

Our Children's Voice

Retarded Children Can Be Helped!

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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Senator William T. Conklin, Senator Richard Schermerhorn, Assemblyman Vincent Riccio listen to testimony.

Hundreds Support Separate Department at Public Hearing

A public hearing on S. 4234 (Schermerhorn) and A. 7249 (Riccio) attracted more than 600 persons, many of whom testified, to Albany on May 14, 1974.

This legislation proposes to set up an Office of Mental Retardation and Developmental Disabilities in the Executive Department, separating mental retardation and developmental disabilities from the Department of Mental Hygiene.

An amazing turnout of more than 600 persons from 18 chapters of the Association as well as many other organizations crowded the hearing room and voiced almost unanimous approval of this measure.

Speaking on behalf of the State Association, Joseph T. Weingold, Executive Director, said, "It is evident that the Department of Mental Hygiene as now constituted cannot cope with the problems of institutionalization for the mentally retarded or their integration into the community. The unwieldy structure that has been created to deal with mental illness, emotional disturbance, alcoholism, narcotic addiction, and mental retardation cannot accomplish what has to be done for this very large group of handicapped persons, the mentally retarded. The record speaks for itself. If we are ever to avoid the Willowbrooks, if we are ever to implement real community programs we must have a Department that concerns itself solely with this disability."

As a matter of fact, said Mr. Weingold, separation of mental retardation in all its phases from Mental Hygiene would enable the Department to better cope with other disabled who, sadly enough, need so much help that they are not now getting.

Legislation identical to this principally sponsored by Senator William T. Conklin was passed two years ago, unanimously in the Senate and with only two dissenting votes in the Assembly, but was vetoed by Governor Rockefeller. At this time, however, it is the hope of the Association and the proponents of the bill, the record of the Department, the failure to better conditions materially at Willowbrook, the failure to implement the plans for new institutions, the breakdown of community integration, to persuade the Governor that such a plan is necessary, feasible, and, in fact, inevitable.

Person after person testified to his or her personal experiences with the Department of Mental Hygiene and how there has been a breakdown in services.

Only two organizations in addition to the Dept. of Mental Hygiene voiced opposition. One was a local unit of Cerebral Palsy in Ithaca, and the other was the New York State Association for the Brain Injured. A reading of their testimony has not disclosed any rational opposition to this plan.



Joseph T. Weingold testifies.

Governor's Budget Misses

A \$9.3 million budget for state government next year includes \$91.4 million more to finance the Department of Mental Hygiene's operations, a total now of \$831.3 million.

Although the 22 per cent hike in expenditures over the current level for Mental Retardation and Children's Services, \$55.6 million, sounds like a great deal of money, an analysis shows that in fact it will not mean that much. As stated by the Department of Mental Hygiene itself, the increase also reflects the scope of additional operational charges. The major share of next year's funding, according to the Department of Mental Hygiene, is required to meet such mandated costs as the 5.5 per cent increase in salaries for the Department's 59,000 employees, and to offset higher costs for food, fuel and other goods which have occurred in recent months.

MINIMUM STANDARDS

The whopping \$9.84 increase in allocation to Willowbrook State School is to meet the minimum standards that had been ordered by Judge Judd in the action New York State Association for Retarded Children, Inc. against Rockefeller, et al. The other increases to state schools are for the purpose of beginning to bring them to the minimum standards ordered by Judge Judd for Willowbrook.

Even this was cut by \$4 million by the Legislature on the theory that the population in the state schools would decrease during the year and therefore new positions that were ordered by Judge Judd, if extended to other state schools, would not be needed and the excess of personnel could then be used as slots for the new state schools such as Oswald Heck and Broome County State Schools now serving very few residents.

It would seem, therefore, at this writing, that the two institutions that were built at a cost of almost \$50 million will not be serving the residents, as was their prime purpose when being built. Mentally retarded persons who came from the areas of the tri-city in Broome County and Capitol District will still be remaining in the overcrowded state institutions, elsewhere, far away from their homes.

LACK OF THRUST

The real thrust of the Governor's budget, or lack of thrust must be found in what is being done for deinstitutionalization or the prevention of institutionalization.

The Governor recommends \$80 million, an increase of nearly \$8 million to be allocated for local assistance funds as the state's share of operation and construction costs to enable local communities to continue to expand their programs for the mentally disabled. Note the term "mentally disabled", because of this \$80 million only \$8 million is for the mentally retarded and developmentally disabled. This preserves the immoral ratio that is being

maintained between the money spent on other mental disabilities and mental retardation in the community.

4407 FOR 8,200 CHILDREN

The Governor's Budget does request \$16.3 million to support 8,200 children in 4407 programs for the year 1974-75. But the Governor also states, "A recent decision by the Commissioner of Education to require the New York City Board of Education to provide educational services to handicapped students, as required under subdivision 2.b of Section 4404 of the Education Law could effectively reduce the fiscal requirements for this program." In addition, there is an implied threat to this whole program in the Governor's statement that a special task force consisting of persons from the Departments of Mental Hygiene, Social Services, and Education and the Division of the Budget have been studying the 4407 program and possible alternatives to it. Although this task force seems to have issued a report, it has been unavailable to this Association.

NO INCREASE FOR PRIVATE SCHOOLS

There is no mention in the Governor's Budget of any increase in state aid to the voluntary agencies and private schools for 4407.

There is no mention in the Governor's Budget of any possible increase in categorical aid to the public schools for the education of the handicapped as recommended by the Regents and the Fleischmann Commission.

There is no mention in the Governor's Budget of dropping the age for our children eligible for special education to 3 as recommended by the Fleischmann Commission and the Regents.

MORE MONEY, LESS QUALITY

In all, although on the surface it would seem there is more money available, the emphasis is on doing what you have to do by court order and eschews proposals for real quality services or even maintaining services in the light of increased costs.

It is noteworthy that the Governor's Budget does propose an increase of \$1,480,000 for the 10 private schools for the blind and the deaf, this is an addition to the increase last year on the basis of increased costs.

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Your Child In Public School

Your Education Committee would like Every parent to be a sub-committee of one in the field of education.

A booklet which capsules the education laws in easy language is "CHILDREN WITH SPECIAL NEEDS AND THE NEW YORK STATE EDUCATION LAW". Read it — then read the questions below, and see if your district is obeying the law. Speak up if you find they are not. You would be surprised how impressed (and responsive) school officials get once they know you, the parents are well informed. The booklet costs 50 cents and can be ordered from CENTER ON HUMAN POLICY, Division of Special Education, Syracuse University, Syracuse, N.Y.

PLEASE LOOK INTO EACH OF THESE QUESTIONS. THEY WILL HELP YOU.

According to New York State Law, children over 5 and under 21 years of age who are mentally, physically, socially, and emotionally mature enough to benefit from classes are entitled to a free public education. **How many children in our country are excluded from public education and why?**

According to the Commissioner's regulations, each school district must have a "committee of the handicapped" to review and evaluate, at least once a year, the status of each child within the school district who is designated handicapped. This committee must include a school psychologist, a teacher or administrator, a school physician, and other responsible school authorities. **Does such a committee exist in our country? Who are its members? Do they meet at least once a year?**

According to the Commissioner's regulations, each school district is required to provide an individually administered psychological examination for each handicapped child. **Is this being done?**

Each child in a special class must be re-examined by a psychologist at least once every three years. **Is this being done? Do the schools inform parents that they have access to their child's school record?**

Under the "Greenberg Law" (Education Law, Section 4407) a child with an unusual type of handicap or combination of handicaps can be excluded from public school classes and enrolled in a private school. **How many children in our county are so classified and why? What schools are they attending and why?**

Syracuse State School

Association Protests Near Fatal Drug Dose

The outrage of the Onondaga County Chapter exposed a near fatal drug dose at the Syracuse State School. Mary Madden, a 28 year old resident of the school, was administered 30 times the prescribed amount of the drug thorazine (3000 mg. instead of 100 mg.). She was admitted to the Intensive Care Unit of Upstate Medical Center.

The Chapter was immediately joined by the New York State Association for Retarded Children in protesting this incident. The highlight of the local statement was a reiteration of the Chapter's position as advocate for all mentally retarded persons and full support of Mary and her parents, Mr. and Mrs. Vern Madden of Syracuse. Madden is one of the founders of the Onondaga County Chapter, New York State Association for Retarded Children. The statement called for immediate administrative re-organization in state schools for the mentally retarded. Telegrams were directed to Governor Malcolm Wilson, Speaker of the Assembly Perry Duryea, President pro-tem of the Senate Warren Anderson and William T. Conklin, deputy majority leader of the Senate.

Education Committee

The maximum class size for educable mentally retarded is 15 at the elementary level and 18 at the secondary level. The maximum class size for the trainable mentally retarded is 10 for children under chronological age 12, and 12 for children over chronological age 12. **Do our classes reflect these maximum figures?**

Local school boards are required to keep a register of all handicapped children up to the age of 21. This register must include name of child, date of birth, address, type of disability, and parents' names. Does such a register exist? Under Section 144 of the Education Law, this register is a public record. **Can the local ARC have access to it? How is the information developed? Are census takers instructed to seek out handicapped children? Is there any follow-up to insure their school attendance?**

It is illegal to place a disabled on a waiting list for educational services because the school district does not have room or funds to hire special teachers. **Does such a waiting list exist in our County?**

Who is responsible for providing psychological services? (BOCES or home school). **How do home schools insure that their handicapped children are receiving quality services? Is there a special curriculum developed for the handicapped? How many handicapped children are being serviced in our county? What classes are available and where? Are any "children" forced out of school before they reach 21? If so, why?**

Are parents of handicapped children invited to attend parent-teacher conferences? If so, how frequently?

In future columns, we'll list publications pertaining to school, learning, magazine articles reviewed, items of interest for your school age child. We got a head start from some wonderful material sent to us by Connie Sullivan, Home Economist of the Albany Chapter, and other listings and professional literature that we have been accumulating and reading.

Let's hear from you — committee members, chapter officers, educational liaison members, regional committee members, and above all YOU, THE PARENT, so that we can better serve YOU. . . AND YOUR CHILD IN THE PUBLIC SCHOOL.

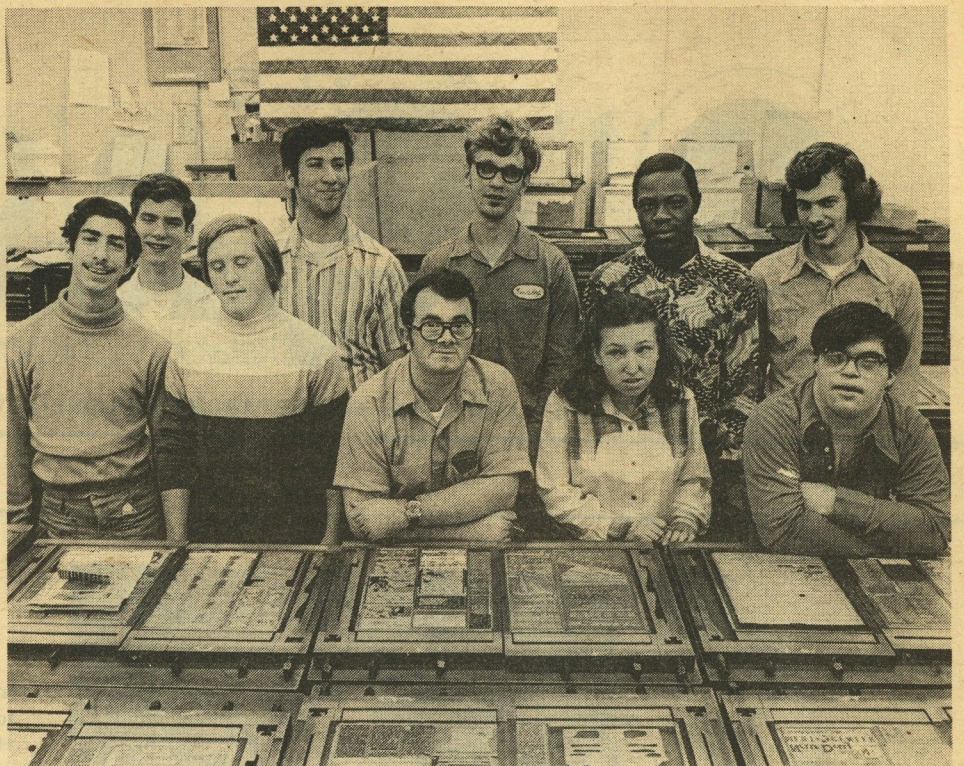
By Betty Pendler, Chairman

The text of the message from the Onondaga County Chapter, signed by Thomas J. Goodman, president and Nicholas Collis, Executive Director, reads in part:

"The association, by this telegram, is making a formal complaint against the Syracuse State School and its staff allowing inappropriate and unsupervised dispensing of dangerous drugs to lethal proportions. Immediate steps should be taken to correct this dangerous situation and an immediate investigation should be made of this incident and its implications."

In a companion communication, Elliott L. Aronin, President of the State Association, stated in part:

"No investigation can remedy an inhumane approach to the residents of the State Schools over which the department of Mental Hygiene seems to have no control. If anything, it demonstrates the need for separation of the mentally retarded from the Department of Mental Hygiene . . . and to begin afresh with a new approach for the delivery of services and new hope for the parents who must remain without much hope if you fail to act."



When we hired mentally retarded youngsters, we weren't thinking about winning awards.

Besides being a newspaper, Newsday is also a business. One that must be run effectively and efficiently. So two years ago, when job openings existed in our composing room, we made a decision on a strictly business basis. To fill these jobs, we hired several mentally retarded youngsters after being assured by educational authorities that they could perform their duties satisfactorily. From a business standpoint, we have never regretted this decision. In fact, after starting with two mentally retarded young people, we now employ 11 of them in various capacities. The fact that we have been rewarded by their dedication and spirit and the love they bring into our plant has been an added benefit to Newsday. And recently, Newsday was honored as Employer of the Year by the New York State Association for Retarded Children. If you have suitable job openings, you might consider hiring the mentally handicapped. Not because you might win an award, but because as Newsday has discovered, it makes good business sense. (Copyright 1973, Newsday Inc., Reprint by permission)

1974 Christmas Winners Chosen

State School artists again took two of the top three awards in the 1974 Christmas Card Design Contest sponsored by the New York State A.R.C. Two winners came from Rome State School in 1972.

Phyllis Arzberger of Willowbrook State School won first prize, a \$100 U.S. Savings Bond. Her picture of a pink Christmas angel was an immediate favorite of the judges, Mr. and Mrs. Edward Licence, Miss Michelle Decker of the Department of Community Affairs, Metropolitan Museum of Art, and Diane Carol Brandt, Creative Director for Williamhouse Regency, Inc., the company that prints our cards. Mr. Licence is chairman of the Scholarship and Awards Committee of the State Board.

Second prize, a \$50 U.S. Savings Bond, went to David Schermerhorn of Ray B. Kelley Elementary School in Lockport. His drawing, a large, red-nosed Christmas reindeer, will appeal to anyone who sends cards during the holiday season.

Sammy Grill, a 1973 finalist, was named third place winner and received a \$25 U.S. Savings Bond. Christmas means a well-decorated tree to Sammy, and this year, his intricate drawing shows how a well-trimmed tree should look.



Judges Mrs. Edward Licence, Miss Michelle Decker, Miss Diane Carol Brandt, and Mr. Licence.

The judges spent hours scrutinizing the designs just to pick out forty top finalists and the three winners. These forty designs will again appear on display at the Metropolitan Museum of Art in December.

Cards featuring the creative designs of the three winners will be on sale beginning in mid-June. We anticipate another tremendous year for Christmas card sales.

OUR CHILDREN'S VOICE

Issued four times a year by

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.
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A Non-Profit, Tax-Exempt Organization of Parents and Friends
of Mentally Retarded Children
Chartered by the State of New York
February, 1949

President: ELLIOT L. ARONIN

Executive Director & Editor: Joseph T. Weingold

Parents File \$1 Million Suit

The parents of Donna Albenese have served notice on the State that they intend to seek \$1 million damages for an injury she suffered while a resident of Willowbrook State School. The notice charges the state with negligence and medical malpractice in connection with a broken leg which their daughter suffered last December 21st in building No. 26 of the school. The claim notes charges that the school recklessly, wantonly, willfully, and carelessly and negligently caused the injury.

In regard to the malpractice allegation the notice charged that the medical treatment to Donna was performed "in so negligent and unskilled a manner in an attempt to reduce the fracture and otherwise treat the patient and set the broken bone that the leg was cast and placed in improper position".

Three Lives For A Fence

A "severely retarded" mute, clothed in pajamas died of exposure outside of Wassaic State School early in February.

Three residents died in 1973 after wandering from Wassaic State School.

The 68 year old mute, who could not feed or dress himself wandered from the school before dawn and apparently fell down an embankment.

School officials said that the walk away could have been due to understaffing.

The unidentified man has been a patient at the state school for 40 years a doctor said. He was found lying in a "fetal position", the doctor said.

A fence was finally erected around a swamp near the school after three residents died last year. One man died after falling off a cliff, another from exposure and the third drowned in a pond, authorities said.

Suit Settled for \$250,000

A \$250,000 federal court settlement has been reached in the case of a Syracuse infant whose parents claimed she became retarded from an aspirin overdose in 1966 after an Army pharmacist dispensed the wrong size tablets.

An infant's compromise order against the U.S. Army and federal government was filed by U.S. District Court Judge Edmund Port of Auburn who presided during five days of trial in July.

The girl, now 7, was 8 weeks old, according to testimony when her mother was given the aspirin at the U.S. Army War College Hospital in Carlisle, Pa. The mother and daughter were residing at the installation while the child's father was serving in Vietnam.

The suit claimed that the child went into convulsions 3 days after her mother began giving her 2 aspirin tablets every four hours as specified on the bottle. A diagnosis of aspirin poisoning was made at a civilian hospital where the child was taken following an examination at the military medical center.

Sometime later the parents claimed the child had problems in growth and development, finally diagnosed as severe mental and physical retardation.

Olympics Benefit

In a recent letter to our executive director, Ray Bohen, the Chairman of the 1973 Convention of the State Association held in Albany writes, the profit from the 1973 convention will be donated to the New York State Retarded Olympic Fund.



Seven year old Donna Albenese, whose leg was broken for four hours before anyone noticed, lies in her bed at Willowbrook State School. (Staten Island Advance photo by Everett R. Harvey)

No one will ever know how much pain was felt by Donna Albenese — a 7 year old, 27 pound child, a beautiful doll you'd love to hold in your arms — the day her leg was broken in Ward D of Building 26 in the Willowbrook State School.

That was the first step in what was termed during a staff meeting at Willowbrook as "unfortunate mishap, an accident."

The second step in the chain of events to follow was that the break wasn't discovered until nearly four hours later, when the leg began to swell noticeably.

Donna, a patient at Willowbrook for six years, can't talk. She can't hold her head up, and she can't move a muscle in her body. She has to be kept in diapers.

According to the report filed by the parents with police and concurred in by Dr. Miodrag Ristich, the institution's director since October 1972, whose attitude was cooperative, the following was the latest in a series of incidents that have happened to Donna during her six-year stay at Willowbrook.

It was 4:30 p.m. December 21st, and children were playing in Ward D Building 26, Donna was on a mattress.

William Nelson, an attendant, wheeled in a food cart and, while manipulating the unit into position, stepped back on Donna's left leg.

A nurse examined Donna but found nothing wrong. No doctor was called.

At 8:10 p.m. a nurse on Donna's floor noticed that the child's left leg was swelling. She called a doctor, and Donna was taken down to the x-ray room where it was learned that the leg was broken. The leg was placed in a temporary splint.

Sometime after 9 p.m. Donna's parents were called but since they were out shopping, the message was left with a baby sitter.

They arrived home around 11:15 p.m. got the message, called the institution and learned that there had been "a serious accident."

They rushed over to the institution and stayed with Donna until after 1:00 a.m.

Sometime during the following morning, an orthopedic consultant to the hospital arrived and placed Donna's leg in a plaster cast that reached half-way to her thigh.

There was talk that Donna might have to

be moved to the U.S. Public Health Service Hospital in Clifton.

It wasn't until Christmas Day at 3:30 p.m. that Donna was moved to the Clifton Hospital and her parents notified.

There had been complications.

At the hospital, the parents learned that the bone in her leg had separated. This was four days after the leg was broken.

Donna has been placed in a body cast, but the doctors there don't know, as yet, whether corrective surgery will be necessary.

Dr. Ristich said that he saw no grounds for any type of harsh, disciplinary action but that "certainly the ward attendants will be talked to about the consequences, that can occur, warned and cautioned about the extent of care that is needed in moving around such an area."

The Christmas Eve incident is not the only happening at Willowbrook that has upset Donna's parents, who kept a record of such "accidents".

In March 1969, they found Donna beaten and scratched. A staff doctor ventured that she did this to herself.

In May 1971, her nose was distorted and her eyes were blackened. There was no explanation.

In September 1971, they found her with a cut over her left eye and were told that another child had struck her.

In October 1971, they found her with bites over the chest, back and face. The explanation was that other children did it.

In May 1972, they found her body with several bruises. There was no explanation.

Last September, they found her left hand burned. Her hand had fallen against a radiator and she was unable to pull it away, even as a reflex action.

The cost of keeping Donna at Willowbrook can be expensive, depending upon the income and expenses of the patient's family.

Many of the patients at Willowbrook require total care, including individual feeding.

But with Willowbrook under attack in the press for the past two years, under surveillance by the federal government, accidents, no matter how unfortunate or undeliberate, such as Donna has experienced, are difficult to understand.

Retarded Need Strong Rights

Retarded individuals should be granted even stronger rights than the average person because their needs are greater. Instead, the rights of the retarded are being violated, according to a state authority.

Joseph Weingold, executive director of the New York State Association for Retarded Children, spoke at the meeting of the Association's Clinton County Chapter.

Weingold quoted Karl Marx who recommended "from each according to his ability; to each according to his need."

"Society should fulfill its responsibilities toward the retarded if we are to be labelled civilized," he said.

These are rights, he specified, that should be provided not "out of the goodness of our hearts. . . or what we provide through the laws, but (because of) their rights under our Constitution."

"My feeling is that they have the same rights as everyone else within their capability to enjoy them."

But, he emphasized, these rights are constantly being violated.

Freedom of choice is granted only where certain facilities exist, he said. For example, a retarded person can live and work only where he is accepted and where someone has provided an opportunity for him.

Rights of free movement and free and open speech have also been violated, he said.

Free public education is not always being provided for retarded children, he said. "Do we mean free education for all children or for all children except the handicapped," he asked.

Some services for retarded children, he said, are being termed "permissive" rather than mandatory. "That is, a school may choose to offer the services, but it doesn't have to. The answer, he added, is to effect legislation making all such services mandatory.

Another difficulty in providing services for the retarded, he continued, is that the law makes no distinction between mental illness and mental retardation. Twice legislation has been introduced into the state legislature to define that distinction. It has not passed, however.

Retarded children are not granted equal protection under the law, Weingold said. Blind children, for example, may attend a state school in Batavia at the state's expense until they are 21.

If a child should become mentally retarded, however, as could be the case through spinal meningitis, for example, he must be sent to an institution at his parents' expenses.

The right to treatment in state institutions for mentally retarded persons has not been established by the state, although there are 20,000 with such handicaps currently in these facilities.

Insurance companies won't write policies for retarded persons, he said.

Overall, rights against discrimination in the state don't cover mental retardation, he said. He pointed to the need for action instead of rhetoric.

Weingold gave three reasons why the retarded haven't been accorded their rights.

Bizarre behavior exhibited by some retarded persons repels people, he said.

Second, people fear what they don't understand. And third, there is the pervasive feeling, as Plato said, that retarded people should be taken to a secret place, put away.

There are two approaches to correct the inequities, he said. One is education of the public and the other is legislation. If the first doesn't work we should be prepared to enforce their rights through the second.

Legislation Introduced

A series of bills have been introduced in this session of the Legislature (1974) to strengthen services for the handicapped on all fronts.

Among these are the following:

— A bill to permit local school districts to transport handicapped persons over the age of 21 to rehabilitation facilities. (S. 8451-Pisani — A. 10035-Levine). This bill was made necessary by the decision of the Counsel to the Commissioner of Education that local school districts may not transport anyone over 21. It was the contention of the State Association for Retarded Children that they had this power under regulations of the Commissioner, but apparently this was not agreed to by the Commissioner and thus legislation is necessary.

— A bill to lower the mandatory age for education of the handicapped in all sections of Article 89 of the Education Law to 3. (S. 7414-Pisani — A. 9134-D'Amato).

— Amendment to the insurance law to provide that no life insurance company shall reject an application for life insurance on the life of a person solely by reason of his mental retardation, in a sum not to exceed a total of \$1500. The purpose of this, of course, is to provide a burial fund, not a windfall for the parents. This was introduced by Senators Dunne, Conklin and Gordon (S. 8760).

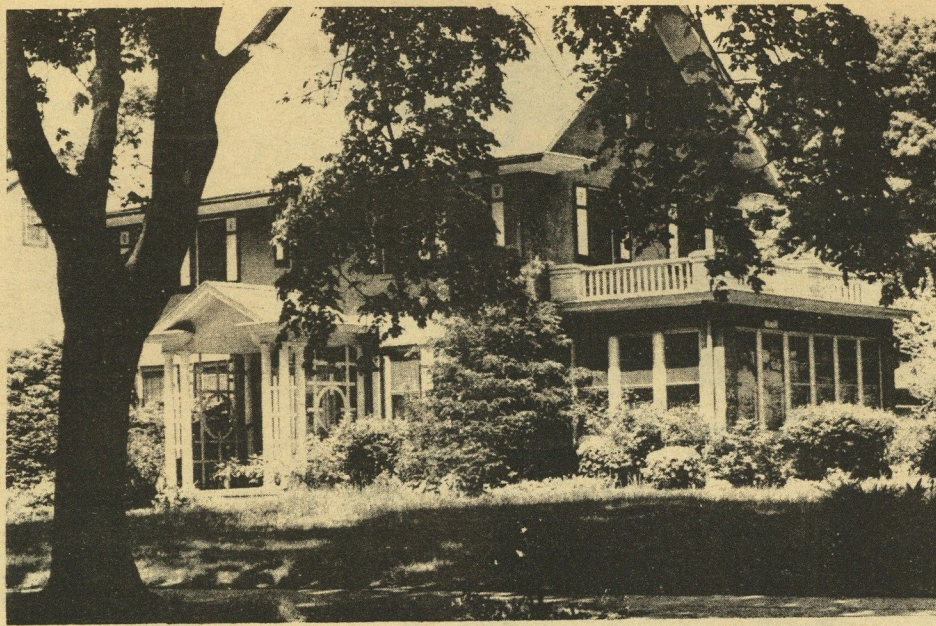
Other legislation that should be of interest to parents and friends of the mentally retarded are as follows:

— A bill to amend the Mental Hygiene Law to define an infant as one who has not attained age 18. The significance of this is the parents would not be liable for payments to the Department of Mental Hygiene after 18 instead of 21 as now in the law. Introduced by Senators Flynn, Marchi, Gordon and Barclay (S. 8306), Barrows, et. al. (A. 9783).

Some bills have been introduced which the State Association cannot support. One of these is S. 8501 introduced by Senator Donovan and others which repeals every section of the Education Law dealing with the handicapped, including 4407 and Section 4403 dealing with the Family Court and substitutes a program which may or may not do the same job, but certainly is much vaguer than what now exists. The suggestion of the Association is that the existing law could be amended to provide for more input by parents and appeal mechanism with regard to their children rather than doing away with legislation that has been on the books since 1917 in some cases and fails only because of failure to implement not because of the law or its intent.

It is the contention of the Association that any such sweeping piece of legislation requires considerable additional study and hearings before it is seriously considered by the Legislature.

Another piece of legislation that the Association opposes is the creation of a Commission for the Developmentally Disabled. It is the Association's position that its bill for an Ombudsman introduced by Senator Conklin and Assemblyman Steingut last year and still before the Legislature is a far better approach than a Commission for the Developmentally Disabled. The Ombudsman would have the power to knock heads together for all the handicapped whereas the Commission would be there as a sort of spear carrier, subject to the whims and wills of the various commissioners and without any real authority or power.



The second AHRC hostel for adult retarded men is scheduled for December 1973 occupancy. The charming 4 bedroom Freeport home will house 7 retarded men who are employed either at our Vocational Training Center in Freeport or in the private sector. As in our Hempstead hostel, there will be house parents and family group living. The property was acquired by New York State, but to enhance the interior, we will again have the gift of Rose Aronin's talent to make the house a home we can all be proud of.

Parents, Those Troublemakers!

A dramatic \$1.1 million remodeling plan that would provide "humanizing" living conditions for an eventual goal of 1500 mentally retarded residents at Willowbrook State School was presented by the administration to a group of parents recently, one of whom labeled the concept "a piece of cake."

Dr. Miodrag Ristich, director of Willowbrook, and Harry Eliazarian, deputy director, described a proposal to remodel Building 27, now housing 150 severely and profoundly retarded adults, as a hopeful solution to the overcrowding and physical disrepair that have plagued the institution for years.

Eliazarian told approximately 40 parents at the meeting in Building 4 that construction should begin in July, and estimated a period of "18 to 21 months to completion."

And then he lit the fuse that ignited the remainder of the two-hour meeting.

"By the end of the renovation," he said, "that building will only house 47 residents, so you can see we plan to cut (the population) by two-thirds."

That's when the parents, some representing the Benevolent Society for Retarded Children, and others the buildings their children live in, grew skeptical.

Their concern was prompted by the sudden closing last month of Building 78 — the institution's "country club" setting — without prior notice.

The building was shut down because of its non-functioning heating system, which was condemned by the city Health Department.

Most of the parents at the meeting believed they were there to discuss plans for reactivating the model program and for greater parent participation in administrative decisions.

Dr. Ristich concurred on the latter assessment. Earlier in the meeting he had

told the group the Mental Hygiene Department's policy is "to encourage citizen participation in the department's programs."

In describing a "geographical unitization" plan soon to be implemented that would segregate residents in five units according to their home borough, the director said his goal was to organize parents into borough groups "and involve them in the planning."

But that was the long-range view, and the parents at the meeting were worried about current problems.

Someone asked Dr. Ristich what he expects to tell the parents of the 100 residents of Building 27 who will be "shifted somewhere else."

The administrator replied, "If they want better conditions for their children, parents must be told that two-thirds of them will have to go. For every one that stays at Willowbrook, two have to be moved somewhere else."

Dr. Ristich was supported by two representatives from the Mental Hygiene Department, Kenneth Skrivanek and Edward Jennings, when he asked the parents to "set up a mechanism of communication that will satisfy you."

He asked Jerry Gavin, Benevolent Society president to select or elect members of his group to serve as an advisory council that would represent parental views in planning.

But other parents, not active in the Benevolent Society, took exception to that suggestion because they, too, wanted to have a hand in administrative decisions.

An agreement was arrived at for the parents to "somehow" appoint a small committee they could trust to represent all parent organizations at Willowbrook and which could possibly be expanded to include agency members and non-parents interested in the welfare of the retarded.

Committee Established

The proposal for an Advisory Committee on Handicapped Children to the Commissioner of Education, consisting of 12 appointees, has passed both houses of the Legislature. The legislation was sponsored by Senator Pisani (S.7049A) and Assemblyman Levy (A. 8300).

Of the 12 appointees, 7 must be affiliated with educational, training or research programs for handicapped, and at least two be parents of handicapped children. Their charge would be to review administration and operation of program authorized by the Department of

Education and other provisions of law administered by the Commissioner with respect to handicapped children and to make recommendations for improvement of such administration and operation.

Of course, there can be no opposition to the purpose of such a bill, but the Association expressed its concern that only two members out of 12 will be the parents of handicapped children. If we are to follow the guidelines of the Federal government and HEW regulations, such an advisory committee should consist of at least 51 per cent parents.

Mainstreaming?

Not in Russia

In answer to questions why the Russian educators felt that mildly retarded children could not profit from staying, at least part time, in a normal classroom they answered that there was no place for children who cannot master the curriculum as normal children do and that mental retardation is irreversible. Apparently they ask the question: why one would put a child who is irreversibly handicapped with normal children expecting he may become normal.

Their point was that it is bad enough to be retarded, but to put a child in a situation where he is exposed to failure even at the preschool and kindergarten level, is to set things up so that other problems, attitudinal problems and motivational problems may soon overshadow the original problem of retardation.

They feel it necessary to protect the child and help him develop the best functional level he can with the resources he has and not allow any opportunity for the secondary kinds of emotional problems that develop. It is noteworthy, quite different from the American system, that when a child is about 10 years old or in the fourth grade a vocational planning commission meets to begin planning for what the child is going to do later on to put him into special training programs actually connected with community work settings. The child will work in this program until 16 or 17 and then move over into a permanent vocational position.

The state gives him a flat and he will be given a salary paid exactly at the level of anybody doing that kind of job he does.

Of course this is for the mildly retarded. In the brou-ha-ha now being raised by some educators for "mainstreaming" on the theory that normalcy will rub off on the mentally retarded if the mentally retarded are exposed to the normal, we suppose, it is important to note this program and this theory which is opposed to "mainstreaming".

Camp Catskill Again

The New York State Association for Retarded Children is very pleased to announce that Camp Catskill will be operated by the Association for its third consecutive summer. Having already enjoyed two successful seasons of camping for mentally retarded persons who might not have otherwise had that opportunity, we are looking forward to service an even greater number of clients this year.

The Camp will be operated for three week sessions. Session one for Campers age 5-12 will be from June 28th thru July 17th. Session two for Campers age 13-20 will be operated July 20th thru Aug. 8th. Session three for Campers age 21 and over is scheduled for Aug. 11th-30th.

As of this writing we have a few vacancies in both Session I for children 12 and under the Session II for teenagers. There is a waiting list for adults 21 and over, but we are hopeful that we are going to be able to make an arrangement to accommodate these people as well, and encourage those who might still be interested to submit an application at this time.

Anyone desiring further information about Camp Catskill or who has not as yet had an opportunity to review material on the Camp can obtain this information by writing to Camp Catskill, c/o NYS ARC Inc. 175-5th Ave., N.Y.C. 10010.

Still Hedging

Nyquist Backs From 4407

In the decision that Commissioner of Education, Ewald Nyquist rendered (Riley-Reid) ordering the City of New York to place all children who have been diagnosed as handicapped in appropriate public school classes or, where public school classes are not available, in private schools under contract in accordance with provisions of Section 4404 2b. of the Education Law, he in fact posed a threat to programs for those children in private facilities under Section 4407 of the Education Law.

That section of the law provides for children who are so severely handicapped or with a multiplicity of handicaps to be educated in private facilities with the state paying up to \$2000 a year. The Commissioner implied that New York City was to take those children under its own wing.

This threat to a program which has proved itself over the years and which has grown to serve more than 8000 children in the state aroused the parents and the Legislature to protest vehemently against this highhanded procedure.

As a result of these protests and the thousands of letters that were written to the Legislature to preserve section 4407 of the Education Law and not permit the Commissioner to do away with it by administrative fiat, the Commissioner held a hearing on February 19th in the Education building.

Hundreds of parents, educators, and legislators attended this hearing. In his statement at that hearing the Commissioner said the Education Department had no plans to eliminate state contracts under Section 4407 but reiterated his order that the City of New York (and this certainly would be extended to other school districts) must provide their own classes for such children or they themselves contract with suitable private schools.

In fact, say the parents of these children, this is a political struggle between the Department of Education and the City of New York Board of Education as to who is going to pay for the program. This concern should be whether the children are being served or not. As a result of the protests, especially of the legislators at the hearing on February 19th, Commissioner Nyquist stated, "If it is found as a result of these further proceedings, that New York City cannot properly and adequately serve the needs of all handicapped children at a public school I will consider issuing an order directing the Board of Education take no action resulting in the withdrawal of handicapped children now served in private schools in the City, whose parents or guardians seek continued services in such schools, through the balance of the school year 1973-74 and the school year 1974-1975, and requiring that the Board of Education contract with private schools for such education under the provisions of Section 4404 2b.

In the very next sentence, however, he reiterated what in effect was the same threat to the 4407 programs.

As the result of the stand of Commissioner Nyquist, Senator William T. Conklin (R-Kings) and Assemblyman D'Amato of Nassau introduced legislation which mandates 4407 and provides that 4407 shall exist, "Notwithstanding any other provision of law". This bill (Senate 9163 — Assembly 11111) has passed the Senate and is now in the Assembly, Ways and Means committee from whence we hope it will be reported out.

The parents' fears were not allayed by the refusal of the Commissioner to answer the question, "Will the state of New York, Department of Education service in 4407 programs those children who reach age 5 in June who would otherwise be eligible for such programs"?

The protests continued and mounted in greater and greater numbers until on March 15, 1974 the Commissioner issued another statement in which he says, "I have previously stated, and now repeat, that I have not and will not require that any child presently (emphasis ours) attending a private school for the handicapped under the 4407 programs to be transferred to a public school program."

He seems extremely reluctant to make the statement that 4407 is still a law on the books and viable alternative to Section 4404 2b. for those children who qualify. Finally, near the end of the statement he gives this qualified assurance. "If legislation providing substantial new financial assistance to school districts for the education of handicapped children is not (his emphasis) enacted at the 1974 session of the Legislature, the State Education Department, will continue within the limits of available state appropriations, to contract for the education of handicapped youngsters in private schools under Section 4407 when recommended by the local school authorities." He goes on to say that if such legislation is enacted the local school authorities will have the option to recommend whether a child now attending a private school under 4407 should continue in 1974 and 1975 or the school district will contract with the private school under Section 4404.

In our opinion this is no assurance whatsoever to the parents and represents the same threat as before, although on the surface it would seem that Commissioner Nyquist has backed off from his original stand.

We can only hope that the parents of these 8000 children and all those who will not be served unless there is a 4407 program continue their efforts to get the legislature to tell the Commissioner that the law is the law and that he cannot change it by an administrative decision.

It might be added that this has nothing to do with the Riley - Reid decision which states that there can be no children on a waiting list and that the public schools must do something about them in accordance with the Education Law.

15 Sign For Unified Services

Of the more than 60 counties in New York State, 15 have notified the Department of Mental Hygiene of their intention to develop plans for joint state-local mental health, mental retardation, alcoholism services under the 1973 Unified Services Law. Counties which have indicated intent to develop plans are Chemung, Delaware, Dutchess, Fulton, Orange, Putnam, Rensselaer, Rockland, Steuben, Sullivan, Tompkins, Warren, Washington, Wayne, and Westchester.

Participation by a county is optional. Counties may remain under the present local services structure and receive state aid on the formula which provides 50 per cent of net operating costs for counties under 200,000 population receiving 75 per cent of the first 100,000 of such costs. Although the Department estimates that 43 counties will receive more and 14 less state aid under Unified Services Plan, so far only the 15 mentioned have signified their intent.

Ann Greenberg Celebrates



Ann Greenberg, founder of the Association for the Help of Retarded Children, helps celebrate its 25th Anniversary with WABC-TV weatherman Tex Antoine, who is celebrating his 25th anniversary in TV. Center is Marlene Daly, who attends one of the Association's schools.

What Do Those Parents Want? Decisions?

A stream of protests hit the administration of Willowbrook State School in the State Department of Mental Hygiene over the closing of building 78 — because of a defective boiler — without notification to the parents.

The operation of building 78 for three years was applauded as the "country club" of Willowbrook and "a fantastic success". This building was put up as a result of the efforts of the board of visitors after the expose of Willowbrook by Robert Kennedy back in 1965. It was one of several buildings, supposed to be prefabricated construction — it was hoped would pick up some of the overcrowding at Willowbrook. The parents claimed that they were not notified of the pending action to move their children and that the school officials had implied the facility would not be re-opened and that state estimates for the repair far exceed what the actual cost would be.

It is interesting to note that building 78 was constructed as a "Temporary facility" and its doors were opened in 1971 with the federal government subsidizing the program at the facility on a short-term basis at a cost of \$100,000 a year and the state paid the remaining costs.

Next month the state was scheduled to assume all the costs and the building was

Craig School Moves Made

More than 170 Craig State School residents were transferred to other upstate department facilities in January, one month after the department announced that it would close 17 Craig buildings "for safety reasons". All of these buildings were built around the turn of the century. 10 of the buildings house 255 residents, while the seven others provide space for school programs.

Of the 172 residents transferred, Sunmount State School received 29; West Seneca 50; J.N. Adam 9; Syracuse State School 36; Wilton 16; Oswald D. Heck Memorial School 32.

The object, of course, is to transfer the residents as near as possible to their original homes.

The residents being transferred to Oswald D. Heck Memorial School are all originally from Albany, Schenectady, Rensselaer, Schoharie, Greene and Columbia County. They are the facility's first residential clients. Its capacity is for about 700.

closed down.

The unit contained an 8 classroom school, a cafeteria and four colorful wards. Each ward contained home-like division for 2 to 8 children and the building can house between 80 and 100 residents.

It was unlike any other facility at Willowbrook.

Although Dr. Ristich confirmed that the state's estimates for repairs ranged from \$168,000 to \$300,000 estimates obtained by the parents come to a fraction of that sum. The Benevolent Society, Willowbrook Chapter of the Association, hired an Island heating agency, Brown's Fuel Service, to survey the heating system of the building. Brown's estimate for the heating project was \$16,500.

The Society of the parents feel that the state must be balking at repairing the heater, and reopening the building for some ulterior and unknown reason.

Parents — those troublemakers.

Tear Them Down!

Surplus bed space at Hudson River State Hospital will not be used to alleviate overcrowding at Wassaic or other schools for the retarded, according to hospital director Dr. Herman Snow.

Dr. Snow's comments are on a report which analyzed the efforts of the State Department of Mental Hygiene to improve its physical plant, suggesting the Department should make provisions to house the retarded in vacant state hospital buildings statewide.

The report was written for the Legislative Commission on Expenditure Review.

"This hospital is 102 years old," said Dr. Snow. "We are abandoning many of the buildings as the population drops because they have been fixed and fixed again and we've come to the point where we just can't fix them anymore."

According to Dr. Snow these old buildings should be razed and not used as a sort of afterthought for the mentally retarded at an enormous cost of rehabilitating the buildings.

In order to remove the temptation to use old buildings for the retarded, perhaps it should be state policy that all these old buildings when emptied should be torn down or sold at huge profits to community developers.

CHAPTER NEWS

What our chapters are doing
and saying for our children.

The ALLEGANY COUNTY CHAPTER opened a sheltered workshop January 2. The facility will be called TREE, for Training, Rehabilitation, Employment Experience. . . The Chapter has obtained the use of a large building in Friendship, owned by Iroquois Gas Co. The Buffalo-based firm has agreed to charge just enough rent to cover property taxes. It is expected that TREE will be able to accept up to 25 clients in 1974. . . . The Chapter negotiated a contract with the county Mental Health Board, for the make-ready phase to be completed December 31. A second contract, for workshop operation in 1974, has Mental Health Board approval, and funds for both periods have been approved by the County legislature.

Good news from DUTCHESS COUNTY CHAPTER as reported by Executive Director Steve Weintraub. DUTCHESS COUNTY ARC can be proud of the progress made in 1973 in their Work Activities Center. The center started with 7 clients and one full time staff member with no transportation provided to any of the clients. At present the staff is up to three full time people, one part-time Community Services Coordinator, 28 clients, and two bus drivers who drive the ARC buses to the center each day with the clients from all parts of Dutchess County. DUTCHESS COUNTY ARC is providing service for five clients from WASSAIC STATE SCHOOL daily. . . . Squinting slightly to be able to read the copy alongside the brilliant new letterhead of the ONONDAGA COUNTY CHAPTER we find the following news: The Onondaga ARC Workshop has received a \$4800 grant for a new workshop van from the Rosamond Gifford Charitable Foundation. This active foundation, located in Syracuse, has been highly supportive of the Chapter over the years, having most recently funded the Community Room of the Association's Center and the 60 passenger bus. The speech therapy departments of the ONONDAGA CHAPTER and the SYRACUSE STATE SCHOOL are offering **without charge** a special, eight-week mini-course for parents of mentally retarded children and adults. Beginning March 4th, the course has been designed to teach parents how to stimulate speech and language development in the home.

The best news sometimes comes in small packages. This is how we felt about the last paragraph of WAYNE COUNTY'S January 1974 Vocational Rehabilitation Center newsletter which said "we have placed two clients from our program". Isn't that really what it's all about? . . . ST. LAWRENCE COUNTY CHAPTER gives its sincere thanks to the Spring Inn of Massena, New York, who held the jamboree on February 17 and turned over the money collected in admissions to the Chapter. . . . HERKIMER COUNTY CHAPTER to complimented on their new brochure. . . . FRANKLIN COUNTY CHAPTER writes to say Ellen Maroun, President of Franklin County Chapter, has been appointed to the Franklin County Mental Health Board, joining another A.R.C. Board member, Winston Hamilton, on the Mental Health Board. Michael Robson, Executive Director, has been appointed to the Committee on the Handicapped of Tupper Lake Central Schools. . . . A complete stereo system has been donated to the Occupational Therapy Department at Sunmount State School. Music, Music everywhere! . . . One year ago the first contract was signed, with the FRANKLIN COUNTY Mental Health Board, for us to provide services for the handicapped. Today we are providing those services, to more than 70 people. . .

CLINTON COUNTY CHAPTER also writes from the North County with the



Rhetta Hughes, featured in the Broadway hit musical, "Don't Bother Me, I Can't Cope", shows Marlene Daly, 7, how to adjust party hat, at the 25th Anniversary party of the Association for the Help of Retarded Children, where she entertained.

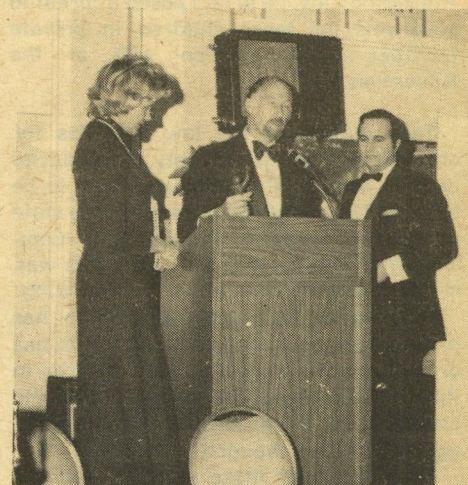
following news:

1. Lakeside School, the educational program of the Clinton County Chapter, has received word from Mr. Murray Schubert, Supervisor, Federal Air Unit, Bureau of Special Programs for the Handicapped, that they have been approved under Public Law 89-313 for \$5,558 to develop a special project entitled "Individualizing Instruction Through Special Programs". Their clients have recently completed a program on "Personal Decisions about Sexuality." The program was developed by Planned Parenthood of Clinton County and the staff of the Rehabilitation Center, according to guidelines set by the Executive Board of the Association for Retarded Children. The Sexuality course is one of the programs offered at the Center to help prepare clients for community living.

MADISON COUNTY CHAPTER has been able to reschedule Past President Robert J. Hodgson for a discussion on Guardianship at their May meeting. You may recall, last issue, we reported how he was snowed out of his trip there. We hope it doesn't snow in MADISON COUNTY in May. . . . Good news from SUFFOLK COUNTY CHAPTER as they announced the acquisition of their first hostel in Riverhead, part of the ever increasing program being offered in SUFFOLK COUNTY CHAPTER. Several interesting additions have been added to recent issues of the Chapter's newspaper. **The Lamp-**

lighter. Included among these are a cartoon called "A Closer Look" which takes a tongue in cheek look of some of the things parents and the professionals in the community do to help the retarded, which sometimes hinder, and a theater review which we found of interest. . . . Not content with a first hostel, SUFFOLK COUNTY CHAPTER continues the press for a second hostel in Bayshore, under the leadership of President Joe Iovino who replaced Mr. Nicholas Messina in January. . . . SCHENECTADY COUNTY CHAPTER looking forward to one of their now famous Parents and Friends night out. An opportunity for members of the Chapter to get together at a nice restaurant and spend the evening mixing with their fellow members. A really nice idea. Also looking forward to having their clients attending the circus. . . . ALBANY COUNTY CHAPTER has added 9 new members to their Board in an attempt to involve more persons with particular community skills. We must comment again on how interesting we find their new newsletter, **Reaching Out**, which contains photographs of many of the Chapter's activities. We note with pleasure that in STEUBEN COUNTY, the Presbyterian Church in Arkport would like to start a camp for retarded persons. Always good to see new friends looking to help. . . . MONTGOMERY COUNTY welcomed new Executive Director Frank Capone. Mr. Capone comes to MONTGOMERY COUNTY CHAPTER from experience with our JEFFERSON COUNTY CHAPTER. Noted with interest, the Chapter had Kirk Lewis Regional Vice-President of YOUTH as a speaker at their meeting. . . . Congratulations to Mrs. Arthur Gasman who has become the new President of WELFARE LEAGUE. LETCHWORTH VILLAGE CHAPTER succeeding Mrs. James Reville. Installation Ceremonies were held at the Chapter meeting on February 6. . . . It has finally happened! SARATOGA COUNTY CHAPTER got even for all of us! They received a contribution from the employees of the Returns processing section of the New York State Income Tax Bureau. Thank you, thank you. We also thank the Saratoga County Deputy Sheriff's Association for their contribution of \$100 to the Chapter. . . . SULLIVAN COUNTY CHAPTER really going strong at 25th Anniversary year, first they were moving their operation to the former campus of the Community College, South Fallsburg, then they're having their first annual Sullivan County ARC dinner, which will occur April 27th and will have Geraldo Rivera as a special guest speaker. They

are also planning to have a gift shop operated by their Workshop and looking forward to their continued expansion of programs and services. . . . CAYUGA COUNTY CHAPTER held what they considered "one of the finest meetings they have ever held" when Dr. Wolf Wolfensberger, who has been so active in the program of Citizen Advocacy for the Mentally Retarded, was their speaker. . .



Justin B. Israel, member of WARC Advisory Committee, presents sculpture to the Honorable and Mrs. Ogden R. Reid.

BENEVOLENT SOCIETY WILLOWBROOK CHAPTER working like everything on their May luncheon. One of the most of our active Chapters in helping get people to our Legislative Hearing in Albany. Sponsoring a Jazz Concert on April 24 at Staten Island Community College for the benefit of Benevolent Society.

NIAGARA COUNTY CHAPTER sends the following news: The City of Lockport has leased to the Niagara County Chapter, the Hickory Park for a summer camp for a five year lease and option for another five years. The camp will be utilized so that mentally retarded children and adults from Niagara County can have overnight trips, picnics, etc. Niagara County Chapter, is also the recipient of two grants from the Division of Physically Handicapped, Albany. The one grant is for \$16,452.00 for a Speech Therapist and an Audiology Program for our children under 4407. The second grant, from the Division of Physically Handicapped, is for the amount of \$35,691.00 for a Physical Education Teacher and a Music Teacher. This is a unique grant for the NIAGARA COUNTY CHAPTER since they have never had a full time Physical Education Teacher and a Music Teacher. The other part of our Physical Education program is that for the first time, the association will receive an indoor swimming pool to be used by our children. . . . WESTCHESTER COUNTY CHAPTER — The Westchester Chapter celebrated its first quarter century in operation with a glamorous Silver Anniversary and Fourth Annual "Friends of the Retarded" Ball at the Rye Town Hilton Inn, January 26th. The Chapter's first Annual "Friends of the Year" Award, an original sculpture by noted artist Joseph Anthony McDonnell, was presented jointly to United States Congressman Ogden R. Reid and Mrs. Reid for their distinguished service on behalf of the retarded. The Ball, which traditionally attracts a number of political figures, was no less luminous this year. . . . WARREN - WASHINGTON COUNTY CHAPTER closes out this month news indicating that the Chapter will be offering two scholarships to Camp Catskill this summer. Chapter Executive Director, Chester W. Joslin writes to indicate that the plans for the hostel are moving along very well.



For the fourth consecutive year, Friends of the Retarded (FOR) have made a sizable contribution to the Onondaga Chapter resulting from the group's sponsorship of the opening night performance of Shipstad and Johnson's Ice Follies. Mrs. Kathleen Rowe presents a check for \$6000, 1973 benefit proceeds, to chapter executive director Dr. Nicholas Collis (L). Looking on is FOR officer Mrs. Carm Doran (R) and six-year-old Christopher Sanborn, a student at the Onondaga Center for the Retarded.



In the cafeteria at 121 Westmoreland Avenue. (Photo — Myron Ehrenberg)

Some ARC founders: from left, Herbert Katzenberg, Jerry Weingold, Mr. and Mrs. Bernie Rosenberg.

Westchester Dedicates Building

On November 13th, Westchester ARC welcomed 250 professional legislative, business and civic leaders to a Dedication Ceremony for the completed renovated headquarters building named Herbert Katzenberg Service Center. Edwin Michaelian, the incumbent County Executive, introduced special guests, including Alfred DelBello, Mayor of the City of Yonkers and County Executive-elect as well as Jerry Weingold, executive director, New York State Association for Retarded Children.

The WARC facility, purchased 5 years ago, was formerly the Norden Bomb Site Research Laboratories. It is presently used to house a rehabilitation, counselling and recreation program for over 200 of the agency's adult mentally retarded clients, and for 10 pre-schoolers (Other agency programs are located in Yonkers and Katonah).

The renovation was a cooperative effort, combining the contributions of the Department of Mental Hygiene, the Office of Vocational Rehabilitation and on the county level, the Westchester County

Executive and the Community Mental Health Board. The building has been dedicated to a tireless volunteer fundraiser, WARC board member and former agency president, Herbert Katzenberg.

According to Eugene G. Laughery, WARC executive director, "The Department of Mental Hygiene not only financed a substantial portion of the renovation but worked closely with us in planning and construction. To Dr. Alan Miller, Commissioner of the Department of Mental Hygiene and his associates in the Office of Community Facilities Planning, Edward R. Curley, Director, Valerie Siniapkin, Senior Engineer, Wallace Boswell, Project Coordinator, and John M. Burns, Senior Accountant, we are especially appreciative."

Funding by the Federal government was obtained through an HEW construction grant.

Due credit was also given to Mr. Harry Katz, Director of the Rehabilitation Facilities Division of O.V.R. who was most active in the planning and implementation of the grant.

HEW Says

There's A Difference

The first supplemental appropriation bill of 1974, signed by the President, has increased the HEW grants to states for developmental disabilities to \$30,875,000, a 40 per cent increase. Assuming that the usual 10 per cent would be set aside for projects of national significance and evaluation, the net amount available for allotment to the state will be about \$27.8 million.

For New York State, which has been starved in its developmental disabilities funding, this means about \$1.5 million for distribution this year. The Council for Developmental Disabilities is seriously considering grants for construction which have not been made since the inception of the program, because of the increased funds now available. The guidelines for applications for 1974 Developmental Disabilities Act funds lists 16 areas for possible support. Among these are included transportation and protective and other social and socio-legal services both of which are given high priorities in this coming year. Applications may be obtained from Mr. Donald L. Hanson, Director, Bureau of Developmental Disabilities Services, Department of Mental Hygiene, 44 Holland Avenue, Albany, N.Y. 12208.

Residents in Howard Park

The Howard Park Unit of the Queens State School recently accepted its first residents, 16 physically handicapped, severely and profoundly retarded children transferred from Willowbrook State School.

They range in age from 5 to 10 and all are residents of the South Queens area, which the new unit serves.

Howard Park will eventually serve 160 residents and provide clinic services to 100 community clients a day, according to Dr. Bernard Tesse, Director of Queens State School. Thus nine years after the idea first started, we see the implementation of this residential unit for the mentally retarded.

The first idea for Howard Park came with the 1965 expose of Willowbrook as an alternative to Willowbrook residents. The facility was discovered by Shirley Epstein, then chairman of the Institutions Committee in the Howard Park Hospital, which was closed. After much negotiation and its allocation to mental retardation, Governor Rockefeller then assigned it to the Narcotics Addiction Control Commission for the use of his program for narcotic addicts. For years it stood empty until finally a few such persons were put into this facility over the opposition of the community. Finally, the whole program being a failure, it was agreed that it would be turned over to the Department of Mental Hygiene and here we are at last nine years later with Howard Park for the mentally retarded where it should have been in 1965.

Buffalo Girl

In News Again

The "homing instinct" brought the 17 year old mentally retarded girl back to Erie County Family Court and to the court workers who tried unsuccessfully for more than three years to find a training program that would take her. The girl told Judge J. Douglas Trost that her boyfriend had beaten her and that she had been living for more than a week in an empty abandoned house. She said she was cold and hungry.

Before caseworkers could take her to the Erie County Social Services Department to arrange for food vouchers, she disappeared again as she has a dozen times in the past.

Mrs. Janet Wilson, casework supervisor, said that as a result of this girl's case a home for such children appears to be a definite prospect for the state budget this coming year or the year after. (What is going to happen to this girl in the meanwhile?) Judge Trost however was more concerned with the girl for whom the court never was able to secure help.

"She said there was a mattress on the floor of the abandoned house but she looked as though she hadn't been asleep for a week, said the Judge. She showed me the scars on her face where her boy friend had beaten her up.

"She had a bandana that was black with dirt marks and stains all over it slipped over on one side of her head. This girl is still walking the streets. She was at 14. She is now."

The girl who has a mental age of 10 was a neglected infant who was later petitioned to court by her mother as incorrigible. Picked up several times for shoplifting, she was refused by children's training program either because of her 54 I.Q. or because of her explosive behavior. Now she is beyond Family Court jurisdiction and if arrested she will be treated as an adult.

Onondaga

Grateful Parent Thanks Chapter

Capping a year-long friendship with the local Association for Retarded Children, that began when a unique form of help was needed for his retarded son, entertainer Glenn Smith appeared in a special benefit performance to aid retarded children in central New York.

Parent is entertainer

The versatile and talented pianist and singer performed with his group of five musicians, "Glenn Smith Unlimited," at the Persian Terrace of the Hotel Syracuse on Sunday, December 9. In between two shows of jazz, popular and classical music, patrons enjoyed dancing, table hopping and holiday refreshments.

Smith's connection with the county chapter of the Association began last December over an unpleasant episode at the U.S.-Canadian border. Natives of Toronto, the 32-year-old performer and his wife, Linda, were entering the United States to fill an engagement at the Syracuse Holiday Inn. With them was their two-year-old only child, Christopher, who is mentally retarded. A border guard denied entrance to their son, on the grounds of an immigration ruling classing the retarded as "undesirable aliens." The guard's action came as a complete surprise and shock to the Smiths, since it is their family custom to have their son join them as often as possible when his father is entertaining in this country. Christopher had been with his family at least twenty times without incident.

Desperate call

In desperation, Mrs. Smith called the Onondaga County Chapter where she found understanding and help. The Chapter, advocates for the rights of retarded persons, joined forces with the Center on Human Policy at Syracuse University, Congressman James Hanley's office, and the Canadian Consulate in Washington, D.C. to persuade customs officials to permit Christopher to be with his parents in Syracuse for the holidays. Through six months of combined follow up efforts, the Smiths received a multiple entry visa for their son, enabling him to visit frequently without incident.

Friendship remains

Christopher lives and goes to nursery school in Toronto when his parents are on the road performing. A tow-headed, mischievous and appealing toddler, he won the hearts of all the agencies connected with the case. Mr. and Mrs. Smith have made many friends among the parents in the Association. Friendships are kept up through correspondence and renewed when the couple entertains annually in Syracuse.

"If we had been able to place her two or three years ago in a program where she could have learned to take care of herself she might have some semblance of a life now. She wouldn't be able to hold a job, but she might be getting along," said the Judge.

The girl told Judge Trost she had gone to relatives who had refused to take her in. "Sometimes it seems we have money for all sorts of things but not the right things", said the judge.

This is in Erie County where we have a supposedly wonderful "transitional" program for placement of the mentally ill in the community. But what about this girl?

Special Ed By States

The trend toward the enactment of mandatory state special education laws in 1973 saw nearly half a dozen states move in this direction.

New York State has had such mandatory law on the books since 1917. Article 89 of the Education Law probably contains the most complete set of laws in the nation for the education of the handicapped.

But other states are beginning to catch up and a number of them are passing New York in what they are doing.

Th Maryland and Nevada Legislatures passed bills requiring the State Department of Education to provide free educational programs for all handicapped children commensurate with their needs. The eligibility age for handicapped children in Nevada is from 3 to 21 and in Maryland from birth through age 20.

Missouri, Nebraska, Arkansas, Arizona and Maine passed legislation which has provisions in it for withholding state education aid to localities which fail to comply with the state laws and standards for special education.

On the other hand, in Arizona, services are mandated for all handicapped children except for the emotionally disturbed, which remain permissive.

In Nebraska, local school districts will be reimbursed for 90 per cent of the excess cost of special education programs with no limitations by disability categories.

How Persons Are Transferred From Willowbrook

The Guild for Exceptional Children is a community organization serving the mentally retarded in a section of Brooklyn. Controlled by parents, it operates a hostel, among other facilities. The following is their experience with Willowbrook:

"The following is the sequence of events in our recent attempt to include a male client from Willowbrook State School as a resident at the Guild for Exceptional Children Bay Ridge Hostel — 310 67th Street, Brooklyn.

Back in early December 1973 our Hostel Director and Social Worker contacted Willowbrook in search of 2 male clients that might benefit from living in our community residence. Two weeks passed and a suitable candidate was selected and the Guild agreed to have him enter the Hostel for a weekend visit as a weaning-in process. As time went on we heard nothing about his arrival date and our director inquired only to be told that Willowbrook could not provide the young man with transportation to our Hostel. (our Hostel is

15 minutes over the Verrazano Bridge by car from Willowbrook). Our Guild then agreed that we would provide the transportation. Again, about 2 weeks elapsed and still no word from Willowbrook. I inquired of their Social Services Department and was told that the building personnel said they had no clothes for him. I then phoned Dr. Ristich's office and asked to speak to him. Dr. Ristich was not available so I explained to the secretary that by this time we were completely frustrated and wanted to know why this young man had no clothes. Within one half hour Willowbrook phoned the Guild that the building personnel had located clothes for him. The young man arrived after many postponements on January 28, 1974 wearing threadbare pants and shirt. He was to stay for Monday, Tuesday, and Wednesday. We were promised that necessary clothing and necessary toilet articles would accompany him. When he arrived at the Hostel, we found he had only the clothes on his back. We were able to purchase some \$40.00 worth of clothing to

include bathrobe, slippers and additional underwear, also a change of clothes, late that evening. Several parents of the agency staff were able to donate additional clothing for later in the week. We made arrangements to extend his stay for the following weekend. We had hoped that he would become a permanent resident at the Hostel, just to return to Willowbrook State School to obtain a final physical.

On Friday afternoon, February 1, 1974 we received a call from Willowbrook State School that his two sisters had arrived to withdraw him for the weekend and were amazed to learn that he was not at Willowbrook State School. In fact, the staff in the building in which he was normally located, told the sisters when they called from Brooklyn, that he was in attendance and that they could pick him up on Friday. His sisters then came to the Hostel to take him with them. The Director and the staff at the Hostel felt abused at the attitude generated by his sisters. In the interview with them, they were talking about "suing Willowbrook State School," "no one told

them that he left Willowbrook State School," "we never gave permission for him to leave." After visiting at the Hostel and meeting with the other residents and the staff, the attitude of his sisters changed. We did allow him to leave with them, after they properly identified themselves. He returned after the weekend, and was again integrated in the program of the Guild for Exceptional Children.

The above accounting of events indicates the kind of harassment this community agency is having in dealing with Willowbrook State School. Even now, we are still pursuing a second candidate from this institution. We certainly hope that we can give another young man the home like atmosphere and opportunity afforded at our Hostel, without the insurmountable delay, confusion and contradiction which I have described above."

(Signed) Olga De Felippo, Executive Director, The Guild for Exceptional Children, Inc.

State Senator Looks at Willowbrook

According to a dispatch from the UPI in Albany, rapes, robberies, assaults, burglaries and auto thefts at Willowbrook State School increased last year, stated Senator Frank Padavan, R-Queens. The Senator said that the increased crime came in a wake of a report by state police recommending improved security. Some of the recommendations were put into effect, Padavan continued, but "some of the most critical ones" were not implemented.

According to Padavan, there were 4 forcible rapes, 40 robberies and assaults, 214 burglaries and larcenies and 17 auto thefts at Willowbrook in 1973. In 1972 there was one rape, 27 robberies and assaults, 202 burglaries and larcenies and five auto thefts.

Padavan said the institution had failed to increase its security and provide additional patrol vehicles, provide vehicle identification stickers, perform spot checks of vehicles leaving the grounds, fence the perimeter and install closed circuit television to monitor critical areas.

The Queens Senator said that of Willowbrook's 4,000 employees, 225 had previous felony arrest records and that Willowbrook's employee screening process was not adequate.

"It is painfully evident" said Senator Padavan in a letter to Dr. Alan D. Miller, State Mental Hygiene Commissioner, "that a complete overhauling of employee hiring practices of your department is called for."

Lucas Appointed

Theodore Lucas, Director of the Bureau for the Mentally Retarded in the New York City Department of Mental Health and Mental Retardation, has been appointed Assistant Commissioner, according to an announcement by Dr. June Christman, Commissioner of Mental Health and Mental Retardation.

Ted is an old friend of the Association for Retarded Children. Coming from the position of Executive Director of the New Jersey State Association for Retarded Children, he assumed for one year the executive directorship of our New York City Chapter and from there went to the New York City Department of Mental Health and Mental Retardation. His efforts there have helped coordinate programs in the five boroughs and has been a great influence for the development of community services for the mentally retarded. The Association wishes Ted success in his new position.



One of the first residents of the new Kings Park Developmental Service gets off the bus and into his mother's arms. The first 18 residents were transferred from Willowbrook State School recently. Eventually the unit will house more than 150 Willowbrook residents whose homes are in Nassau and Suffolk counties.

Kings Park Hospital Opens M.R. Unit

The State Department of Mental Hygiene has announced that a special Mental Retardation Unit on the grounds of Kings State Park Hospital has been opened as part of the project of moving residents out of Willowbrook State School.

Three hospital buildings which can house up to 195 residents and a dining hall have been renovated to accept residents from Willowbrook. The buildings are clustered apart from the main patient-living and treatment areas of the state hospital.

The State Division of the Budget has approved 200 clinical and support jobs for the new unit. It will be directed by Gerald Large who joined the program after one and one-half years at Brooklyn Developmental Center.

The residents moving into Kings Park Mental Retardation Unit were originally admitted from Nassau and Suffolk Counties. Many still have families living in those counties. It is estimated that there are about 300 Willowbrook residents who originally came from Nassau and Suffolk Counties.

The overall goal of the project is not merely to reduce the Willowbrook resident population, but to provide a better living environment and increased opportunity for the personal development of each resident for appropriate program whether he be placed in the community or is relocated in another state facility or remains at Willowbrook as many will have to.

Transportation Grants Checked

The Urban Mass Transportation Act has been amended to permit grants to states, local public bodies, and private nonprofit agencies to provide transportation services for elderly and handicapped for whom mass transportation services are unavailable, insufficient, or inappropriate. Funds are for capital investments only (e.g., buses) and not for operational subsidies. Recipients must make a five-year commitment to continue the service. Writing to Patricia Cass, Office of Transit Planning, Urban Mass Transportation

Administration Mr. Weingold inquired about grants under this Act and was told that the regulations have yet to be written and we must wait and see.

Anyone who wishes to follow this up may write to Miss Patricia Cass, Office of Transit Planning, Urban Mass Transportation Administration, Room 9307G, 400 Seventh St. S.W., Washington, D.C. 20590.

If you get any results, please communicate them to the State Office.

Transfers Questioned

The Mental Health Law Project, through Bruce J. Ennis, and the New York State Association for Retarded Children have expressed their great concern about the transfer of adult residents especially from Willowbrook.

In a letter to Brenda Soloff of the Attorney General's Office Mr. Ennis wrote "We have heard accounts of residents being sent to other parts of New York State to places which have no substantial program."

The concern of these two organizations is that informed consent, as required by the Mental Hygiene Law is not being given by these adults.

"In the case of a severely retarded adult over the age of 18" wrote Mr. Ennis, "or severely retarded child without a parent or guardian who is incompetent to give consent, we propose that a guardian be appointed by the court and that that guardian must then consent to any transfer plan for the resident."

This concern has also been conveyed to the Mental Health Information Service which expressed great interest in what is happening.

Up to now, however, no action seems to have been taken by the Department of Mental Hygiene and these transfers are taking place, too many of them, on the consent of the adult alone and without any court involvement.

As part of the project which is being funded through Developmental Disabilities in this office, Tom McCauley, Project Coordinator, will be investigating every single facility which houses a person transferred from all the state schools in the state, beginning with Willowbrook to see what is happening to them and whether in fact they are in a decent place, better from whence they came, and with a program in the community suited to the development of such a person.

What is happening to those who are being transferred out of the state schools is as important as what is happening to those who remain. We must find out what is happening.

Wants Parents to Speak Out

Meyer Schreiber, Associate Professor, Department of Sociology and Social Work, Kean College of New Jersey, Union, N.J. 07083 is compiling a volume titled "Families of Retarded Persons Speak Out". He is interested in any material that parents and siblings may wish to share with him. Such materials may be sent to him at the address indicated.

Y.O.U.T.H. Group News

For and About our Y.O.U.T.H.
ARC Chapters around the state

FROM SHARE (CATARAUGUS COUNTY)

The Share group has sponsored many dances this year for our local Mentally Handicapped people. The most recent, the Sweetheart Ball, was the biggest success. With refreshments, decorations, a band, and the selection of the court, all the guests and members had a terrific time.

Share has sponsored the basketball team "racers". With money earned early in the year, we were able to buy uniforms and finance the team's away games. Lunches were served for the W. Seneca team when they came here. In the New Hampshire Tournament, on which we spent \$300, many of the "Racers" won first and second place awards.

We are preparing to send six counselors to the State Special Olympics.

One hundred dollars was donated to J. N. Adams School for recreational facilities.

Also, we recently donated to our local Rehabilitation Center, two heavy-duty tape players for classroom and workshop use.

Around Christmastime, Share held a party for the small tots at the Rehabilitation Center. Christmas gifts were distributed and Santa put in an appearance.

The money that Share raises each summer at the Miss New York State Pageant Concession is donated to the Dickie Cassella Memorial Campership Fund to send some children to Camp Cornplanter. This past summer it totalled \$300 and we hope for more this summer.

An Easter dance is planned for the end of April.

Also in the works is a Bike Rally in May to finance other Share activities.

IN PUTNAM COUNTY

Putnam County A.R.C. provides services such as job training and placement, vocational evaluation, applied academics, physical therapy, and a pre-school for youngsters ages one through six, with gait training and precursory academic skills. These services are free to participants, but they do cost. Much of the budget for these projects must come from huge fund-raising efforts. PARC's first event of the new year was a ten mile hike on March 31st, with prizes awarded to various walkers. First prize was a cruise for two from Flagship Cruises, Inc. Through the combined efforts of the people of Putnam County and their local A.R.C.—Y.O.U.T.H. A.R.C., the mental retardate in Putnam County can hope to gain a sense of dignity and personal worth. We salute this program under the fine directorship of Mr. Stuart Greif and Mrs. Lois Sloboda, Director of Adult Services.

FROM SCHENECTADY COUNTY

Y.O.U.T.H. in Schenectady are always doing something. They are still running a very successful Saturday morning recreation program. They are presently opening this program to adult workers.

Kirk Lewis, Schenectady Y.O.U.T.H. President, says they are planning to start training people, ages eight years and up, for the Special Olympics District Meet at SUNY, Albany. Kirk boasts Schenectady representatives will sweep the field under his group's expert direction. All other Y.O.U.T.H. groups can take that as a challenge. Anyone interested?

Schenectady Y.O.U.T.H. are sponsoring a spaghetti dinner on Sunday, May 5th from 12 to 6 p.m. at the Maple Ridge Center. Y.O.U.T.H. members are selling tickets for \$2.25 for adults and \$1.75 for children. This appears to be an excellent way to raise money and enjoy a good meal also. In conjunction with this dinner, Schenectady Y.O.U.T.H. A.R.C. is making May their membership month.

Y.O.U.T.H. SALUTE

MRS. SOPHIA M. DABROWSKI

For the past twenty years, Mrs. Casimer J. Dabrowski has actively aided the less fortunate members of her community. A member of the New York State Association for Retarded Children, Erie County Chapter, since 1959, Mrs. Dabrowski serves as the editor of that chapter's newsletter, the *Echo*, and as chairman of the parents group for Work Activity and Sheltered Workshops.

We are especially grateful to Mrs. Dabrowski for establishing the Erie County Y.O.U.T.H. Group, to which she has served as Advisor since its inception in 1973.

In addition to her dedicated work with the mentally retarded, Mrs. Dabrowski is founder and director of the Transfiguration Parish Boys' Choir. Through her leadership, this group of 21 young boys has become widely known in Western New York State for their expertise in the singing of Polish songs.

Recently, Mrs. Dabrowski was cited for her humanitarian service to the Polish American community. We would like to join A.M.P.O.L. in recognizing such an outstanding citizen.

Mary Jo Iovino Advisor

Mrs. Mary Jo Iovino, the eleventh president of Suffolk Chapter and first woman president, has accepted the position as New York State Y.O.U.T.H. A.R.C. Advisor.

Born in Pascagoula, Mississippi, Mrs. Iovino became involved in A.R.C. activities in Topeka, Kansas, where her husband, Anthony, served in the United States Air Force. She served as President of the Kansas State Association for Retarded Children and attended a reception in Washington given by President John F. Kennedy in October, 1963.

A delegate to numerous state and national conventions, Mrs. Iovino has become one of the best informed volunteers of activities and events in the field of Mental Retardation.

Mrs. Iovino has been a member of the Concerned Parents of Smithtown and the Smithtown Auxiliary. A member of the Board of Governors of the New York State Association, Mrs. Iovino is a familiar figure at conventions and conferences on Mental Retardation.

Her interest in the field is broadly based. She is an outspoken lobbyist for improving



Mrs. Mary Jo Iovino

conditions at state institutions for the retarded. She has supported the Y.O.U.T.H. movement in Suffolk County, serving as coordinator of Junior Auxiliaries for over three years.

Mrs. Iovino's husband works for Grumman. They have three sons and make their home in Nesconset.

Welcome to the Y.O.U.T.H. State Board, Mrs. Iovino, we're delighted to have you!

Mrs. Kito In New Position



Mrs. Kerry Kito

Mrs. Kerry Lynn Kito was named last January to be Coordinator of Junior Auxiliaries of Suffolk County. She also brings energy and effervescence to her job as Assistant to the Communications Director. Kerry came to the Association a

year ago to assist in auxiliary activities, special events, and public information.

Mrs. Kito is a former resident of Port Jefferson. She attended Suffolk Community College in Selden, Springfield College in Springfield, Massachusetts, and has taken courses at Nassau Community College and the State University of New York at Farmingdale. She is presently completing her work for an English degree at Southampton College in evening courses.

Kerry approaches her work enthusiastically. Her diversified duties include regular participation in publishing "The Lamplighter", the A.H.R.C. newsletter for Suffolk County, preparation of community information material and coordination of Suffolk Chapter-wide events.

Her husband, Ben, is a school teacher in Eastport. They presently live in Coran.

Congratulations and best wishes to Kerry and the Junior Auxiliaries of Suffolk County.

Y.O.U.T.H. Attend Albany Rally



L to R., Deborah Hunter, Randi Bobrow, Sharman Mancher, Amy Elbaum.

A number of Y.O.U.T.H. Groups participated in the Legislative Hearing on March 14th for a separate Department of Mental Retardation and Developmental Disabilities in Albany. Many Y.O.U.T.H. members braved the wind and cold to picket the front of the Legislative Office

Building carrying signs and banners. This participation was certainly appreciated and just went to show that when there is a need concerning retarded children, Y.O.U.T.H. Groups are always ready to help.

Remember....YOUTH Affiliates

Every Chapter President should have received by now the 1974 Reaffiliation Form and Membership List. We have tried to streamline this process as much as possible. Let us know if you did not receive this material. If you did, please get it in as soon as possible.

We have received no completed applications for the two \$250 Y.O.U.T.H. scholarships to be awarded this year. Any Y.O.U.T.H. Group member interested should contact their Chapter President or Tom McCarley in the State office. Applications must be in by May 15th!

The State Convention will be held in New York City October 10, 11, and 12. We are presently negotiating with the Americana Hotel for space for the Y.O.U.T.H. Convention, which will be held jointly with the N.Y.S. A.R.C. Convention. Anyone having any good ideas concerning programming for the Convention or desiring space for an exhibit, please contact Carolyn Fetter, 304 East 4th Street, Brooklyn, New York 11218.

Don't forget that the week after the State Convention has been designated as State Y.O.U.T.H. Week! The 14th of October is the date set for the State Hika-Bika-Swimathon and the 19th of October will be the special statewide Hand-in-Hand Day.

Anyone who is interested in participating in these activities or who has not heard of the planned activities for that week, please get in touch with the State office or your regional representative.

We hope all Y.O.U.T.H. Chapters will be involved in the Special Olympics activities this year. Susan Dickerson, Y.O.U.T.H. State Secretary, attended the Special Olympics Board Meeting on March 30th at Syracuse University. Any chapter interested in participating or needing information concerning the Special Olympics should get in touch with her through the State office.

The State Y.O.U.T.H. Board has chosen a statewide Penpal Program as their pet project for 1974. Presently Carolyn Fetter is contacting the Directors of Volunteer Services of all of the state schools in hopes of receiving lists of names of institutionalized people who would appreciate receiving more contact with young people outside the institutional setting. We hope that this will lead to greater visitation to institutions, as well as special remembrances on holidays. We hope every Y.O.U.T.H. member will want to participate in this worthwhile and rewarding project.

Care Formalized

The Division of Mental Retardation and Children's Services of the New York State Department of Mental Hygiene has standardized the procedures used for Time-limited Admissions (formerly referred to as Respite Care).

The philosophy of respite care was to maintain the individual in the community for the following services:

- A. to provide a temporary relief in crisis situations.
- B. Observation and evaluation
- C. Stabilization
- D. Intensive therapy
- E. Temporary relief for families

The draft of the regulations state that each residential facility shall make available an appropriate number of beds for time-limited admissions. These beds shall be a part of existing units and shall be established or staffed separately.

Whenever possible a definite time frame shall be established, not to exceed 30 days.

The parent or person seeking time-limited admission shall agree in writing to remove the client at the expiration of the time.

A specific plan of care and treatment shall be established and recorded for each admission.

Any parent or person seeking such admission shall apply to the Community Services Unit of the residential facility.

This is a service that the New York State Association for Retarded Children has been urging our Department of Mental Hygiene for some time. What has inhibited this in the past under other commissioners, and until now, we suppose, is the fear that many parents getting their children into a state institution for respite care might be reluctant to take them home again where the intent was to place them permanently, in the first instance.

The directive from the State Department of Mental Hygiene is an immense step forward in the community service, in a way to prevent permanent institutionalization in many cases.

California Programs Fail

Although almost \$5 billion a year is spent by Federal, state and local governments to help handicapped youth, a two year study by the Rand Corporation has found that the programs lack direction and coordination. Moreover, the study centered in California shows that the programs fail generally even to identify those eligible for aid and inequitably serve those they find.

Because the parents of handicapped children are confronted with a bureaucratic maze of overlapping jurisdictions and because no central agency coordinates the many programs, thousands of youths needing help are not getting it, according to the study. More than one third of the handicapped children between the ages of 5 and 17 are not enrolled in special educational programs to which they are entitled, according to Dr. James S. Kakalik, who directed the study for the Department of Health, Education and Welfare.

By Rand's criteria, more than 9 million American youths are handicapped — roughly, one in 10 of the United States population under 21. Rand defines handicapped youth as persons under 21 years of age who are physically or mentally impaired, to the point that they need help not required by normal youths.

A second part of the \$415,000 study, due soon, will recommend steps to alleviate the inadequacies identified in the first part.

The first part concludes that the programs serving handicapped youth are "varied, fragmented, uncoordinated and not responsive to an individual's total needs."

The SSI Mess

It Started With High Hopes

What started out with high hopes, the Supplemental Social Security Income which was to replace Aid to the Disabled has turned into a real nightmare for many parents of adult mentally retarded persons.

Under Aid to the Disabled, for example, the parent was not legally liable under our Social Service Law for the support of the adult handicapped person. The assets, therefore, of that person only were considered in determining eligibility on the means test and if that person's assets did not go beyond the limits set he received Aid to the Disabled.

Under SSI this has changed very materially apparently. Under one of the regulations of HEW (416.1125) it is stated "income to a possible recipient of SSI includes both unearned income including support and maintenance furnished in cash or kind. Support and maintenance may generally be defined as room and board and would also include other incidentals necessary to an individual's normal sustenance."

Under this paragraph, apparently Social Security has been ruling that a mentally retarded disabled person living in a private school for which the parents (although not legally liable) are paying, cannot receive SSI where such payments exceed the income level ordinarily applied as a means test.

On the other hand, in the next paragraph the regulations state that where an eligible individual is living in another person's household and receiving support and maintenance in kind from such person the

payments were reduced by one-third "in lieu of including the value of such support and maintenance as unearned income to the individual".

These are contradictory paragraphs and discriminate very strongly against the disabled person living in a private institution or school because his parents can afford or wish to make the sacrifice and pay for him.

The logic of this escapes the Association which has been receiving dozens of protests from distraught parents who feel that they are more concerned with the welfare of their children than others are.

"If we are to talk about deinstitutionalization," said Mr. Aronin, President of the Association, "this regulation in fact may be an open invitation to the parents not to pay, making the disabled person eligible not only eligible, but also a prime candidate for public institutionalization."

Although everyone at Social Security and HEW agrees that this is a terrible mess nobody has done anything about it except Congressman Rangel of New York City who has introduced legislation exempting all SSI recipients under 18 years of age from the diminution of their grant if they are living in someone else's residence or at home and reducing the deduction from one-third to one-fifth for those who are adults living with their families or friends.

Although all the New York State delegation has been apprised of this situation this is the only action we have received thus far.

What You Can Do

If a Social Security caseworker tells you that an applicant for SSI is probably not eligible that is not a formal determination of the fact. When in doubt, request a formal determination of eligibility. Then, the Social Security Administration must provide a written notification as to whether the applicant is eligible for SSI. If you receive written notice that a disabled person is ineligible for SSI and you think that determination is wrong, you have the

right to a hearing on the matter. You have 30 days from the time you receive written notification from the Social Security Office that the applicant is ineligible to request a fair hearing. At this hearing you have the opportunity to explain to a hearing examiner why you think the applicant was wrongly denied SSI payments. This is not a court hearing, and you do not need to hire a lawyer. However, you may have a lawyer present and you can call witnesses.

Family Care Rates Increase

Family caretakers began receiving increased payments January 1st as a result of the federal take-over of family care clients who previously received public assistance through the State Department of Social Services.

The new family care rates are \$280 a month in New York City and \$225 in the rest of the State.

At the same time, the Department of Mental Hygiene received approval from the Division of the Budget to reimburse family caretakers at the new rates for residents not receiving public assistance but whose expenses are paid through department voucher. The Department also made arrangements for supplement to caretakers for children under age 18 to bring these payments in line with the new adult rates.

The increased monthly payments include a \$17 allowance for clothing and incidental needs for each family care resident. Thus, the caretaker may not receive more than \$263 a month in New York or more than \$205 elsewhere in the State.

The patient's income is deducted from the supplemental security allowance after an exemption of \$20 for unearned income and a combined allowance of up to \$85 for a working patient. In many instances, therefore, the amount due the caretaker is made up partly from the patient's income and partly from Social Security.

Lead Poisoning Attacked

Approximately 275,000 children under the age of six were tested for lead poisoning the first year of a broad government attack on the lead based paint problem, according to HEW Secretary Caspar W. Weinberger.

In 42 communities receiving \$6.5 million in funds administered by the Department of HEW, an estimated 30,000 children had potentially dangerous levels of lead in their bloodstreams, Secretary Weinberger said. Approximately 4600 children received treatment. In many of the children the level of lead will decrease if the sources of lead in their environment are removed.

The programs are directed at children living in deteriorated housing with hazardous amounts of lead based paint which is old and peeling.

The goal for 1974, the second active year of the program, will be the testing of 300,000 additional children.

President Nixon signed a Lead Based Paint Poisoning Prevention Act of 1973 early in December, amending the original legislation enacted in 1970. The new law calls for a closely coordinated multi-agency attack on the lead based paint problem and authorizes programs of research, demonstrations and grant assistance to communities in preventing lead poisoning in children. Among the communities receiving federal funds combating paint poisoning in New York State are Albany, Erie, Onondaga and New York City.

Pay Enforced

A federal district judge for the District of Columbia has ordered the U.S. Department of Labor to begin enforcing the Fair Labor Standards Act as it affects working residents in non-federal institutions for the mentally ill and mentally retarded.

In his ruling granting summary judgement, Judge Aubrey E. Robinson, Jr., found the language of the statute quite clear despite the lack of a lucid expression of Congressional intent when the 1966 amendments were enacted. He also noted the Act includes specific provision for exceptions to FLSA coverage and yet the Congress had not seen fit to exempt working residents. Finally, since the Act established a procedure whereby less-than-normally productive handicapped workers can be certified as such by the Secretary of Labor and paid an appropriate competitive rate for their services, the court ruled that the amount of time and administrative resources necessary to certify handicapped patient-workers under the Act is "no excuse for failure to implement the statutory mandate."

"Economic reality is the test of employment," Judge Robinson said, "and the reality is that many of the patient-workers perform work for which they are in no way handicapped and from which the institution derives full economic benefit. So long as the institution derives any consequential economic benefit," he went on, "the economic reality test would indicate an employment relationship rather than mere therapeutic exercise. To hold otherwise would be to make therapy the sole justification for thousands of positions as dishwashers, kitchen helpers, messengers and the like."

The decision came as a result of a suit filed on March 13, 1973 by the American Association on Mental Deficiency, the National Association for Mental Health and three individual plaintiffs. In their suit, the plaintiffs charged the Labor Department with failure to enforce the minimum wage and overtime compensation provisions of the Fair Labor Standards Act as they apply to mentally ill and mentally retarded resident workers and, thus, violating the rights of such residents under the Fifth and Thirteenth Amendments to the U.S. Constitution.

There's A Difference

The U.S. Department of Health, Education and Welfare issued an official statement on the distinction between mental retardation and mental illness.

"MENTAL RETARDATION is usually a condition resulting from developmental abnormalities that start prenatally and manifest themselves during the newborn or early childhood period. MENTAL ILLNESS, on the other hand, includes problems of personality and behavioral disorders especially involving the emotions; it usually manifests itself in your older adults after a period of relatively normal development.

There is always a deficit in intellectual function in mental retardation; mental illness may or may not involve such a defect. If there is an involvement of intellectual function, it is usually not of the nature and degree found in mental retardation.

The two problems are related in that they may occur in the same patient and frequently involve some of the same kinds of professional skills to diagnose or assist the patient. On the other hand, EACH PROBLEM DOES OCCUR INDEPENDENTLY OF THE OTHER and adequate professional skill to deal with one problem does not assure competency to deal with the other. The ability to distinguish clearly between these problems in a given patient and to deal with each appropriately is often the crux of good care."

Javits, Justice Department Assail Intermediate Care

The federal standards recently issued for intermediate care facilities, including institutions for the mentally retarded, have been blasted by Senator Javits as inadequate and possibly unconstitutional.

The regulations which are final, and published in the Federal Register by the Department of HEW, set minimum physical and staffing standards which the institutions must meet to be eligible for medicaid payments.

Between 8000 and 9000 institutions with a capacity of more than 400,000 residents are involved.

Hospitals and schools for the retarded are given three years to meet a set of proposed regulations of the unofficial Joint Commission on Accreditation of Hospitals. Other institutions have two years to meet the physical plant portion of a separate set of standards.

Unless the regulations are promptly strengthened by amendment, Javits expressed concern that the federal court battle in New York to upgrade staffing and schools at Willowbrook State School and other state institutions for the retarded would be undercut.

Javits, chief sponsor of a bill to enact a "Bill of Rights" for the retarded, called the establishment of minimums a step in the right direction but charged the regulations were not even "adequate to the constitutionally required minimum adopted by the federal court in 'Wyatt vs. Stickney'".

That ruling, issued by federal judge Frank M. Johnson in Alabama in April, 1972 listed specific standards for institutions for the retarded if their Constitutional rights were to be observed.

Javits accused HEW of issuing minimums short of those standards in spite of specific Justice Department ad-

vice that to do so would be against the Wyatt ruling.

The Senator's concern for Willowbrook was based on the fact that "the judge in that case (Orin Judd) indicated his intention to rely heavily" on the forthcoming HEW rules in determining what minimum standards the State Department of Mental Hygiene has to meet.

Among the specific objections are:

There are no requirements for minimum numbers of toilets, showers and lavatories.

The staff - to patient ratio for the most seriously retarded is set at one for every two patients, spread over all shifts. This is only half the ratio regarded as minimum in the Javits Bill.

Many basic personal rights are completely omitted such as the right to private mail and phone conversations, right to use one's own clothing, right to one's private toothbrush.

There is no requirement that new facilities be located accessible to the communities served.

There is no requirement that residents be confined under "the least restrictive conditions necessary for treatment and habitation."

A spokesman for HEW said there would be no immediate comment on Javits' criticisms, all of which were made to the department while it was revising the regulations first proposed last March.

In addition to the objections by Senator Javits the Department of Justice which has intervened as amicus curiae in the case of New York State Association against Rockefeller (the Willowbrook case) filed extensive objections to regulations as has the New York State Association for Retarded Children.

To date there has been no reaction.

Service Priorities For Severely Handicapped

For the first time State rehabilitation agencies are directed by HEW regulations to give priority to serving "those individuals with the most severe handicaps" in their basic state vocational rehabilitation program. In addition, state agencies are required to describe "the method to be used to expand and improve services to handicapped individuals with the most severe handicaps." These regulations implement priorities granted severely handicapped clients in the vocational rehabilitation law itself under "Innovation and Expansion Grants", "Vocational Training Service Grants",

"Special Projects and Demonstration" as well as "Research".

It is the hope of people versed in the field of vocational rehabilitation and certainly that of this Association that this is a forerunner to an amendment to the Vocational Rehabilitation Act that will not put the emphasis on vocational rehabilitation but on the development of the individual up to his capacity whether indeed there is a vocational goal in the plan or not.

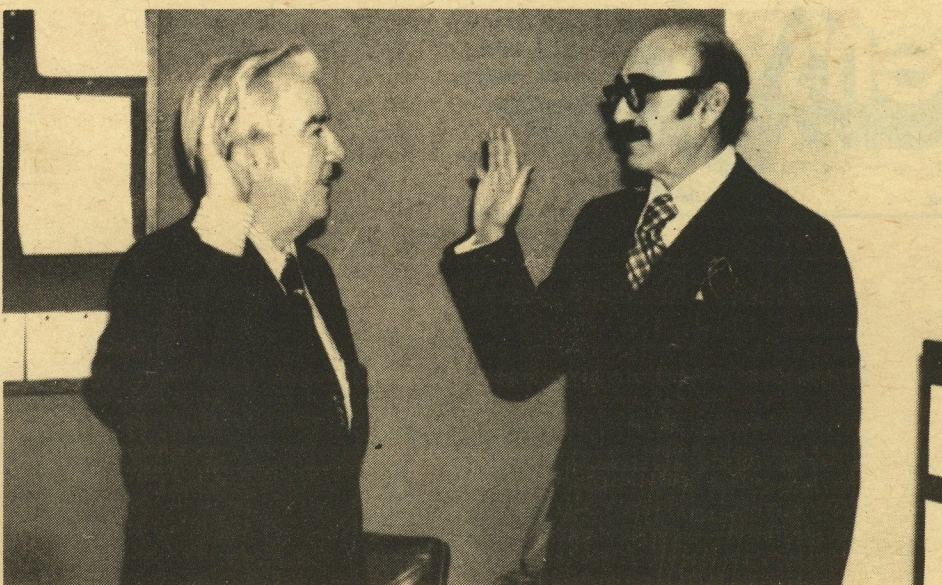
Suffolk Hostel Underway

As a result of the recent purchase by the Department of Mental Hygiene of a house in Riverhead for use as a community residence, Suffolk County Chapter of the Association will have its first hostel.

The hostel in Riverhead will be within view and walking distance of the Association's Riverhead Vocational Training Center where the 8 people who will live in the hostel will work.

On the same day that the Department representatives signed an agreement to purchase the property the Riverhead Town Board approved the plan and passed a resolution in support of the "concept of the community residence program for mentally retarded persons."

Bob Sansone, executive director of the Chapter called this the Department's "Christmas present" to the Suffolk ARC.



Senator William T. Conklin, Deputy Majority Leader swears in Joseph T. Weingold of the State Association as Consultant on Mental Health and Mental Retardation.

No Refuge!

A badly bruised, retarded youth ran away from the Willowbrook State School after allegedly being beaten by an attendant, and wound up in a South Bronx police station, where two officers cared for him most of the evening.

The policemen tried to place 18 year old Anthony Marino in another hospital because "we just couldn't send him back to Willowbrook," said Detective Robert Gardner.

But he was refused admittance at Bronx State and Bellevue Hospitals because his residence is still, technically, on Staten Island, the officer said. And at Jacobi, he said, "the only way they would take him was if he would sit in a waiting room with a police officer all night. Then they said they would try to send him back to Willowbrook in the morning."

Marino, who has been a Willowbrook patient since he was 7, ran away and took the subway to his mother's home at 670 Barretto Street in the Bronx. His mother is on welfare and was unable to take care of him, police said, and brought her son to the Simpson Street Station.

Resting in a precinct room, Marino told Gardner and his partner, officer Victor Larini, that he had gotten into an argument Wednesday with another Willowbrook patient, who clubbed him in the back with a lead pipe.

The school attendant in building no. 5 pulled Marino away, then hit him in the face, stomach and legs with a baseball bat, said Marino, who displayed a large red welt on his right side, and a swollen nose.

Woman of Year And Retarded

Mrs. Edith Yanklowitz, wife, mother and community leader, was honored recently by the Glens Falls Business and Professional Women's Club as their choice for Woman of the Year. A very active member of the ARC, Mrs. Yanklowitz in answering the question, "What can a lay person do?" said, "Give understanding; adopt someone in the state institution, or send gifts; volunteer your services; support legislation; inquire into the teaching your local school gives to the retarded; encourage religious training of the handicapped; encourage young people to go into the field of mental retardation; join your local chapter.

"The Association for Retarded Children is not just for parents of the retarded. We would like everyone to join and give their support."

Any further questions?

He said he reported the incident to school officials and yesterday, as a punishment, was not allowed to eat. The food the officers brought him last night was his first meal in more than 24 hours, he said.

Marino was returned to Willowbrook in a patrol car at about 2 a.m. after police said someone in the precinct called the school and was told they "had no way to come and get him." According to Willowbrook officials, after 5 p.m. the school's transportation services are available only for "medical emergencies."

Police said Marino had received first aid treatment at Jacobi Hospital.

Reached for comment, Willowbrook director Dr. Miodrag Ristic said that he did not yet have full details of the incident but expected a full report sometime.

He said the attendant has denied hitting Marino. "There were no witnesses apparently; it seems to be a case of one word against another. It's certainly an unfortunate incident."

Asked about the presence of a lead pipe in the patient's quarters, Ristic said: "This is an open institution; we have no gates here. They bring in all kind of things, even switchblades. We have to watch them very closely."

Officers Gardner and Larini said they know of Willowbrook "by reputation" and when they saw Marino's bruises they began calling other hospitals.

"We took him to Jacobi and they kept telling us, 'This is not a dropping ground; we won't take him,'" Gardner said. "It was very frustrating. A doctor told me, 'We are releasing him in your custody. How can he be in my custody? I'm not a doctor.'"

Another Federal Office

HEW Secretary, Caspar W. Weinberger, announced recently the creation of a special office for the handicapped "to deal more effectively with the special needs of the nation's millions of handicapped citizens."

"I am pleased to take this important step to focus the Department's planning and resources more effectively on this vital area," Secretary Weinberger said. "The Office for the Handicapped will help the handicapped to develop their fullest human potential, to make the services they receive more effective and better coordinated, and to make the Federal Government more responsive to their needs."

The new Office would be under the supervision of Stanley B. Thomas, Jr., Assistant Secretary for Human Development, who is also principal adviser to the Secretary for policy development related to special populations. Mr. Thomas said the Office for the Handicapped would:

- prepare a long-range projection for the provision of comprehensive services to the handicapped.

- continually analyze the operation of programs for the handicapped, and evaluate their effectiveness;

- encourage coordination and cooperative planning among programs serving the handicapped;

- develop ways to promote the utilization of research related to the handicapped; and

- provide for a central clearinghouse for information and resources available to handicapped people.

Mr. Thomas announced that Wallace K. Babington, Director of the Office of Mental Retardation Coordination in the Office of Human Development, has been named Acting Director of the Office for the Handicapped, in addition to his regular duties.

Creation of the new Office was authorized by the Rehabilitation Act of 1973.

Weingold Sworn In

Residents Oppose Home for Retarded

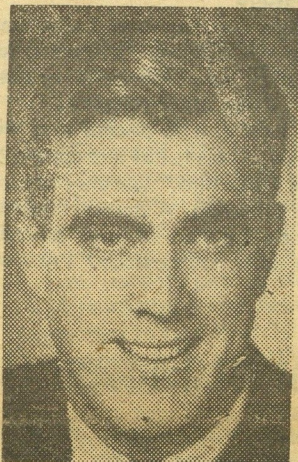
Residents of Owego at a public hearing overwhelmingly opposed the purchase of a home in the village of Owego by the Department of Mental Hygiene for use as a transitory house for retarded persons. Although a variety of reasons were given for opposing the purchase by Broome State School of a home at 81 Front Street, one that was not given was fear of or ignorance about the retarded. Mental Health officials, however, said that they felt that these were the dominant reasons.

This house which was to be a home for only 10 mentally retarded persons 21 and over posed an enormous threat to the community. Actually the retarded would spend about a month in this half-way house and then would be cared for by foster parents in the village. The ostensible reasons for opposing this was the lowering of property values which we have heard over and over again, but fear pervaded the whole tone of the meeting. One of the reasons for this hostility according to Fowler Wilson, executive director of Broome-Tioga Counties Chapter was the lack of preparation of the community for this venture. Only a few residents were

asked opinions in advance of the negotiations, and several of those polled at the meeting said they had been misinformed about the home. The State Association intervened and urged the Department of Mental Hygiene to proceed with this plan on the theory the public would learn to accept the retarded once they knew who they were and lived with them. In spite of all these efforts, however, the Department of Mental Hygiene felt it wiser not to proceed further and, in a letter to our executive director, Dr. Alan Miller, Commissioner of Mental Hygiene stated, "It seemed clear that it would be very difficult to mount an effective program at that location in Owego."

"Accordingly," he continued, "we have abandoned efforts to acquire this property. Broome School officials are now developing plans to work with the Tioga County Community Mental Health Board and your Chapter to locate alternate property in Tioga County. We are hopeful that the Owego episode will have a salutary effect and that a half-way house program will be established in Owego in the very near future. We would appreciate your continued support in these endeavors."

Murphy Named



James P. Murphy

It is with great pleasure that we inform our readers that James P. Murphy, regional vice president for the Southeast Region of the State Association has been appointed by Mayor Abraham Beame to the Board of Higher Education of the City of New York.

Jim is a graduate of Manhattan College and Fordham University Law School and Vice President of the Chemical Bank of New York. He also served on the Citizen's Commission on the future of the City University of New York and has been a delegate to the State Constitutional Convention, representing the Borough of Queens.

Congratulations and good luck. Some of our kids should be able to get into CCNY now.

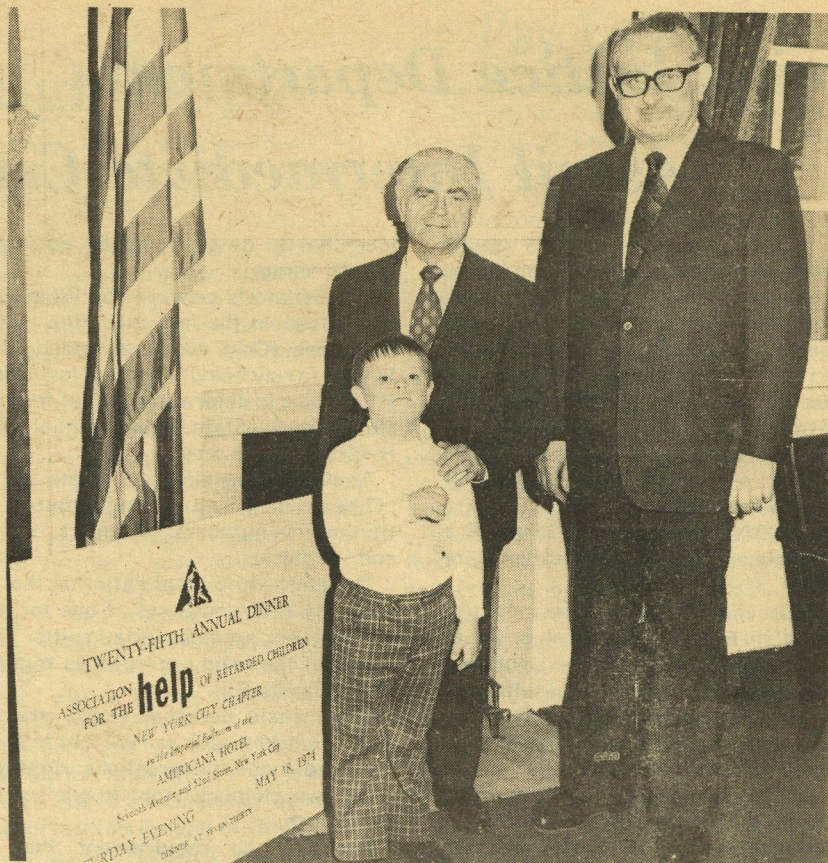
Governor's Proposal

In his Message to the Legislature on January 9th, Governor Malcom Wilson stated that he planned to establish by Executive action an interdepartmental commission on services to children and youth made up of the commissioners or directors of the following state agencies: Social Services, Health, Mental Hygiene, Education, Youth, Probation and Labor.

He would also establish by Executive action an advisory council to the commission composed of private citizens, local government representatives, professionals and lay persons engaged in children's services.

No one can object, of course, to a commission, even though we should in fact say "another commission", but the composition of this commission consisting of the very persons who must enforce the law and see to it that services are provided for children and youth leads us to adopt a skeptical attitude towards the efficiency of this group.

There have been interdepartmental committees in the past consisting of the commissioners of various departments whose efforts have been less than spectacular in providing services, certainly for the handicapped. Again we urge that a better alternative to such a commission, so far as the handicapped is concerned would be the Ombudsman bill introduced by Senator Conklin and Assemblyman Steingut. We suppose, however, this is too simple.



Mayor Receives Honor

Dirk Weiher, 7, presents giant invitation to Mayor Abraham Beame, at City Hall, for the 25th Anniversary Dinner of the ASSOCIATION FOR THE HELP OF RETARDED CHILDREN, at which the Mayor will receive the organization's highest yearly honor, the Humanitarian Award. Looking on, right, is I. Joseph Harris, Executive Director of the Association.

Aronin's Letter to Editors

The following letter by Elliot Aronin, president of the State Association was sent to the New York Post and New York Times. It was printed in the New York Post.

The letter expresses Elliot's concern about the relative value placed on people and horses by the legislators in Albany.

Remembering, however, that the Albany legislators have so many good laws on the books for the retarded, we must await the end of the session to see whether indeed they feel more for horses than for people — The letter follows:

"The priorities as spelled out by our Albany lawmakers seem to be weighted more towards horses than people, especially mentally retarded people.

Last week, The Senate passed a measure designed to assist race-track owners in their quest for financing new racetracks. It would permit industrial development agencies to finance tracks on the theory that they are 'recreational facilities' that create jobs and contribute to the 'prosperity and economic welfare' of an area.

Now, we don't have any objection to the concept of 'creating new jobs' etc., however, the record of Albany in showing similar concern for the mentally retarded is less than satisfactory. We have been made aware of the brutal conditions which exist in the State institutions for the retarded (Willowbrook, etc.). Funding for these institutions has always been inadequate.

For many years, we have been advocating proper financing for the institutions and at the same time proposing alternatives to institutionalization for the many residents who do not belong there but were forced to be there because of lack of alternative - housing.

Despite the fact that such alternatives would prove to be less costly than institutions, the state has been sadly neglectful in this area. It is all the more pathetic that the aforementioned race-track measure should be given priority when the needs of our handicapped, including the mentally retarded have been so neglected.

It is time for Albany to take its responsibility towards people, at least as seriously as it does animals."

Our Children's Voice
Retarded Children Can Be Helped!
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