence through intensive, individualized programs that are oriented toward practical goals.

Rather than being catch-all programs planned on the basis of IQ level, the newer programs are designed to answer unique needs, and to remove those personal, inner barriers that tend to set mentally retarded persons apart from the rest of society.

In many cases, retarded mental development is not the major problem. The main factors blocking individual progress may be uncontrolled emotions, or negative self-image, or entrenched negative habits that are reinforced with repetition, or physical handicaps. These "side effects" are often more inhibiting to development than mental retardation itself.

For Bryan, the road to freedom has been filled with barriers, both external and internal, from the day he was born.

He was premature, and weighed just a little over two pounds. So he stayed in the hospital for the first five months. There, at least, he survived, though just barely.

From then on, because his mother was unable to care for him, and because of his "failure to thrive," he was in and out of hospitals for five years. When he was out, he was in receiving homes except for a brief time after his first birthday, when he went home.

A social worker found him there, alone, abandoned, eating his own feces.

Each receiving home, each hospital did for him what their limited resources allowed. He wasn't neglected. The hospitals treated him for his physical ills, and one started him on a sensory stimulation program, which began to bring him out of his emotional prison.

It wasn't that no one cared. They cared deeply, wrote long, agonized descriptions of his behavior and his needs—"but his needs reach beyond this program. . . ."

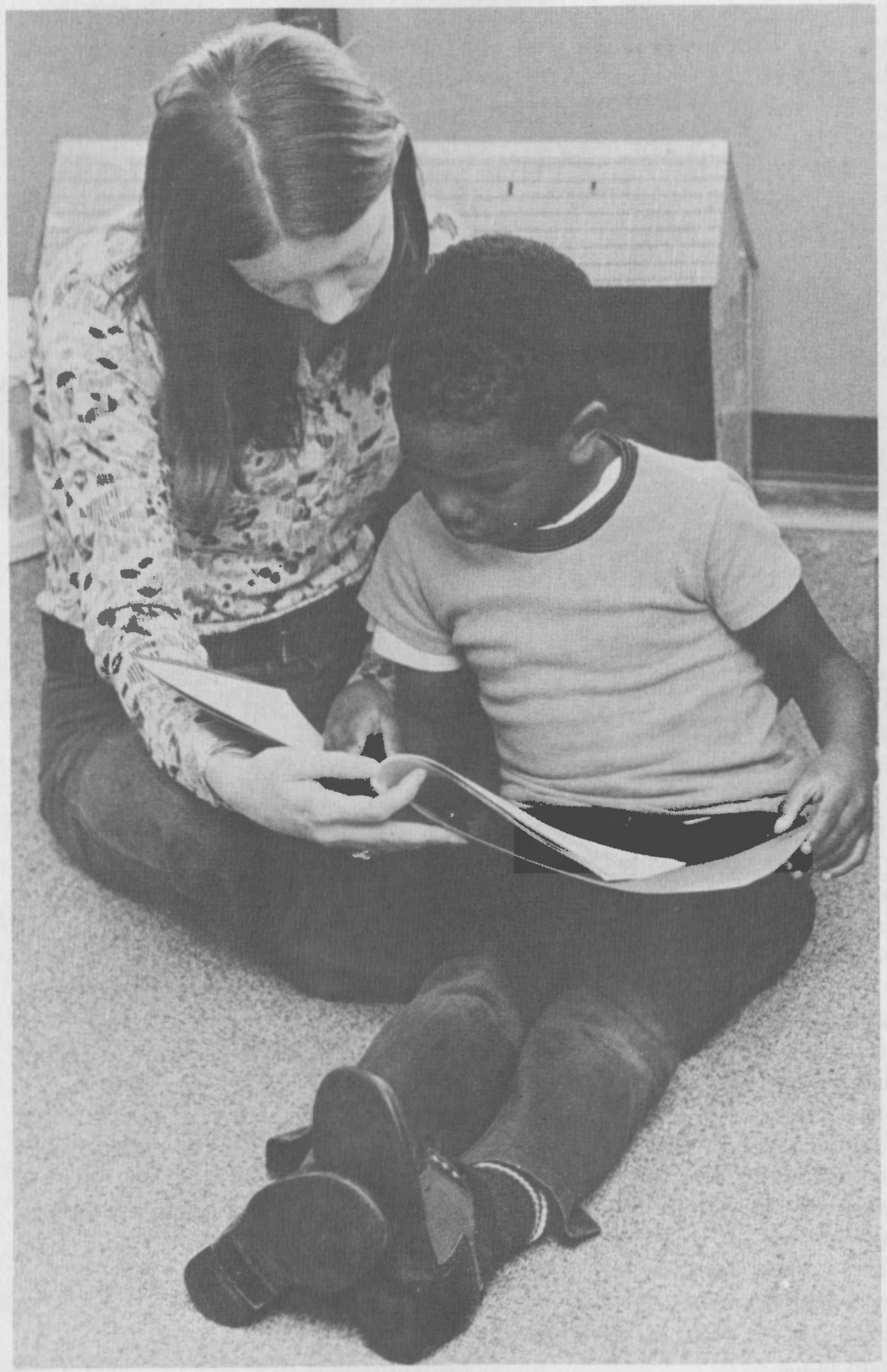
From tests made when he was four, he appeared to be functioning at a little over a one-year-old level, IQ 30+, although the psychologist noted that his bizarre behavior and deprived background made meaningful results almost impossible.

He screamed or cried constantly, rocking back and forth in bed or on the floor. He plucked at his skin until it was raw. No speech. No relationship to people. A little boy tuned out, captive of his own inner world of terror.

When he was referred to the children's center they ignored the test results.

But there was no way to ignore Bryan.

During the first few months there he would tear into the director's office whenever he got the chance, destroying papers, pictures, books,



anything he could reach. He was five then.

Less than six months later he was still running into his office, but now for a daily hug, and a little talk.

By that time, he was quite a little mimic with his new-found method of communication: Speech. The staff often wondered if he would pick up the director's Hungarian cadences. He didn't.

The specifics of treatment at the center are carefully and individually prescribed, but, more important, the attitudes of the staff and administrators are shaped by the philosophy expressed in every act: Each individual is precious and each is capable of continuing development.

When a child is deprived of normal stimulation, he often begins to stimulate himself. This can become destructive in certain children who may injure themselves severly by head-banging, biting, or other kinds of self-mutilation. So the staff attempts to substitute the negative acts with positive ones, the destructive stimulation with constructive stimulation.

"Early age is the best time to get them," says the director. "When they come here they are already failures, rejected by the system, rejected by themselves—sometimes by the time they are five years old.

"Here we try to reinforce success. Success is sweet, and it's fun to succeed."

Bryan had no tolerance for failure. At first, during the behavior shaping, there were very few successes to reinforce. They came more frequently as he began to respond to the unfamiliar experience of having one person's fulltime attention all day in the beginning of his therapy.

Then he moved up to groups of two, three, then a class of five or six. The temper tantrums, the screaming, the rocking, and finger plucking at his skin gradually subsided.

Eventually—it took many months—he decided it was more fun to do what the class was doing than to go his own way. He was discovering that cooperation has its rewards. He began to choose to cooperate.

Slowly, the academic program started. It took weeks of training for him to be able to sit still on a chair and observe the teacher for even the briefest length of time, one of the first of the "educational survival techniques" the children are taught. When he mastered this art, the first objective had been reached toward the goal of learning how to learn.

The check marks on his achievement chart were moving further over from the "Never" column, through the "Sometimes," the "Usually," and more into the "Always."

Bryan was ready now to learn how to read.

And so on up the ladder of learning and behavior. He may not make it all the way to the top. The scars of his formative years run deep. But he is still climbing.

Even though the program at the children's center is individualized and highly personal, it is systematized and structured, the program director, a psychologist, explains. "We structure the situation, and build the environment around the child in order to get constructive change."

Each instructional program is broken down into specific units, each unit containing both a detailed procedure and a clearly defined behavior goal.

The teacher then can record baseline behaviors for each of the children studying the unit. Thus, research and services are joined. The children's progress can be measured, and also the relative effectiveness of each of the components can be analyzed.

After behavior is modified to the extent that the child is able to exert inner controls, the staff begins to introduce academic learning.

One of the goals is to give the child the skills needed to survive in the educational system. Another is to promote inner motivation that will carry him through on his own.

"These flowers must bloom in the cold, outside world, not just in this hothouse."

The staff tries to involve the parents as much as possible, although only about half are able to take part. Some are employed by the center.

IQs are seldom mentioned there. And although there are records containing diagnoses, test scores, performance assessment and other relevant information, they are used only as aids to individual program planning and assessment—never as a means of identifying the person. They are kept confidential. When a child goes from the program into a regular classroom in public school—as many do—no labeling goes with him. "He's then just a nice kid in school," says the director. "Some administrators love to call children by their diagnosis. We don't give them the chance. If there's any trouble, his mother knows where she can come for help."

The center's basic goals are best described by the director:

"When we get the children at four or five or older, the cycle of behavior, of performance, is turning one way—negative, negative.

"A temper tantrum is negative fun.

"Then we give them a taste of something that's more fun. Being hugged, patted, smiled at, cuddled for doing the right things. They soon find that, yes, that is more fun than biting and screeching.

"Pretty soon the cycle begins to reverse. Slowly. We all—all of us—push, push toward the positive. Replace all the negatives with positives. You take away something bad, you have to put something good in its place. Reach an objective, put the next one higher.

"Now we introduce a little academic learning—a number, a letter.

Just a little bite at first. Once they taste the joys of learning, the learning itself becomes reinforcing.

"We give a little more push. Positive, always toward the positive. The cycle is beginning to turn more quickly now.

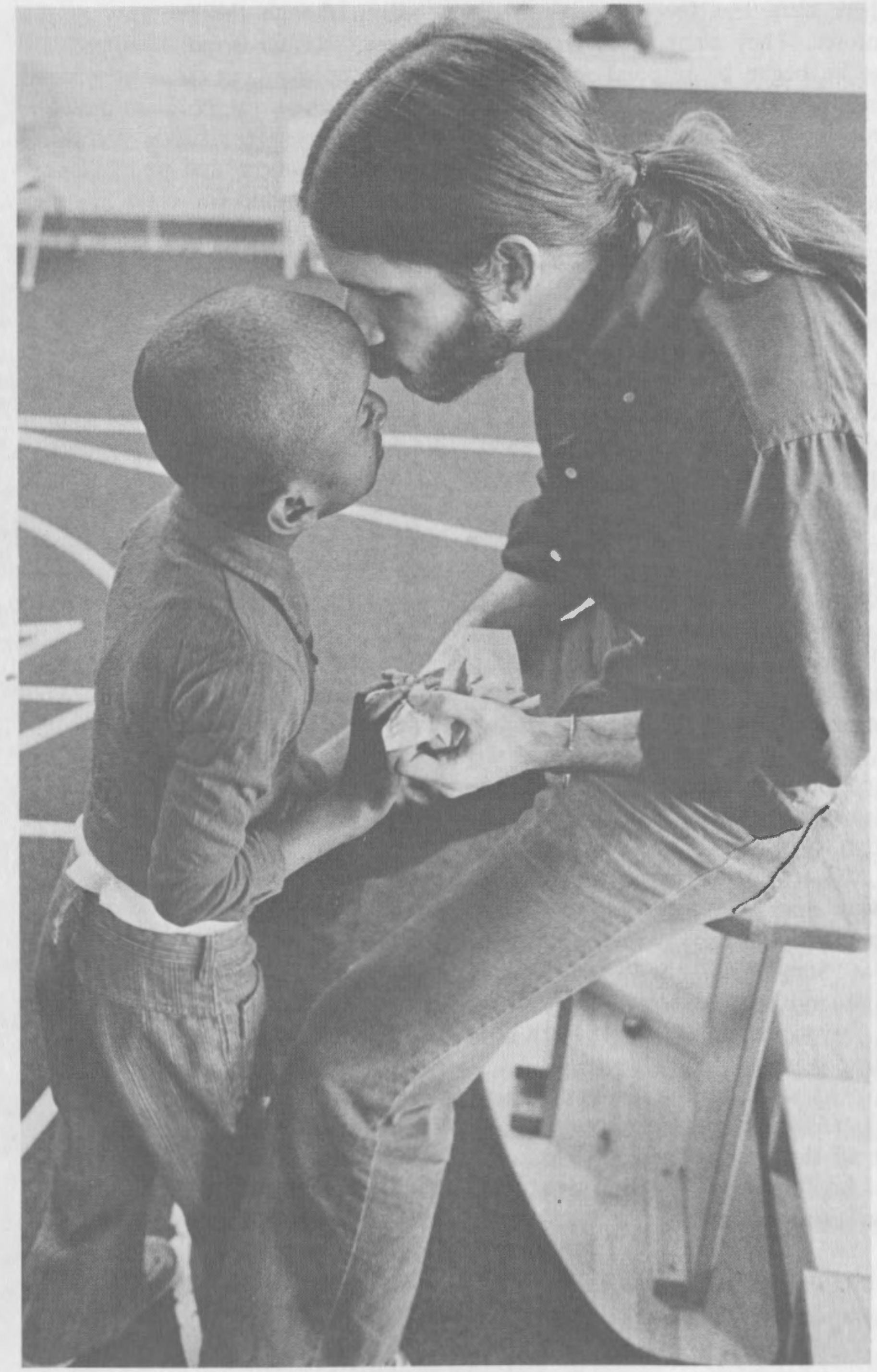
"Then all of a sudden something clicks.

"And you know that the child is beginning to push that inner wheel himself. That is the wonderful time.

"When the wheel inside is turning all by itself, then he is ready. We are done. And, God willing, then he has gained enough inner direction, motivation, momentum to carry him through. When someone on the outside yells at him, he can take it, because there is still the inner strength.

"And the wheel is still rolling—positive, positive."

Contained in those words are the "secrets" of helping handicapped individuals move toward a life of quality: Replacing negative with positive, emphasizing strengths, and setting objectives higher and higher—but still attainable—as each one is reached, toward the goal for each individual.



> **"You never know how far a person can go, once she decides she wants to go there."**

Last year Yolanda came out of the State school where she had been since she was two years old. She had stayed there for 16 years, becoming an institutionalized "retardate," fearful, docile, dull.

Her first attempt to hold a food services job and live in a group home failed, and she had to return to the institution.

The second venture into the world has succeeded.

She now has a job as a "Girl Friday" with a large corporation, where her puncture-proof good humor has made her an office favorite. Through her own initiative, she has parlayed the job from messenger to "office assistant," maintaining office supplies, and opening and closing the office each day, since she is on the job earlier and later than anyone else.

In a project she calls her "insurance for the future," she is teaching herself to type.

Yolanda originally had requested the business course at the occupational center where she was trained for employment but, because of her past experience with failure, the staff preferred to start her in something less stressful. So she was prepared for food services instead.

"That just proves," the center's program director commented, "you never know how far a person can go once she decides she wants to go there."

Only a few of her fellow workers know that she used to be labeled retarded.

Yolanda failed in her first job not because she was retarded, but because she wasn't making the most of her abilities. When she found what she did best—working in an office—she bloomed. And she is still progressing.

She may not ever become the president of the firm, but she'll never again stagnate in an institution. Even in economic terms, that was a poor investment. She was costing the taxpayers about $6,500 yearly. She's now proudly paying taxes and contributing in many other ways to society and the nation.

The first experiment in group living failed because Yolanda prefers living alone. Also perhaps because she was not so mature then as she is now. Counseling and personal adjustment courses at the training center have raised her level of maturity. And she's grown out of the rebellious adolescent stage that retarded as well as most other young people go through.

She's enjoying living by herself in her own apartment—a prime example of the necessity for offering a choice of life-styles geared to the individual.

Candidates for community placement, such as Yolanda, are bussed in daily to the training center from nearby residential State schools.

Because most are in their teens, the center provides a high school atmosphere, and offers sports and recreation in addition to the classes. Most of the classes are concerned with personal adjustments and job training, but there is academic work also, fitted to job requirements.

Initial concentration is on personal adjustment: Developing good work habits; eliminating the internal obstacles to progress; telling time, and developing a time sense; social and emotional adjustment.

There is a great deal of role playing and simulation of social and work situations.

"We work to get them to a level of maturity that will enable them to live in a group home or half-way house or independently, and to work successfully on a job," says the training center's director.

After much counseling and evaluation of their skills, they then start on actual job training for food services, maintenance or business work. For two to three months, six hours a day, they work in a simulated job situation.

Around this time, a couple of months before job placement, they move into a half-way house. "The program is set up and timed so that there will be as few simultaneous traumatic experiences as possible," a counselor says. "Starting a job and moving into a community at the same time is too much, especially if there are transportation problems."

The length of preparation varies for each individual, depending on whether he or she meets the criteria of the center, and whether goals have been met.

When the staff feels a client is ready, and has met the criteria, the placement officer goes into the community and seeks the jobs to suit individual talents. There are several sessions with potential supervisors, counseling with them as well as with the clients.

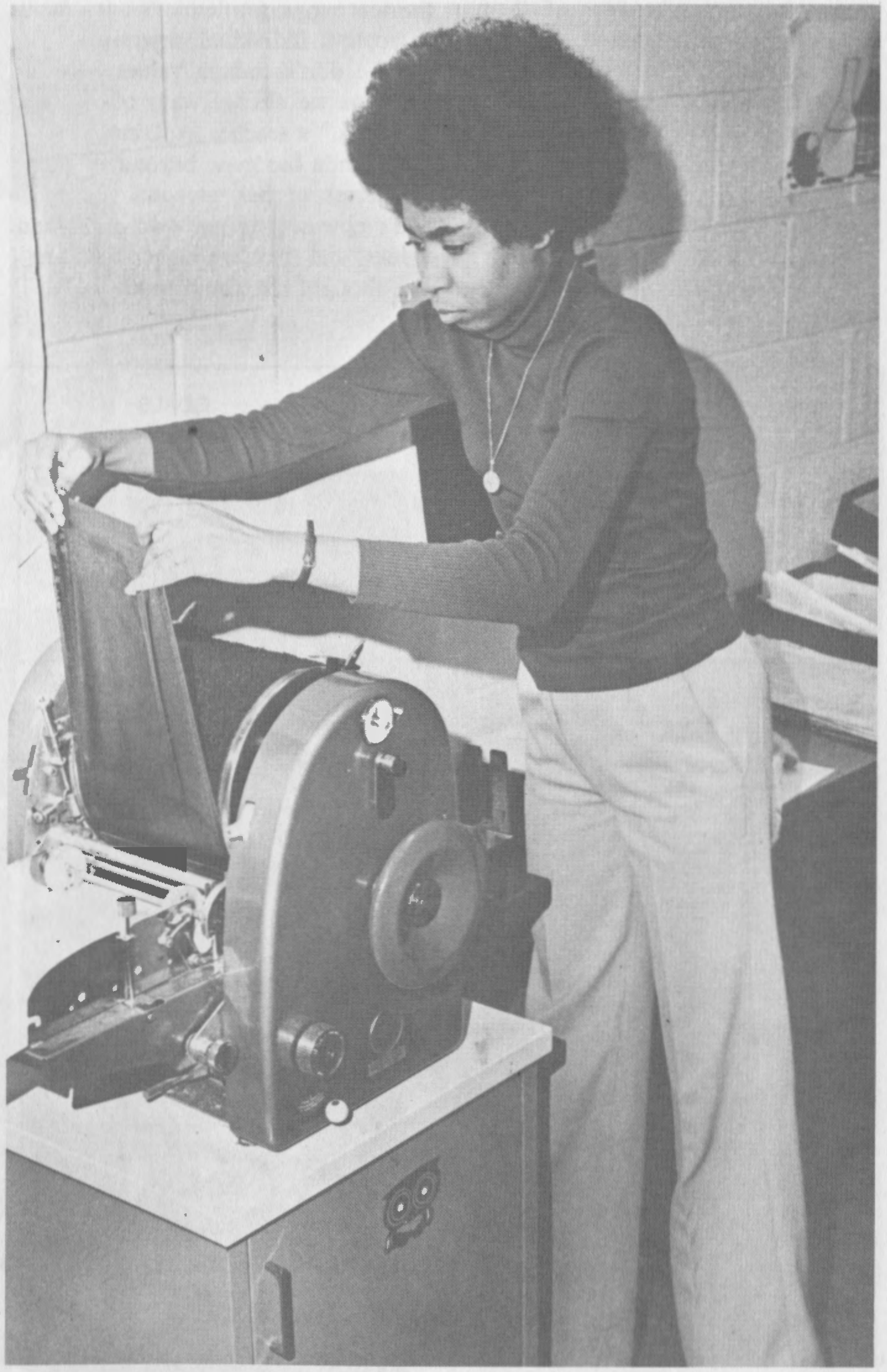
Sometimes the placement officer goes with the client for the initial job interview. In some instances, this is more for the benefit of the supervisor of the job than for the employee.

Before the job starts, there is transportation training. Transportation can be one of the largest external obstacles encountered. But accessibility of the job to the living situation is always a major consideration, before job placement.

There is frequent follow-up for the first few months, then periodic checks for the first year or so.

The alumni keep in touch, many returning once a month for a social evening at the center.

"We don't deal in IQs," the director says. "It doesn't even make any difference whether our students are supposed to be 'educable' or 'trainable' or whatever label someone has slapped on them. All that's important to us is whether they can get and



Gary Fine

hold a job and take care of themselves either in sheltered or independent living after they leave here. The vast majority make it."

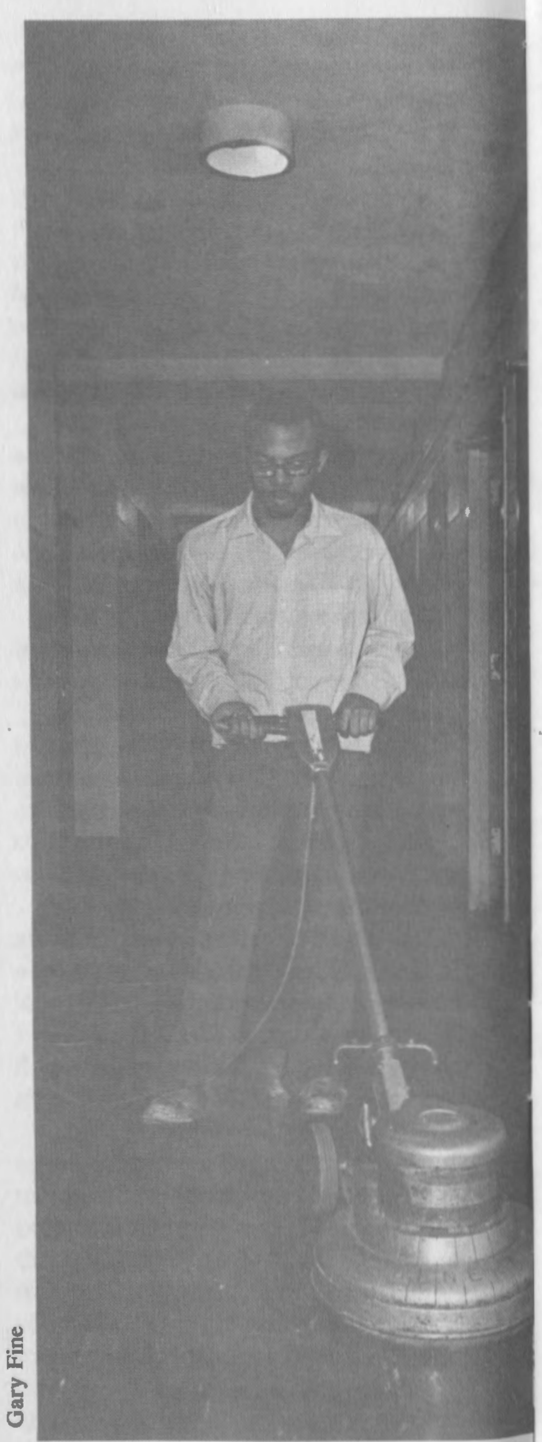
Throughout the classrooms, there are charts listing personal goals, arrived at after many sessions with the teacher and counselor.

Hanging beside the goals chart is a folder containing contracts made with themselves in cooperation with the teacher, a gentleman's agreement to achieve individual objectives.

"We don't change values here so much as we change ways of arriving at values," a teacher explains.

Yolanda has gone beyond fulfilling the terms of her personal contract. She's now setting her own goals and values, and they are higher than anyone thought she could reach.

NAME	GOALS *(Training)*	GOALS *(Personal Adjustment Training)*
Jimmy	Increase speed on assignment	Stop rolling eyes
Elrod	Stop complaining about work	Stop roving about class
Terry	Improve attitude	Lower voice level
Denise	Be punctual	Stop flirting



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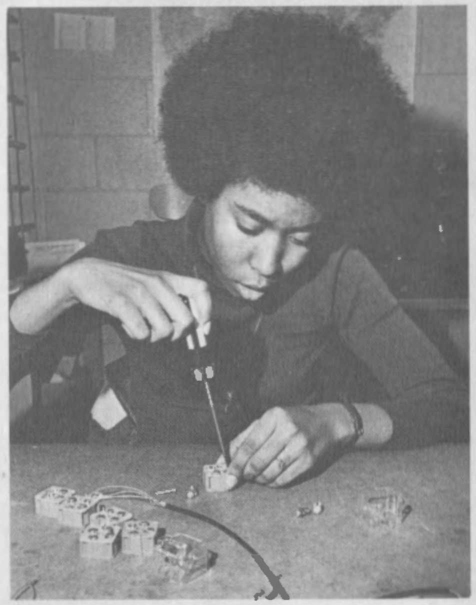
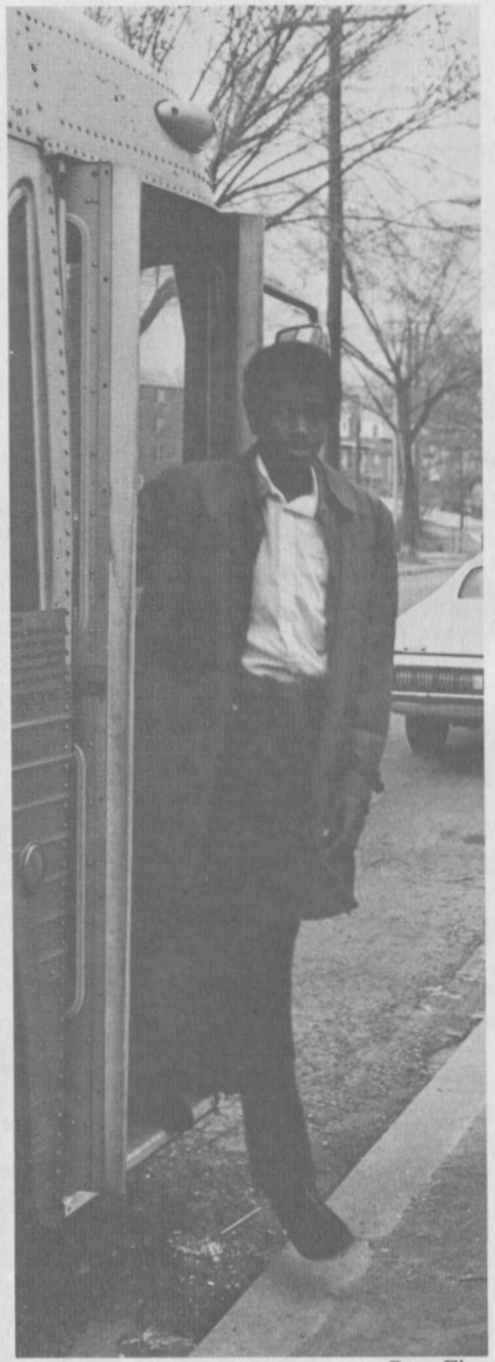


Michael Day



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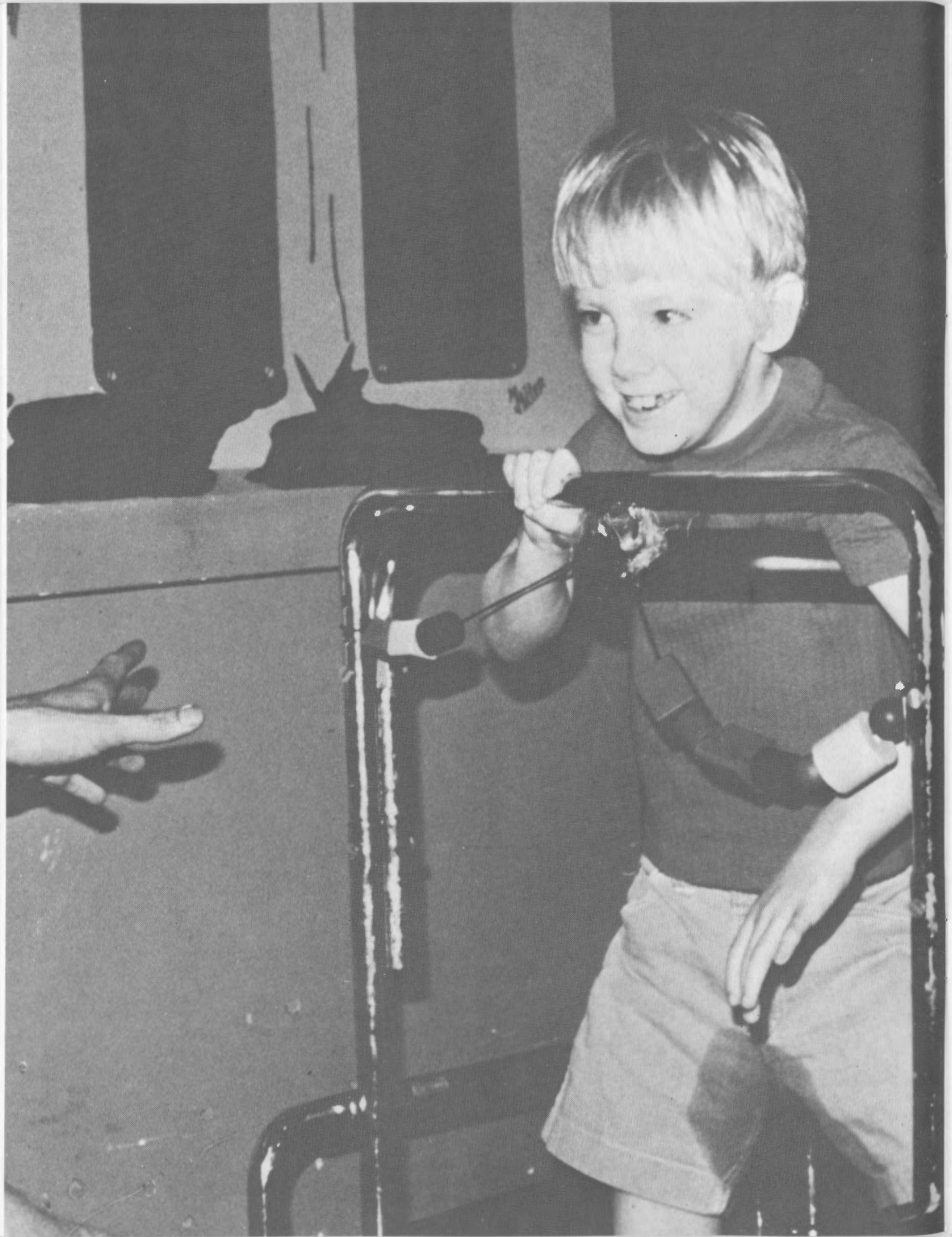


Open-ended progress for each individual

The setting of goals and objectives for persons who are retarded is quickly gaining acceptance throughout the various planning levels, from individual programing, through to the federal level. The approach is realistic and geared to the human scale.

Some programs employ minutely detailed individualized assessment charts covering every facet of functioning. Others use a more informal procedure that requires a minimum of record-keeping. Measuring techniques also vary according to age, severity of handicap, and other factors.

In goal-oriented, individualized assessment and program planning systems—there are several varieties—there is, first, a one-to-one procedure to modify or strengthen behavior. This is done to enable the person to move up from whatever functional stage he is in to the next higher level. (Example: John now combs his hair unaided. The next objective may be brushing his teeth unaided.)

Each step is measurable on individualized assessment scales.

Group planning is possible for several persons in a given situation when they have reached a certain common objective. (Example: X number of bed-ridden clients have become ambulatory, or X number of clients living in a group home are moving into independent living.) The administrator can then chart realistically the broad functioning level of a group of individuals and can plan programs according to the next objective for these clients.

Requirements for staffing, equipment, budget planning, daily programming and all other aspects of program planning must be kept flexible to meet clients' current and actual needs.

Community, then State, and federal planning can also be based on cumulative data on functioning levels and resultant needs for clients in order that they can advance toward higher objectives.

Traditionally, in the program-centered approach, "the mentally retarded" within certain IQ ranges have been fitted into existing programs. Many of these kinds of programs are a dead-end for the retarded person.

Client-centered programs, goal-oriented and based on individual assessment charts, on the other hand, fit the program to the client. Resources can then be redirected toward actual needs.

For instance, clients in a day care center might be enabled to progress to a higher level of functioning if given intensified occupational training and socialization. Some may need orthopedic surgery, or dental work, in addition. Remedial programs of various kinds may be needed simultaneously.

Each step is a prelude to the next step in an open-ended progression.

Benefits of the intensive training toward an objective extend beyond the person served. Each person who learns to dress himself, for example, not only moves up from total dependency to semi-dependency, but also frees the person who has been dressing him for more constructive duties.

For people with severe handicaps, there are some fundamental objectives. With rare exceptions, being toilet trained and ambulatory are basic requirements for going to school or getting a job, or group living. Both are high priorities.

Once toilet training is accomplished, self-feeding may be possible. Then dressing unaided. Then. . . .?

Who knows how far the ladder of development reaches for each individual?

The ultimate goal is the achievement of maximum functional independence for each person within his capabilities.

Is such a goal feasible for even the most severely handicapped individuals who are incontinent and bed-ridden? The next pages indicate the answer.

"Human beings inside. Handle with care!"

Viewed through the bars of the oversized crib, the diapered form lying there appears to be all arms and legs, frozen at grotesque angles.

Rows on rows of similar cribs holding similar faceless, nameless, sexless bodies line the walls.

In four wooden chairs drawn together, white-clad nurses' aides sit mutely folding mountains of diapers.

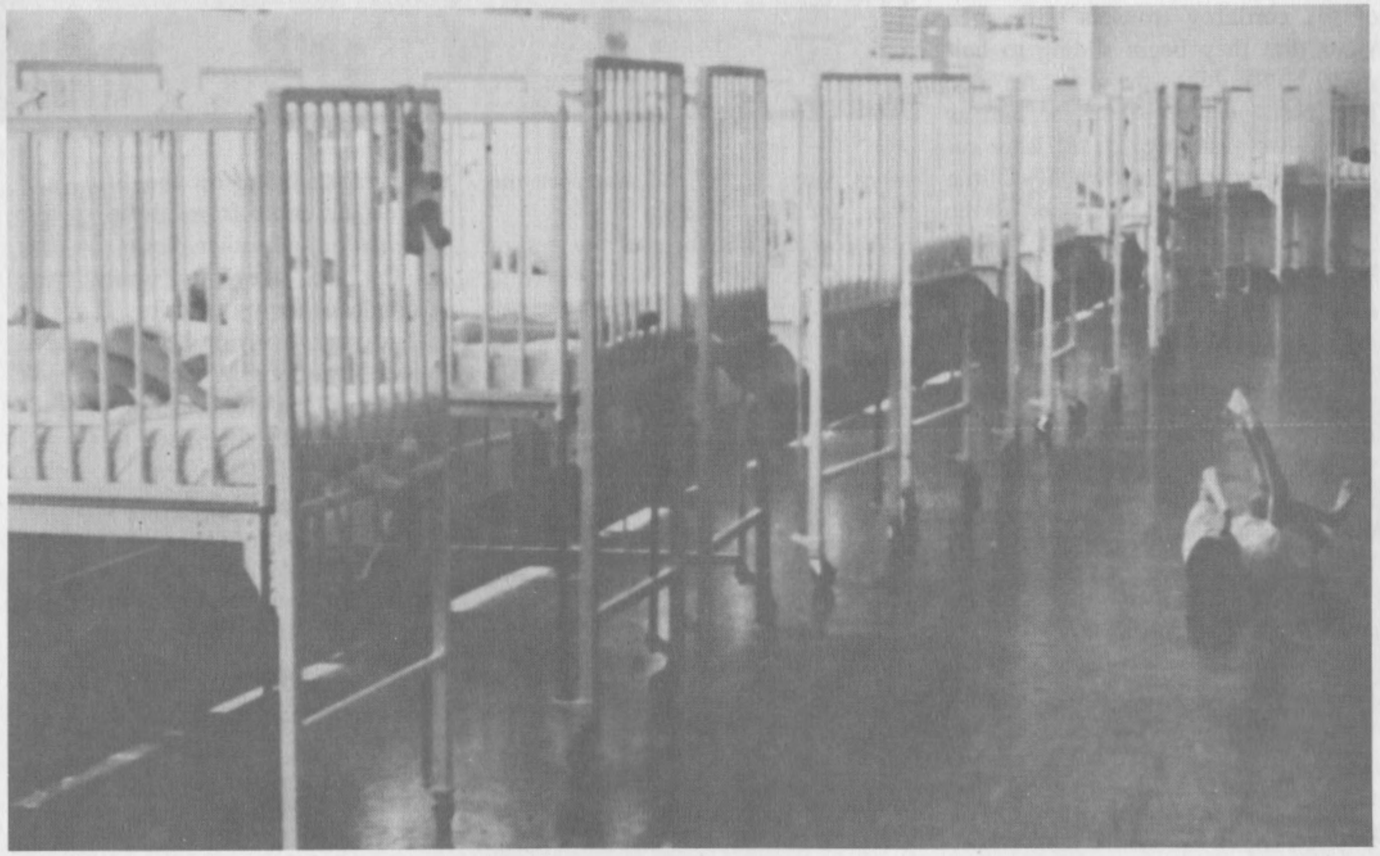
From the other end of the ward comes the only sound in the room, three community youth workers huddled together on a bench, giggling nervously.

The place reeks of a great variety of human waste.

This is one floor of a hospital for the "hopeless," the non-ambulatory, mentally retarded patient with multiple handicaps.

The linens, floors, walls are hospital clean. The patients, incontinent as they are, are as clean as they can be under the circumstances. They are fed as well as possible, considering their limited ability to chew and swallow. The staff-patient ratio is good.

In short, these patients are being served adequately. Requirements for



this patient population needing nursing care are being met.

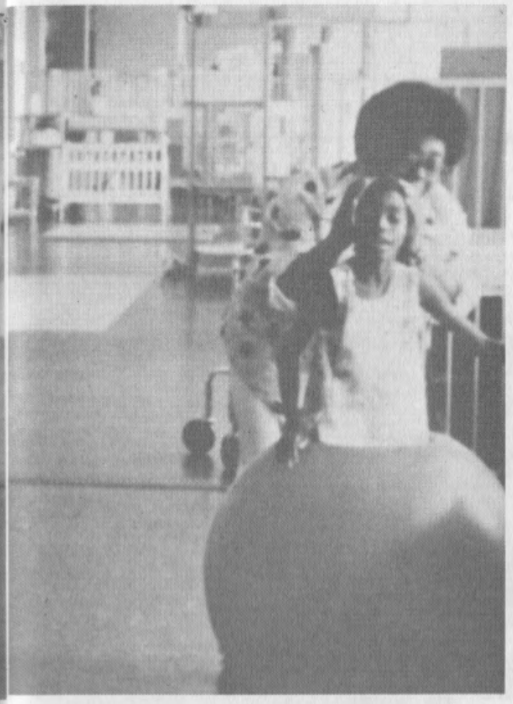
All other floors of the hospital are mirror images of this scene.

Except one.

The fifth floor, freshly painted in happy colors, is alive with murals and artistic designs by art students and community volunteers. A bright corridor leads to a door with a pronouncement attached: "CAUTION: Human beings inside. Handle with care!"

The door opens onto action and interaction, involvement, motion. A formerly nonambulatory boy of about eights walks up to greet the visitors. He plunges a hand into the pocket of his corduroy trousers with such vigor that they begin sliding to half mast, but he hikes them up. An aide in a blue pantsuit smiles at him as she rushes past to catch a frisbee released rather than thrown by a little girl seated on a mat. Near her on the same mat another aide is on his knees taking a blind child through the motions of tumbling.

A small group of children and adults doing art work at a table are so involved with one another that they are oblivious of the visitors. Some are staff, some residents. It is impossible to differentiate from the clothes they wear. There are no uniforms.



In a side room, two young children are asleep in cribs. But they are there because it is nap time, and they are taking their naps. Except for their shoes, they, like all the others on this floor, are fully clothed.

A few are in wheel chairs getting ready to be taken to the swimming pool. Everybody on this floor gets out at least twice a week.

The walls are in attractive pastels, decorated with residents' art work and posters proclaiming: "If you hear the music, join the singing." "No bird soars so high as he does with his own wings."

Basically, the needs as well as the physical and mental competencies of the *persons* living on the fifth floor are no different from those of the *patients* on all other floors. A few months ago, they, too, were lying motionless in rows of cribs.

The staff has not been increased for the fifth floor. When they weren't changing diapers or washing or feeding the patients, they used to sit and fold diapers like the staff on other floors. The staff is more in evidence on the fifth floor, but it is because on the other wards the staff tends to disappear for long periods during the day, to give in to the human urge to escape from a depressing scene, either down the corridors or to be absent for days at a time.

There is no appreciable increase in the cost of the fifth floor center of action over the wards of inaction below.

The changes are not due to a demonstration grant, and these persons on the road to mobility and selfhood will not slip back to being immobilized, faceless forms in a deadend hospital after a spurt of progress.

A total learning experience is taking place here for residents and staff alike. It has started on the fifth floor; it will gradually include the entire resident population. [Since this section of the report was written, the other floors have been included in the program with comparable results.]

The changes encompass the colors, the light, the furniture, the living space allotted each individual, the person-oriented design of that space, dynamically and effectively used. Words that shape attitudes are changed.

Hospital, ward, patient, retardate —all the inappropriate terms are being removed from signs as well as from vocabularies. Uniforms are disappearing, though roles remain clearly defined, and each knows that he has a responsibility in the total program plan—the laundry workers through to the director.

First and foremost, though, the change from immobility to forward motion on the developmental scale has been accomplished through the establishment of an ultimate goal: Liberation of the person.


Michael Day

"Can you help me get out?"

Age is no deterrent to further development and successful community living, even after nearly a lifetime of institutionalization, for some people.

"Can you help me get out?" The request came unexpectedly from a man raking up leaves on the institution grounds. He had not been on the list of residents to be interviewed by a county Association for Retarded Citizens group, there to interest residents in community living.

His hair was white, but his step firm, despite his 70 years. "I don't know how long I've been here," he told the group. "Long as I can recall."

He had heard from others about the program of training being offered, and decided that he wanted to be a part of it. In a very short time, he was accepted as a candidate. For the next month he went through the evaluation tests, including social adaptability. He passed with ease.

Now he is having the time of his life, living in a group home with some younger men.

He likes gardening and yard work. So the goal for him is a job as a yard man in an apartment complex for elderly persons, situated conveniently near the group home. Meanwhile, he is making the transition in a sheltered workshop run by the county ARC.

"This is really living," he says, as he draws up a chair for a checkers game with the other men after dinner.

"I'm staying here."

Some move toward independence and freedom of choice with ease. Some hold back, shackled by restraints too ingrained to overcome.

Miss Bessie's production rate outdistanced even the youngest worker in the sheltered workshop attached to the State home for retarded people. Every day she tried to better her record, and often did.

She was 56, a tiny, bird-like woman who had been in the institution since she could remember.

For the past 12 years she had been assembling components for hair driers, and she was proud of her work. "Nobody here can work any faster than me," she boasted, tilting back her head with mock arrogance.

A candidate for community living? She could make money with her skills.

"They better not try to get me out of here." She bristled at the thought of moving. "This is my home. I'm staying right here. And you'd better believe it."

When Miss Bessie was placed in the huge, isolated asylum, as they termed State schools in those days, it was thought to be the ideal life for retarded people.

Miss Bessie still thinks so. And for her, it is. Life "outside" would defeat her.

Out of the nest

Janice is 26. She has lived at home with her family all her life. The only time she was away from home overnight was when she spent a week at a camp for retarded adolescents.

For six years she has worked in a sheltered workshop doing routine jobs, and generally being pleasant, shy and quiet.

Perhaps that was her problem. She was so agreeable that she was no problem to anyone, so she was passed over when chances for advancement were being offered.

One day a teacher in the program had a long talk with her and found she liked the idea of working with people—"doing things to help them."

Evaluations showed she was capable of developing beyond her present job, and also seemed to be ready for moving out of the protected environment of living at home at the age of 26.

In this case, it was the parents who needed counseling more than their retarded daughter. After several sessions they began to see that she could grow more as a mature person if she were out of the nest. So she's now living in a group home and working a few hours a day giving lunch to children in a nearby nursery school. Gradually the time she spends there will expand.

She is making plans to move into her own apartment whenever she is financially capable of the move. A friend at the workshop will share the apartment.

In her spare time, Janice is now trying to organize a volunteer group to go on regular visits to a State school and provide friendship and recreation for the residents.

Long-range goals for Janice are being revised, with the sights raised, based on her short experience with new-found freedom.

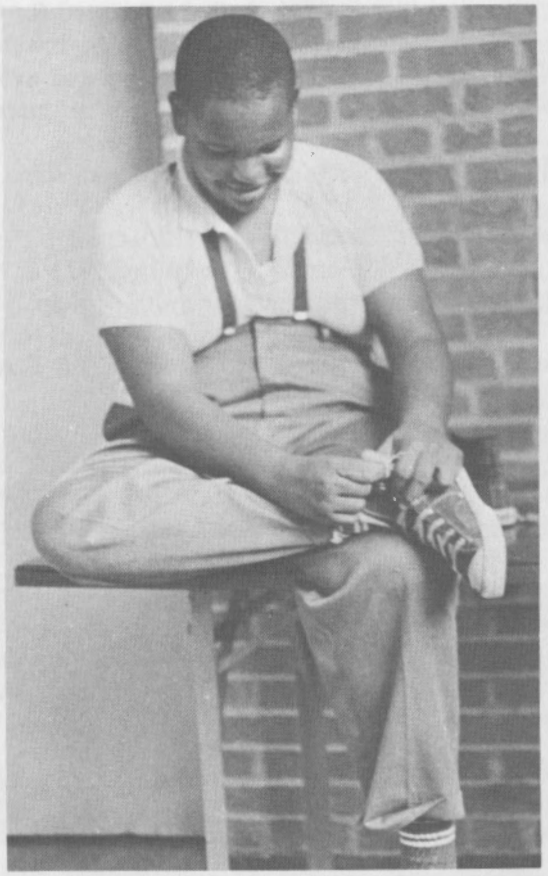
"If I get a job will I have to leave here?"

The staff of the group home couldn't figure what was wrong with Harold. He was the most helpful and affable of the seven men who lived in the home. No one was more happy than he was to get out of the institution. But he resisted all efforts to place him in a job.

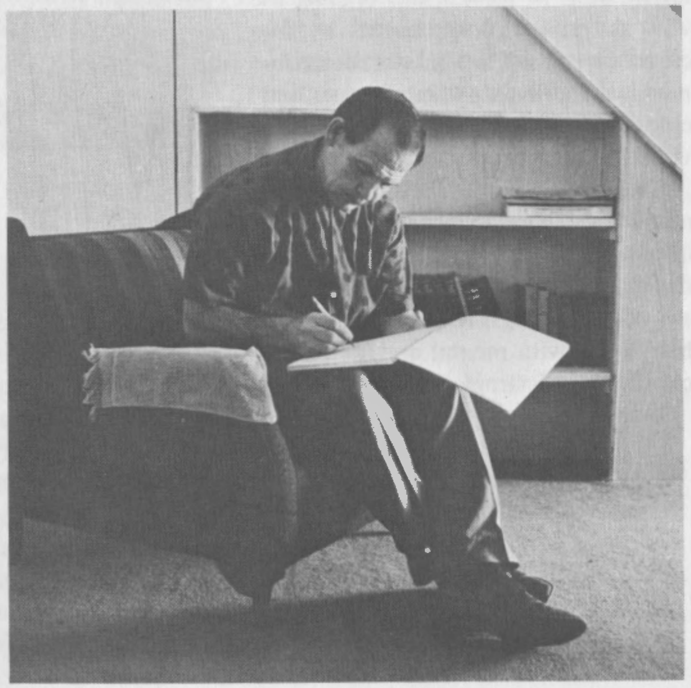
Finally, he confessed. "If I get a job will I have to leave here?"

Reassured that he would be involved in any decision concerning his life, and offered freedom of choice, he stopped worrying. A week later he had a job.

Home, for him, was the group home—at least for the present time.



Michael Day



The positive approach

The best hope for reaching the goal of freedom is prevention of the handicapping conditions that can rob individuals of their freedom and keep them dependent throughout their lives.

Across the nation, research is delving into the factors that promote healthy human development or those that disrupt development and result in damage that is often irreparable. The health and environment of both mother and father, even before conception occurs, is of importance, as is the genetic inheritance they will pass on to the child.

From conception on to completion of pregnancy, development and differentiation of tissues and organs, as well as growth (represented by increase in mass) are major determinants of the eventual intellectual and emotional functioning of the individual.

Though research has uncovered many causes of disorders beginning in the prenatal period, discovering the cause is but one step in the process of correcting the problem. Every baby born with mental and/or physical disorder is tragic evidence of the need for further research and application of present knowledge.

So, if preventing handicapping conditions is the best hope of freedom and avoidance of dependency, early and intensive treatment is the second best hope.

A handicap can usually be made much less severe when treated in the early developmental period. When retardation is the result of sensory deprivation, research has indicated that early childhood stimulation and improved environment can often correct the condition.

For many children, it is already too late for such remedial intervention. But it is still possible to lessen the handicap considerably, and make these children less dependent than they would be if left untreated.

Many such research and treatment programs are going forward across the country. Results of the work strongly indicate the need for further positive action directed toward prevention of retardation and avoidance of dependency, so that more may benefit.

In order to hear from some of the people who are directly involved in these fields, PCMR held a Regional Forum in the Fall of 1973 at Kansas City, Missouri, with participants from Kansas, Missouri, Iowa and Nebraska. Other Forums are planned for the future.

The material in the next few pages is based on relevant, selected presentations made at the Forum. They start at the beginning of the chronology of prevention, with research on reproductive biology. They then move on to attempts to prevent disorders in high-risk pregnancies; through an early intervention program for infants and young children and their parents; and, finally, to an intensive, short-term program for severely handicapped children to prevent their long-term institutionalization.

"The entire potential ... in one cell."

"There is a moment in time when the entire potential of the individual is in one cell, a single microscopic cell invisible to the human eye," said Dr. John Spaulding in the opening words of his presentation at the PCMR Forum.

Dr. Spaulding, Director of the Children's Rehabilitation Center at the University of Kansas Medical Center, reviewed the Center's research into various stages of prenatal growth. In every stage of pregnancy, he explained, a number of events must occur in sequence in order to produce a healthy child.

First, researchers at the Medical Center are exploring the relationship of hormone levels to ovarian function in order to learn how conception is enabled to take place.

Then, to determine the elements that affect the survival very early in pregnancy, they are studying tissue implanted in the mouse uterus.

"A severe disruption at this very early stage would lead to death," said Dr. Spaulding, "but a less severe one may still distort the entire growth and development of that individual from there on."

The Medical Center is also investigating placental transfer in goats, with exactly dated pregnancies. They are especially looking into placental transfer of various significant drugs, to determine the effect of the drug on the goat fetus, and the dosage relationship.

Dr. Spaulding also discussed the Medical Center's fetal diagnostic studies, using the technique of amniocentesis, to draw fluid from the embryonic sac. [Many university medical centers and some other large medical centers are now offering amniocentesis and prenatal diagnosis to families.] He stressed the necessity for an experienced obstetrician to perform the amniocentesis; the need for a competent lab to do the chromosome, or biochemical, studies; and an expert in genetic counseling to interpret lab results and to offer a prognosis if the individual is diagnosed as affected.

What, for example, will it mean in the life of the person if he is found to have Down's syndrome?

"Counseling," he said, "has to be connected with some way of taking action. If the pregnancy is to be terminated, an expert obstetrician is needed. If the pregnancy is to be continued, there must be follow-up programs."

In the area of neonatal physiology, he described tests being done on newborn infants that may indicate whether or not the child can hear. Earphones are placed on the baby, and a pacifier put in his mouth. The pacifier is connected to sophisticated recording devices. The researchers then induce the child to suck, and feed sound into the earphones—a mixture of classical and folk music. The infants can be conditioned to suck for longer and longer periods because they seem to like to hear the music and "they will work (suck) for it."

When they reverse the process, said Dr. Spaulding, and turn off the music as soon as the child sucks, he will then suck less and less and less—indicating, it would seem, that he can hear.

> *"When this test is done in the incubator, it has shown that the background noise in there is deafening. The inside of an incubator is a loud, noisy, dripping, roaring place. One questions whether that's very good for the nerves of the infant."*
>
> John Spaulding, M.D.

"The most attractive isolette ever made."

From five to twenty percent of all women who are pregnant will have an infant who is at some degree of risk, Dr. Gerard Van Leeuwen told the PCMR Forum. The range is related to the socio-economic structure of the area.

The six major causes of death or brain damage in babies, he said, are low birthweight, maternal diabetes, maternal toxemia, blood incompatibility, congenital malformations, and complications of pregnancy.

Dr. Van Leeuwen, who is Professor and Chairman of Pediatrics at the College of Medicine, University of Nebraska at Omaha, is a "practitioner of newborn medicine," a specialty that requires at least two additional years of training after pediatric residency.

In small communities, he reported, there is usually one doctor who delivers the mother, and if the mother has difficulty, this means there is no one there to take care of the baby. Therefore, Dr. Van Leeuwen and his team emphasize the importance of a second, trained person to resuscitate the baby.

He pointed out a few of the dangers at the time of delivery. Too much oxygen may cause blindness and lung damage; not enough may cause brain damage. Letting a baby get cold also may produce brain damage, he said.

Other causes of neonatal brain damage that he cited are low blood sugar, infection, and jaundice when it is severe enough for the bilirubin (which causes jaundice) to reach a certain level in the blood and enter the brain—one of the common causes of cerebral palsy.

One of the methods Dr. Van Leeuwen and his team use to prevent disability in high-risk newborns is a transport isolette which carries its own oxygen and can be used in a car or airplane. This equipment plus a box of medication and supplies are all that is needed to provide total care of the infant from the moment he is picked up at the emergency entrance of the referring hospital or the home, and brought to the newborn intensive care unit at the University of Nebraska Hospital.

> *"Those of us who are in the business of preventing mental retardation and developmental disabilities and those who are treating the problem often don't realize that we're in the same business."*

"Probably the best way to move the infant, however," Dr. Van Leeuwen said, "is inside the uterus."

He called the uterus "the most attractive transport isolette ever made. It hardly ever gets dropped. It never runs out of electricity, and it has a number of other advantages. It keeps the baby oxygenated and warm."

He reported that during the first six months of 1973, 75 mothers were transferred to the hospital; in 1963 none were. The team transported four babies in 1968. During 1973 they transported 250 babies.

By taking these extra measures, they initially believed they could reduce the number of deaths by half, and prevent some of the brain damage and disability. The results, however, have exceeded the expectations.

Dr. Van Leeuwen reported that a 1949 to '53 long-term survival study in Colorado on 91 babies who weighed four pounds or less at birth indicated that 66 percent had handicaps. One-third of these handicapped children were severely mentally retarded or had cerebral palsy or were blind.

In the Nebraska program, he said, serious handicaps are down to about 6 percent of the survivors. The survival rate has doubled.

In 1973, he said, at least 75 percent of the infants under four pounds in their program appeared to be mentally normal and have minimal developmental disabilities—despite the fact that these were all high-risk infants.

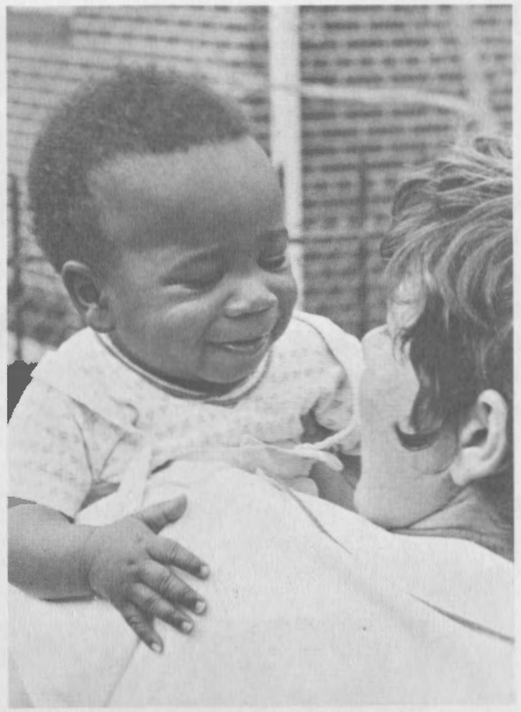
Dr. Van Leeuwen added that there is still a possibility that a number of these children may have minor disabilities that would not be discovered until they may have learning problems at school.

Cost for the intensive medical care of a high-risk newborn infant is often $5,000, he said, and frequently reaches $20,000, paid for in a number of ways—insurance, parents, the State. State dollars have not been used for air transport, however. "This is a small price to pay for a normal brain and a normal body," he concluded.

Goals for each child

The purpose of the Infant Development Center, Lake Quivira, Kansas City, Kansas, is to provide developmental education immediately upon identification of high-risk or suspected atypical infants, and to provide supportive and informative counseling for the family. The program was described to the PCMR Forum by the Center's director, Lee Ann Britain.

> *"The impact of the birth of a handicapped child on the family is a devastating experience."*
>
> *"We like to get to the mother right away and give her emotional support, and let her meet other mothers in similar circumstances."*
>
> *"The mother, or whoever has the primary care of the child, is the developmental educator, trained by the Center's staff."*
>
> *"Highly individualized goals are set for each child by the staff in the development of gross motor, fine motor, adaptive, language, and personal-social skills."*



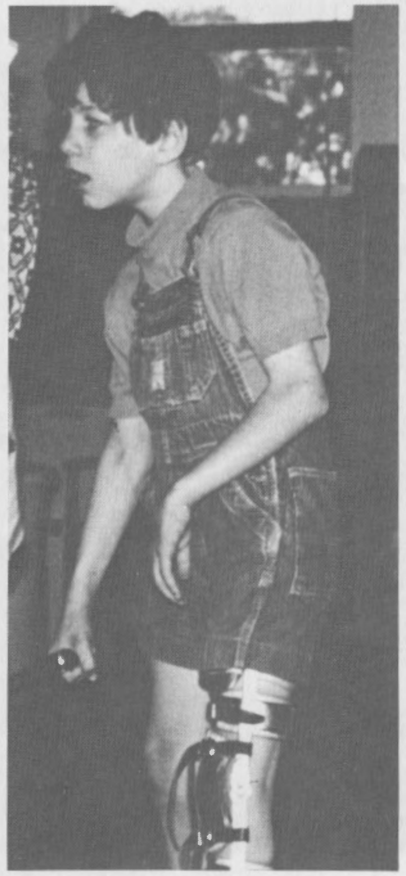
"If we don't do anything for this child now . . . "

To prevent long-term admissions, Woodward State Hospital-School, Woodward, Iowa, has started a short-term intensive treatment unit and respite care program for children from birth to 12 years of age, Dr. S. B. Hussain, Clinical Director, reported in his PCMR Forum presentation.

The expressed purpose is to assist parents in the home management of their child and possibly avoid the need to place him in an institution.

"The difficulty of rearing a retarded child in the home can be reduced through early intervention in behavior management and special therapy techniques," Dr. Hussain said. "When we see a child in the Diagnostic Clinic with serious problems, we know that if we don't do anything for this child now, he'll be a long-term institutionalized person."

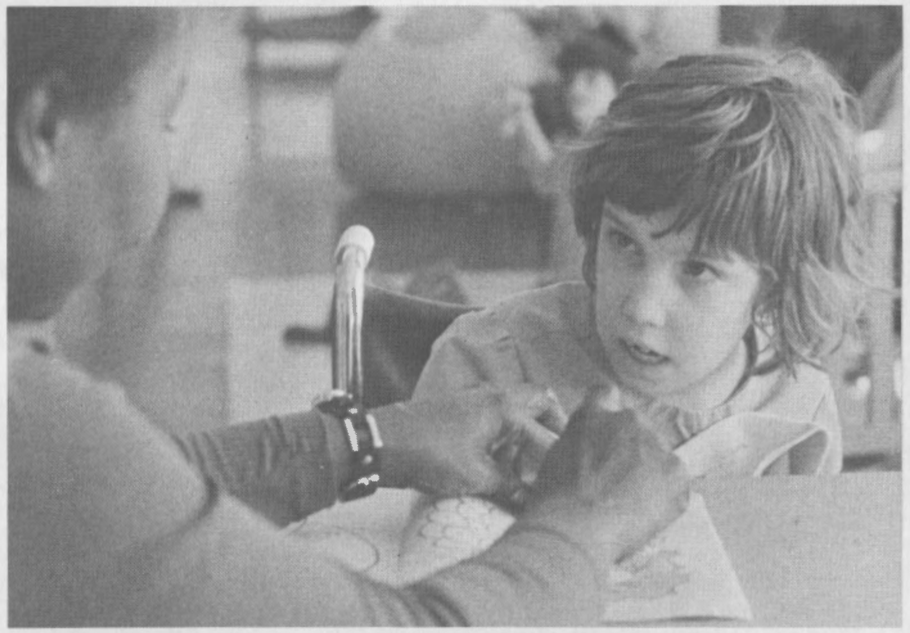
He cited examples of children with "legs like scissors," children who are hyperactive, or not toilet trained. The schools can't serve these children, he said. So the clinic admits them for two or three months, has orthopedic surgery done, or toilet trains the child, or provides behavior modification. Then they train the parents in physical therapy or behavioral techniques, or whatever is needed to continue the treatment. The child can then live at home and go to school.



The teachers are also advised on the child's needs.

Dr. Hussain told of an 8-year old child with Down's syndrome, who was in the short-term respite care program. At the time of admission, she had no independent self-help skills. Three months later when she was discharged, she was able to feed and dress herself and meet her toileting needs independently.

All of the children given the intensive, short-term treatment at the unit are back in their communities and progressing well, according to Dr. Hussain. Left alone, he said, these are the sure candidates for long-term institutionalization.



PCMR BELIEVES THAT:

Mentally retarded people are capable of continuing development

The fact that people who are retarded can develop with intensive care and under favorable environmental conditions has been effectively demonstrated. A hostile environment, however, can block progress even when the internal barriers to growth and development have been removed.

In order to promote a more receptive environment in which persons who are retarded can develop in the freest possible way, with the opportunity to exercise the same rights as other citizens, in 1973 PCMR:

Held the first national conference on The Mentally Retarded Citizen and the Law to help educate the legal profession and the public to human and legal rights to which retarded persons are entitled;

Assisted in the preparation of two publications resulting from the legal rights conference: One a professional legal reference document; the other an action-oriented report for a general audience;

Promoted acceptance of retarded citizens in communities, and emphasized their right to choose a place of residence, through radio and TV public service announcements, distributed nationwide;

Launched a joint effort with architects to improve building codes, zoning regulations, and other barriers to community living;

Contracted for updating the PCMR publication that was so influential in promoting the normalization principle, *Changing Patterns in Residential Services for the Mentally Retarded;*

Directed preparation of a monograph on planning community services for mentally retarded persons living away from home;

Cooperated with the Law Enforcement Assistance Administration in a Southeastern Regional Conference on the Mentally Retarded Citizen and the Criminal Justice System;

Joined with the American Association on Mental Deficiency in a regional conference on legal rights in Morgantown, W.Va.;

Participated in a Conference on Services for the Retarded Adult held in Santa Barbara, California;

Published a professional paper on *Experimental Studies of Memory in the Mentally Retarded,* which explores the learning process and possibilities for accelerating it;

Took leadership in exploring the effects of the energy shortage with several private and governmental organizations serving retarded persons, and designed a survey on the impact of cuts in heating fuels and gasoline on mental retardation programs;

Proposed to the Secretary of DHEW ways and means to meet the urgent need to develop executive manpower for mental retardation and other human services programs.

Corrective measures introduced in early childhood can reduce the severity of the handicap and sometimes reverse its course

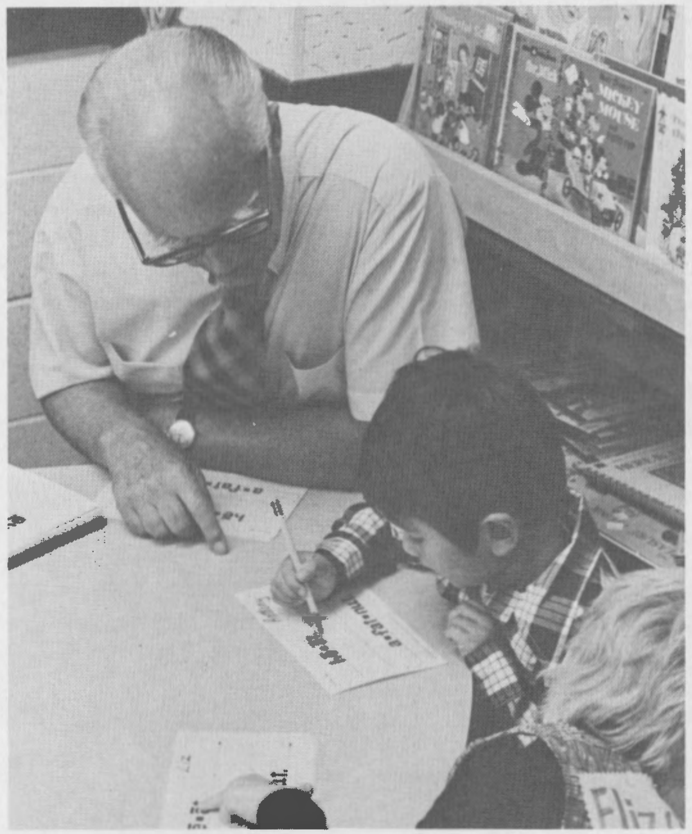
Research data strongly indicate that the first five years of life are crucial in the development of each individual. This is especially true of children born with a handicap. If problems are detected and treated in these early years, the damage can often be considerably lessened. In some cases, the course of the condition can be reversed.

To encourage early detection and correction of handicaps, and to publicize the most recent advances, in 1973 PCMR:

Published a definitive monograph on *Screening and Assessment of Young Children at Developmental Risk*, an extension of the theme of a 1972 PCMR conference on the subject; (Available only from Superintendent of Documents, GPO, Washington, D.C. 20402. $2.40. SN 4000-00294.)

Completed plans to cosponsor a Conference on Infancy and Early Childhood Education, with the Association for Childhood Education International, and several other agencies, to be held in the spring of 1974;

Published a professional paper on *Malnutrition, Learning, and Intelligence*, summarizing research data on the effects of malnutrition on brain growth and learning ability.



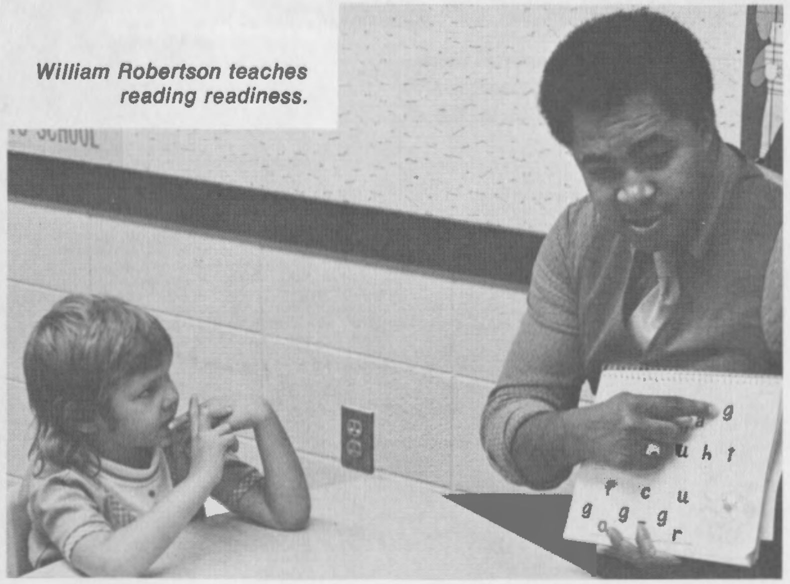
Dr. Henry Cobb lends a hand with phonics.

Committee members actively participated in the programs at the Kansas Center for Mental Retardation and Human Development at the University of Kansas in Lawrence, during a visit in conjunction with a Regional Forum in 1973.

Nan Ulle beating the drums in music therapy.

Kenneth Robinson astonishes a friend with his block-building skills.

Ralph Ferrara gives a friend a head start.



William Robertson teaches reading readiness.

PCMR BELIEVES THAT:

Prenatal and neonatal biomedical intervention can prevent many forms of mental retardation and related handicaps

Reproduction is an intricate process. One extra chromosome in the genetic inheritance, a virus contracted by the mother at a certain time in the pregnancy, an untreated infection, these and many other factors can cause the child to be damaged.

To stimulate advances in the techniques of prevention of mental retardation, and to inform the public on preventive measures, in 1973 PCMR:

Brought together a group of leading geneticists to review the state of the art and to identify methods of meeting needs;

Produced a series of radio spot announcements in English and Spanish to inform prospective mothers on how to increase their chances of having healthy children.

Marianna Beach offers a reward for improved behavior.

There was other Committee business in 1973 that touched on each of these areas. Members and the executive director addressed numerous groups and attended conferences in this country, Europe, England and Latin America. They testified before committees; they were interviewed on radio, TV, and for newspapers and magazines.

Some 1973 Committee activities that touched on all areas in the mental retardation field included:

A Mid-Atlantic Leadership Training Institute held in Richmond, Virginia, which brought together people from Pennsylvania, Delaware, Maryland, Virginia, West Virginia, and the District of Columbia, to report and discuss progress and problems in mental retardation in those States;

A Midwest Regional Forum held in Kansas City, Missouri, at which representatives of Kansas, Iowa, Missouri, and Nebraska gave presentations and demonstrations of their programs to aid persons who are mentally retarded and to prevent handicapping conditions;

Advance meetings to plan for a major Inter-American Conference on Mental Retardation to be held in 1975, in which PCMR will participate.

Louise Ravenel and PCMR Executive Director Fred Krause get involved.

Dr. Cecil Jacobson observing a pre-school class.

PCMR MEMBERS 1973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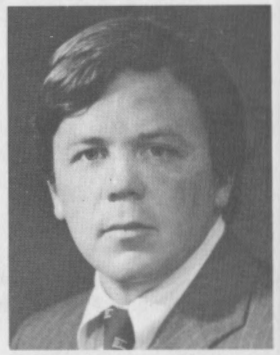
Chairman


N. Lorraine Beebe
Vice Chairman


Marianna Beach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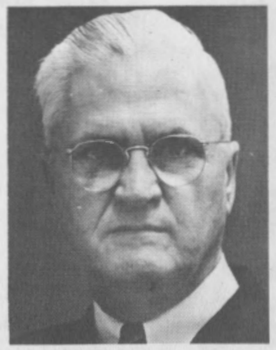
Hon. Thomas J. Meskill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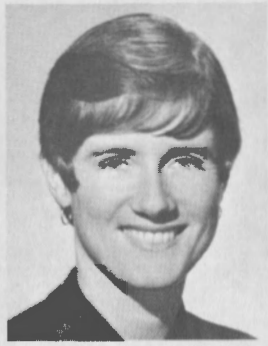
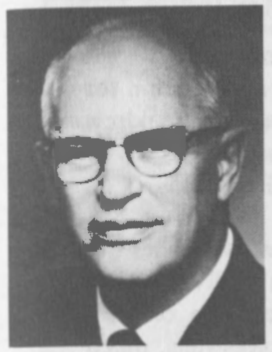

Louise R. Ravenel


William B. Robertson


Kenneth S. Robinson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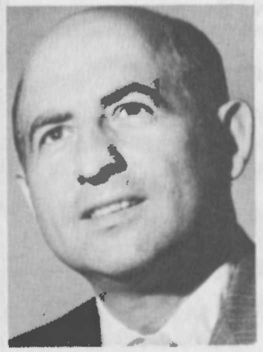
Robert A. Collier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Aris (Bob) Mallas


Will Beth Stephens, Ph.D.


Margaret B. Ulle


Miriam G. Wilson, M.D.

The Secretary
of Labor,
Ex Officio

The Director of
the Office of
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The President's Committee wishes to express its sincere appreciation for the gift of time and talent by Andrew J. Molnar, Vice President and Art Director of Ceco Publishing Co., Troy, Michigan.

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University of Kansas Medical Center, Kansas City
College of Medicine, University of Nebraska
Infant Development Center, Kansas City, Kansas
Woodward State Hospital School, Woodward, Iowa
The Hospital for Sick Children, Washington, D.C.
Mental Retardation and Child Psychiatry Media Unit of the Neuropsychiatric Institute, University of California, Los Angeles
Illinois Braille and Sight Saving School, Jacksonville, Ill.

A FINAL WORD FROM THE EXPERTS

"Not everybody's the same."

In a completely spontaneous, frank discussion, a group of eight adolescents sat down together one evening in 1973 and talked about mental retardation. All had been in special education classes, all have grown up with the label "retarded."

Their conversation was video-taped at the Mental Retardation and Child Psychiatry Media Unit of the Neuropsychiatric Institute, University of California, Los Angeles. With UCLA's permission, these quotes were taken from portions of the discussion.

"I think when we were being born, Mother Nature made some mistake and it damaged part of the brain and something didn't turn out right, and it held us back."

"A different thing happened to each of us."

"Not everybody's the same."

"It depends on the person—on how much they have on the ball."

"Like my cousin Russell. All the time, 'I can't do this,' and 'I can't do that.' I tell him, 'Russell, yes you can. You can, too' "

"Like me. I *try* because I want to get ahead. In 9th grade I got out of Special."

"To accomplish something takes you twice the effort. . . . To get a C, I would have to work like an A student."

"Once I sat down and cried because I was in a gym class and I had a problem. Everybody threw rocks at me and ran up and hit me and I turned around and hit them back. The teacher walked around laughing and showing this roll book. It said F F F F. Eventually I got out of this class. . . . I was put in a special gym class where some people had problems and where people were more grown up. Later on, I went to a doctor for some help, and I found out what the problem was: . . . Very poor visual perception. That was the thing that was holding me back."

"I realize that I'm 21 and I . . . want to have a car and . . . all these things. And yet I get uptight about it with myself . . . I'm my own worst enemy. I just told the guys the other day, 'There's only one person in this apartment that I don't get along with: Me!' "

"The emotion does figure in it. It's reversed. Because you want to do things but you know you can't. And you keep on fighting it and you keep on pushing harder and harder to get there faster and faster."

"We'll have problems with holding certain types of jobs. Like I know I'll probably never make it to be an engineer. . . . The question is still open."

"I wanted to be a social worker. But it would take me 14 or 15 years to do it. So, realistically. . . ."

"You have to face the fact that that's one thing you can't do."

"You know you are [retarded], and everybody calls you it. . . . But you don't want to say it. You know you are within. It chops you down."

"It's more the way it is said. It's not just that word. It could be any word, really."

"I think parents should tell the kid what is wrong with them. They're going to have to find out sooner or later."

"Sooner is better than later."

"You can't hide it from the kid because he's going to find out eventually anyway that there's something wrong—like I did."

"You gotta evaluate the youngster on an individual basis. Not compare one to another, like a tennis match."

"But discipline should be the same for all children."

"Even though they* may have learning problems, they're human beings just like *everybody* else, and they deserve basically the same treatment as any other human being."

"The object is to motivate them to try harder . . . and to encourage them."

"You never stop learning. You learn things every day of your life."

"Let the kid go out and make his own mistakes and learn from them."

"They'll grow out of some [of the mental retardation], but if the mother protects them, they'll never grow out of it."

"They'll go into a shell. A live vegetable."

"You aren't going to learn anything if somebody's doing something for you all of the time."

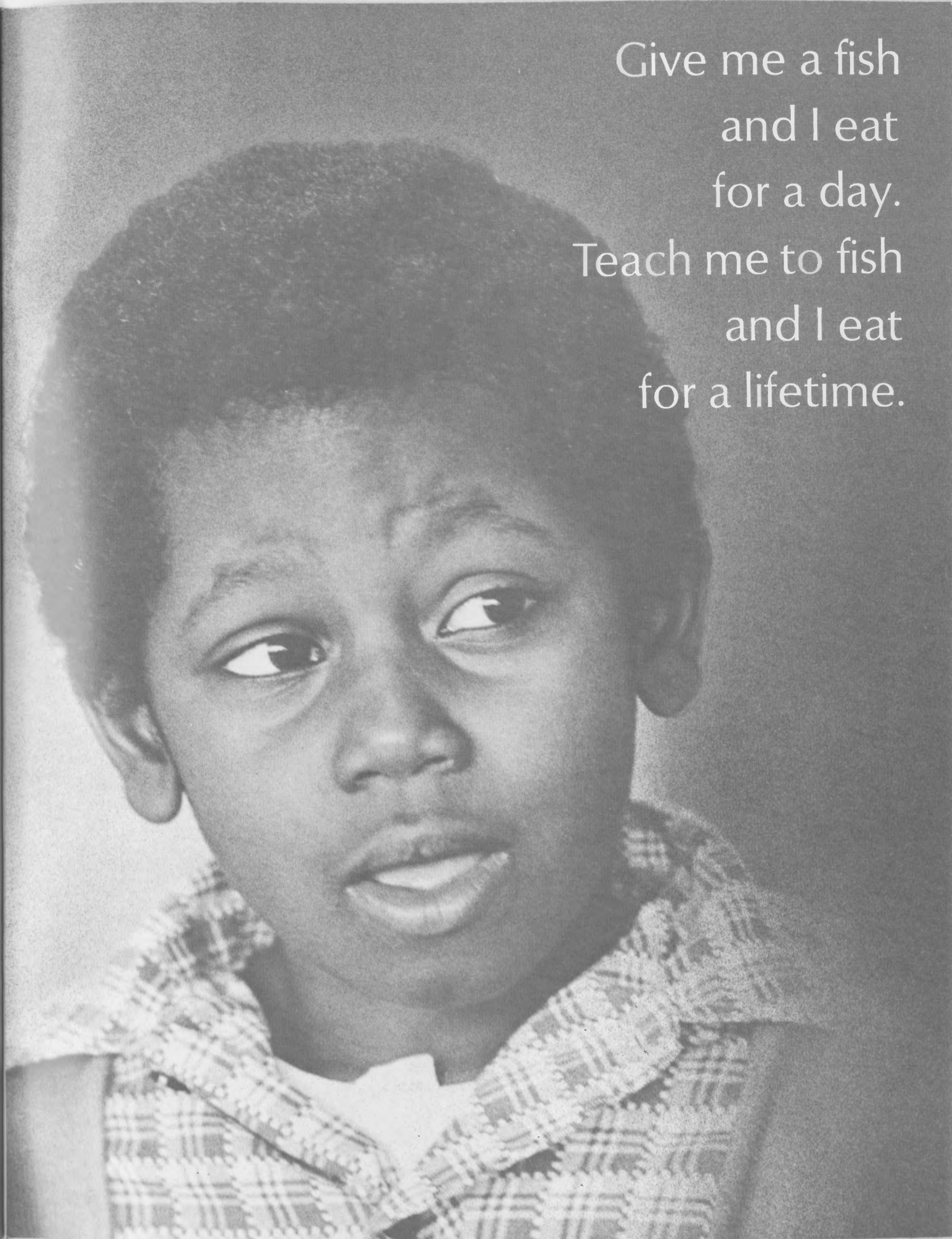
"My mother will always see me as a baby, no matter how old I get."

"You have to have the experience of knowing how to live when Mom and Dad aren't around. Because one day they die, too."

"And later on in life, nobody's going to teach you how to be independent and what to do."

"There comes a point when you have to let go . . . when you've got to get them their freedom. Slowly, but surely, they'll get their independence."

*** Some of the speakers use "they" in referring to other retarded persons.**



Give me a fish
and I eat
for a day.
Teach me to fish
and I eat
for a lifetime.

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
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