

# Our Children's Voice

Retarded Children Can Be Helped!

Vol. XXVII No. 3

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

August 1975

Sept. 25 - 28

## State Convention "Looks Ahead"

"Looking Ahead".

These two words accurately reflect the mood of the Association, and were chosen as the theme for our 1975 Convention. Hosted by our Erie County Chapter, the 1976 Annual Affair will be held at the Sheraton - East, 2040 Walden Ave, Buffalo, from September 25-28, 1975.

"Having done a great deal of reminiscing at our 25th Anniversary Convention in New York City last year, and with the entire Association stunned over the Governor's cruel veto of our bill for a separate office of mental retardation, it will be a good time to recharge ourselves and begin looking ahead", said Elliot Aronin, President of the Association.

Following a traditional format, the Convention will open with a meeting of the Board of Governors on Thursday evening, September 25th and Friday morning, the 26th.

On Friday afternoon, in addition to the fine tours available, we will have a session on, "The Legislative Process". State Senator William T. Conklin has already accepted a place in this group, and we are hoping to have Assemblyman Arthur O. Eve of Buffalo as his Co-panelist.

Friday evening and Saturday morning will be devoted to our business sessions, including the election of officers and four Workshops will be presented Saturday afternoon. These will be on Education, Guardianship, Advocacy and Institutions, the latter focusing on the recent Willowbrook decision.

A social hour beside the hotel's magnificent indoor pool, with its many exotic plants, will precede our dinner-dance.

Sunday morning will see the newly elected Board convening to act upon any unfinished business, or anything sent to them by the delegates.

The 26th edition of the Association Annual Convention promises to be exciting, and marks our first trip to the far western reaches of the State since our 1963 meeting in Niagara Falls. It is hoped that those members in the Western Region will avail themselves of the opportunity to attend, when the Convention is so close.

An outline is on the back page. Everyone is urged to register in advance on the form provided there for you.

We're "looking ahead" to seeing you in Buffalo.

## VETO: Separate MR office Carey's first veto

Governor Hugh Carey's first veto of any bill passed by the legislature was a veto of the Conklin - Steingut bill (S. 11B) to separate mental retardation from the Department of Mental Hygiene by the creation of an Office of Mental Retardation in the Executive Department. In the debate preceding the passage of the bill, Governor Carey denied stating at a speech before the ARC at its annual convention in October, that he would sign such a measure if Senator Conklin got it passed.

Dozens of affidavits have been sent to the office attesting to the fact that spectators had heard him say just that.

In addition, a few days later, Doctor Leonard Stavisky, Assemblyman from Queens, at a legislative convocation in Queens, stated on tape that the Governor would sign exactly this bill. A transcript to Dr. Stavisky's talk is printed in full in another article in this newspaper.

The measure passed overwhelmingly in both houses with more than 85 per cent of the votes in each house in favor of the measure. Governor Carey waited until the very last day before he vetoed it.

In doing so, he displayed a callous disregard for the truth, shocking in the Governor of the State of New York. Furthermore, his trusted advisor on health matters, Dr. Kevin Cahill, completely disregarded the recommendation of his own subcommittee on Mental Retardation and the Task Force on Mental Health that reported to the Governor. This Subcommittee, under Dr. Joseph Wortis, stated that mental retardation should be separated from the Department of Mental Hygiene.

The Governor's veto message covering some five pages is full of specious arguments that this bill would fragment services, as if services for the mentally retarded are not now fragmented or almost disregarded. In quoting his own Task Force on Mental Hygiene, he forgot to mention the recommendation of the Subcommittee on Mental Retardation altogether. Particularly picked out for quoting is Dr. June Christmas, Commissioner of New York City Department of Mental Health and Mental Retardation Services, who opposed the bill on behalf of the City of New York. This is the same Dr. June Christmas who last year opposed the New York City Council measure to vote \$2 million for mental retardation. She refused to have this money earmarked and succeeded in blocking it. The \$2 million was voted, but Dr. Christmas used it as she wished.

The Governor further states that the proposed Office would cost between \$4 - 7 million, but there is absolutely no back-up for this figure.

It is interesting to note some of those he states as objecting. They are:

The New York State Catholic Conference, The Federation of Protestant Welfare Agencies, Federation of Jewish Philanthropies, Citizens Committee for Children, Traveler's Aid Society, Jewish Board of Guardians, New York State Association for Brain Injured, New York State American Association on Mental Deficiency, Fordham University School of Social Work, the Walworth School for Boys, Community Services Society, and One-Hundred Black Men.

None of these, to our knowledge, have been very active in the field of services for the mentally retarded. Some of those mentioned in his veto message now deny they ever wrote him officially. These are the Fordham University School of Social Work, the New York State American Association on Mental Deficiency, and many of the organizations supposed to comprise the New York State Council of Organizations for the Handicapped.

According to a spokesman for the State Association for Retarded Children, "This

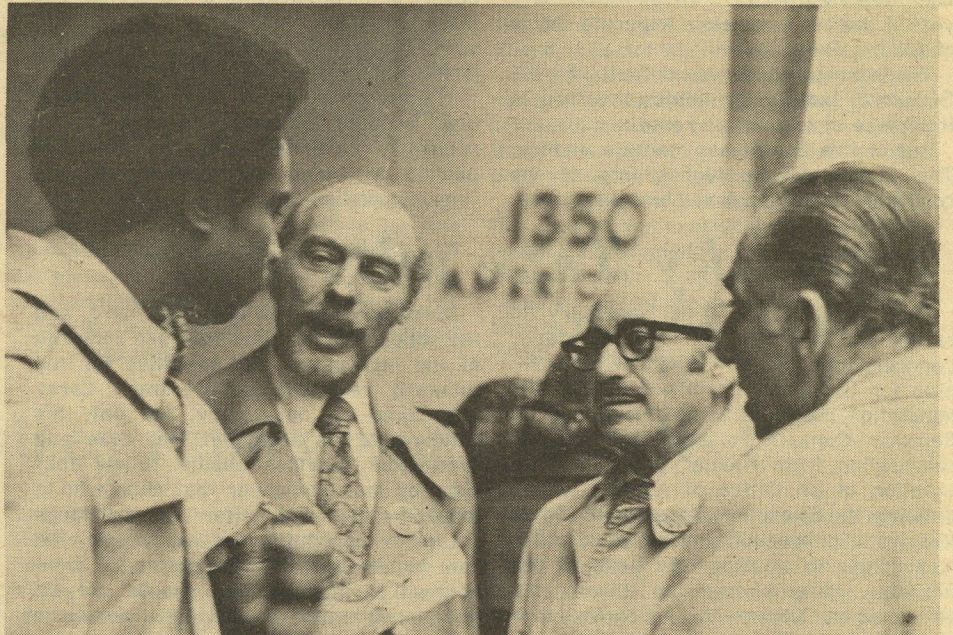
is a most callous display of deceit from this direction, with utter disregard for the dismal performance of the Department of Mental Hygiene in the field of mental retardation. In addition, the veto message is so full of misstatements as to be a deceitful document of its own."

"We deplore," said Mr. Elliot Aronin, President of the New York State Association for Retarded Children, "The Governor's action and only time will tell that he has made a horrible, unforgiveable mistake."

Commenting on the Governor's veto Senator William T. Conklin Deputy Majority Leader of the Senate stated, "This act is an arrogant defiance of the overwhelming will of the Legislature and a specific rejection of his personal promise to sign such a bill."

"Mr. Carey," continued Senator Conklin, "does exercise a pattern of deceit surpassing anything I have seen in over 30 years of political life."

In commenting on Governor Carey's counter proposal, which will be discussed elsewhere, he said, "This counter proposal is in truth a sham and a delusion designed to complete the deception." He ended with the statement, "I will never again believe Hugh Carey."



President Aronin, and Executive Director Weingold and Gabe Martini, Guild for Exceptional Children, discuss bill with reporters. More pictures, Page 15.

## Report rejects MR subcommittee

Dr. Kevin Cahill's report to the Governor on his Mental Health Task Force completely ignores the conclusion of his own Subcommittee on Mental Retardation under the chairmanship of Dr. Joseph Wortis with regard to the place of mental retardation in the Department of Mental Hygiene.

The full report of the Subcommittee is not available. We have in our hands a summary from the Chairman which states, "In spite of the sincere efforts of many good people, and the expenditure of large sums, too many of our mentally

retarded citizens languish in vast impersonal institutions, sometimes under inhuman condition; many in the community receive too little help, and many no help at all. The huge institutions should be dismantled as fast as new living arrangements in smaller homelike settings can be provided. Since our handicapped need special educational and training services, sheltered workshops, home visiting, social, nursing, medical and other services, an office directly under the Governor should be established to coordinate these services. (emphasis ours) It should also make policy, advise the

executive office and have an adequate staff for these purposes. It should be provided with a budget to use itself or distribute to the regional offices for the purchase of local services. Its director should be independent of any existing department and should be assisted by an appointed advisory committee that would include consumer representation."

There is a little more to this summary, but the essential part is the recommendation that there be an Office of Mental Retardation directly under the Governor and not in any way subordinate to the Commissioner of Mental Hygiene.

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## Forgive? Forget?

Another battle in a long war for the rights of the mentally retarded has been lost. The Governor's veto of S. 11B the Conklin - Steingut bill spelled the death, for now in our opinion, of a meaningful approach, a new way to create the mechanism of the kind of services, we the parents of the mentally retarded want for our children and our adults.

It is obvious that we do not want what the Department has been doing. It is obvious to everyone that what they have been doing has been wrong. It is obvious that the present mechanism and system of delivery of the services is not the vehicle to accomplish the changes needed.

Nevertheless, this defeat is just a battle lost. The war is not lost. It is obvious that we must go on. We must work with whatever mechanism of government there is and, until changed, to accomplish what we have set out to do.

The cliché, "forgive and forget" comes to mind almost immediately. Is it necessary to forgive? Is it necessary to forget? Is it necessary to wipe out what has happened so that we may cooperate with government?

We should never forget. We should never forgive this golden missed opportunity.

But to remember and not to forgive does not mean sulking, it does not mean remaining on the sideline, it does not mean retreat.

On the contrary, memory of promises made and not kept, the memory of the opposition of agencies who have done almost nothing for the mentally retarded, memory of brute strength wielded without mercy, stiffens our resolve to do more than we ever did for the retarded, both in the community and in institutions. Furthermore, it stiffens our resolve that we are in the right path and will continue in that direction.

## Victory or defeat?

There may be those who say that the parents of the mentally retarded have been defeated because of the Governor's veto of the bill to create a separate Office of Mental Retardation.

The bill may have been defeated by the Governor, but the principles involved in this piece of legislation remain.

Out of this defeat has come a victory. The victory is the highlighting of the conditions in the Dept. of Mental Hygiene.

## Stavisky Tape tells truth

Once and for all, it is necessary to establish whether or not, indeed, Congressman Hugh Carey, when running for Governor, promised to sign the legislation that was being introduced by Senator Conklin to separate mental retardation from mental illness by the creation of an Office of Mental Retardation in the Executive Department. To do this, we print herewith, in full, a verbatim transcript of a tape of Leonard P. Stavisky, Assemblyman, in a talk he delivered on October 17, 1974 in Menorah Hall, Flushing, Queens at a symposium on legislation attended by more than 200 people. The verbatim transcript follows:

"Permit me not to speak on my own behalf; and permit me to speak at the request of Congressman Hugh Carey; in behalf of the six million Americans who are among the retarded and in behalf of the 60,000 residents of Queens County, who are in that category.

You have heard tonight, about how necessary legislation to separate the administration of programs for the mentally retarded from the administration of programs for the mentally ill have been passed in Albany, in the Assembly, and in the Senate, and have been vetoed by the Governor of New York. I give you this commitment tonight, FROM Hugh Carey, that Governor Hugh Carey, will sign such legislation into law.

## A political move without significance

# Governor proposes MR legislation

"A POLITICAL MOVE WITHOUT SIGNIFICANCE," — WEINGOLD

In an obvious attempt to soften his veto of the Conklin - Steingut bill to separate mental retardation from the Dept. of Mental Hygiene, Governor Hugh Carey has belatedly submitted a measure supposedly to strengthen the programs for the mentally retarded.

The Governor's proposal would create a Division of Mental Retardation and Developmental Disabilities within the Department of Mental Hygiene completely under the authority and domination of the Commissioner of Mental Hygiene with authority to supervise regional and local programs, services and facilities for the mentally retarded and the developmentally disabled. The only difference between what is happening now, and this, is the present Division of Mental Retardation and Children's Services does not have the authority to supervise local services. In addition, the Governor's Program also calls for an ombudsman to be attached to the Dept. of Mental Hygiene. The purpose of the bill according to the Governor's Release is to create "a distinct chain of command and separate budget line for mental retardation and developmental disabilities, within the Dept. of Mental Hygiene," (emphasis ours). It replaces the present Mental Retardation Advisory Council or Committee with a 15-person advisory committee, 12 of whose members shall be "selected from among persons having demonstrated interest in the field of mental retardation and developmental disabilities, including (but not mandated) concerned parents and representatives of consumer groups."

The victory is the highlighting of the need for new approaches. The victory is exposure of the bankruptcy of the system and those who hang on to it like the shreds of some memory, dear to them but irrelevant to reality.

The major victory is that all of us have been brought together in this field, the mentally retarded and the cerebral palsied, with a renewed determination, a renewed dedication.

Many have spoken about the care, and the supportive services that are required at the institutions and facilities for the mentally retarded. Congressman Carey has asked me to convey, not only his concern in this area, but that care and supportive services should follow that man, or that woman or that child who is mentally retarded, after his discharge from the institution as well, into the community and into the home, if it is necessary. That person should not be abandoned simply because that person is ready to return to the community.

Congressman Carey has asked me to say that, if there are sheltered workshop programs, a living compensation has to be given to those individuals, not peonage; and that transportation must be provided, so that employment in the regular market can be guaranteed.

He has asked me to talk to you about the educational needs of the retarded and he has asked me to say that education does not stop at age 21, but if there is need for educational programs they must be funded by State, and local, and yes, even Federal Government, beyond the age of 21, on a continuing basis.

And he has asked me to pledge to you his willingness to work with you, to cooperate with you, in a partnership, whereby those in Government, and those who are parents of the mentally retarded children, can

(Continued on Page 11)

### ADVISORY COMMITTEE DUTIES

The duties of this advisory committee shall be to consider things relating to improvement, advise the deputy commissioner of the Division and the Commissioner; it shall evaluate; it shall review and evaluate; it shall inform the Commissioner when it determines that something should be done in the best interests of the retarded or the developmentally disabled; it shall advise the Dept. Commissioner on the preparation of a budget. (Emphasis ours).

There should be an executive Director of this committee who is going to serve as an advisory to the Dept. Commissioner, coordinate studies, refer complaints and recommend action.

The bill also says he shall act as an advocate but does not indicate how.

### DEPUTY COMMISSIONER'S POWERS

As for the powers and duties of the Deputy Commissioner of Mental Retardation and Developmental Disabilities, we only have to see that he will be appointed by the Commissioner, subject to the approval of the Governor. And the Commissioner shall charge the Division with responsibility subject to the Commissioner's veto to be involved in planning and coordination, help establish policy, provide for effective rendition of services (how?) and shall enforce the rights of the residents in facilities (what about the Mental Health Information Service?); and generally supervise in-patient facilities.

The only new approach is the creation of Deputy Director for Mental Retardation and Developmental Disabilities for each region wherever a region is set up by the Commissioner. The Mental Health, Mental Retardation and Alcoholism Boards only have to coordinate their efforts with respect to program for the mentally retarded and developmentally disabled with the Deputy Commissioner and note that the Commissioner shall appoint each Director of a Department, Developmental Center or facility.

In effect, although there is the appearance of progress and concern in this piece of legislation the net effect is to render the whole thing under the

jurisdiction of the Commissioner of Mental Hygiene and under his authority. This is more of the same according to the State Association for Retarded Children.

### ANALYSIS SHOWS WEAKNESS

A close evaluation of the legislation distinguishes it as quite different from separating mental retardation and developmental disabilities from the Dept. of Mental Hygiene and the psychiatric - medical model for the delivery of services.

According to an analysis of this bill made by Mr. Weingold, all this bill does is push the food around the same plate."

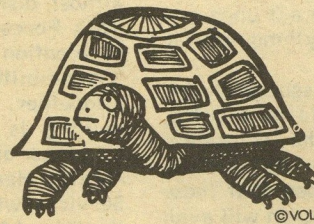
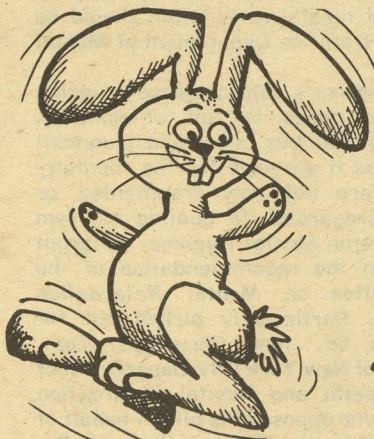
Further analysis of the bill by Mr. Weingold states as follows: "The Governor's statement — that no state agency now has the clear responsibility for the care of those with developmental disabilities affecting mental development attributable to such conditions as cerebral palsy, epilepsy, clearly demonstrates the Governor is unaware of the Developmental Disabilities Services Act, which specifically includes these disabilities as well as brain injury and is under the aegis of the Dept. of Mental Hygiene. Nothing new has been added with regard to these developmentally disabled that is not already in the law.

The creation of an "ombudsman" is eyewash, states the analysis. An ombudsman should be completely independent, not the part of any department. Furthermore, under the Governor's bill this ombudsman will be merely another super-numerary in the army of the Dept. of Mental Hygiene at a large salary but will have no powers to enforce even the primary power of subpoena.

In conclusion, the analysis said, "this bill may have had some meaning five years ago, but it is almost meaningless now.

"The Department does not need reorganization in this sense, but surgery. The Governor's bill is a bandaid."

The Association has expressed its opposition to this bill to all the legislators and hope that it will meet the fate suitable to this maneuver, that it will die in committee.



BEAT YA TO  
BUFFALO!

**Our Children's Voice**  
Retarded Children Can Be Helped  
NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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# Willowbrook decree signed

Monday, April 21st 1975, a Consent Agreement was entered into between the New York State Association for Retarded Children Inc. and other plaintiffs and Governor Carey and the principal defendant in the, so-called, Willowbrook Case. The Decree was later approved by Judge Judd and contained an appendix of 29 pages, single spaced, with the various standards to be established at Willowbrook. The key points mandated in this landmark agreement include (1) the establishment within a 12-month period of 200 new community placements (not hostels) but just placements in hostels, half-way houses, group homes or sheltered workshops, etc.

(2) A request from the State Legislature to provide at least \$2 million for financing, leasing, and operating the 200 new community placements.

(3) Request the legislature to provide additional funds to develop and operate community facilities and programs annually for the next five years.

(4) Develop individual plans of care, education and training for each of Willowbrook's 3000 residents to prepare them for life in the community.

(5) No resident shall be transferred from Willowbrook unless the director determines that the new placement will offer better service and opportunity.

(6) The reduction within six years of Willowbrook to a population of approximately 250 beds to serve people requiring institutional care on S. I. only.

The agreement establishes detailed standards to guarantee the Constitutional right of the more than 5000 mentally retarded persons who were residents at Willowbrook in March 1972 when the law suit was filed. Commenting on this Agreement, Governor Carey said, "We mark now the beginning of a new era of cooperation, and begin the hard work necessary to carry out this Agreement and to improve the services and opportunities for the retarded at Willowbrook and across the State".

Major portions of the Agreement also call for the appointment of a seven member review panel to assure compliance with the Agreement. Within six months, this panel will recommend a plan to expand community-based mental retardation facilities. Actually this panel will consist of three members to be chosen by the plaintiffs and approved by the Court, two to be chosen by the defendants and approved by the Court, and two others to be chosen by common consent of the plaintiffs and defendants and to be approved by the Court.

Commenting further, Governor Carey said, "These items are promised to Willowbrook immediately. They should be adopted statewide. We intend to do so. All the retarded — not just those at Willowbrook — can benefit from the standards and policies contained in the agreement. It will be the policy of my administration during the course of the next four years to extend the standards contained in the Willowbrook Agreement to programs and facilities for the retarded throughout the State."

At the same time that the Agreement was signed, a statement was also issued by President Elliot L. Aronin of the New York State Association. "Such action on the part of the State Association," said Mr. Aronin, "was with reservation." "Although there are considerable advances in the Consent that promise a better life for the residents of Willowbrook State School, significant portions dealing with the means to develop community facilities as alternatives to Willowbrook were vetoed by the defendants."

Mr. Aronin went on to say — Furthermore, the success or failure of the objectives of this Consent Decree hinge almost entirely on the bureaucracy charged with implementing it. This implementation rests on the same

bureaucracy which created and perpetuated Willowbrook and failed to carry out to any great degree the interim order of Judge Judd. We are hopeful, however, that this Consent will become more than a lengthy scrap of paper. . . This hope by Mr. Aronin was based on the supposition that Governor Carey would sign S. 11B, the bill to create a separate Office of Mental Retardation which Governor Carey subsequently vetoed.

Naturally, the Association will be closely involved and watching the developments concerning the implementation of this Decree. Decrees such as this are not easy to obtain, but they also may become exercises in futility without real implementation.

In answer, for example, to a question by a reporter at the signing of the Decree as to how Governor Carey is going to reduce the population in Willowbrook, he stated that some 600 or 800 would be transferred from Willowbrook to other state developmental centers (institutions) during the year. In the opinion of this Association this is merely moving people like baggage from one place to another without a meaningful program. The reduction of population at Willowbrook was not the end result, in this Decree, but a better life for them, which cannot be promised in institutions of the State of New York.

## Cahill appointed

Governor Hugh L. Carey earlier this year announced the designation of Kevin M. Cahill, M.D., of New York, as his Special Assistant for Health Affairs, and coordinator of all of the state's health programs.

Dr. Cahill was chairman of the Governor's task forces on health and mental health, and will serve without salary as chief advisor to the Governor on medical affairs.

Dr. Cahill is a practicing physician in New York City, and Clinical Professor of Public Health and Preventive Medicine in this country and a teacher for the World Health Organization abroad. He is a consultant to the U.S. Public Health Service and the United Nations on health matters.

As part of his position, Dr. Cahill will be passing on all the programs and projections of the Department of Mental Hygiene as well as the Department of Health.

In response to a letter from Thomas A. Coughlin, III, and the Mental Retardation Advisory Committee, to the NYS Department of Mental Hygiene calling to the Governor's attention that the budget does not make sufficient provision for implementation of a number of laws created to provide services for the mentally disabled including Chapter 620, Laws of 1974, (which provides for full payment for services for those released from the institutions who have been there for five years as of January 1, 1975), Governor Carey promised that programs such as this would be fully funded by the transfer of funds from other programs or by requests for a deficiency appropriation. The letter to Mr. Coughlin, dated March 20, 1975 follows:

"Dear Mr. Coughlin: This is in response to your recent letter regarding the 1975-76 Executive Budget recommendations.

First, the 1975-76 Budget recommendations for the Department of Mental Hygiene must be assessed within the

## Waiting in vain for Governor's signature



Margaret Curry of the Association for the Help of Retarded Children, New York City Chapter points to sign celebrating the New York State Senate's overwhelming vote to separate mental retardation from mental health. She is now waiting for Governor Carey to sign the bill.

## State ARC Amendments

There has been considerable question as to whether or not the New York State Association for Retarded Children, through its chapters, may engage in such activities as day care, group homes for young children, psychiatric clinics, etc. It was determined by the Board of Governors that the Certificate of Incorporation powers be amended to provide for all of these.

After considerable consultation with the Board of Social Welfare and the Department of Mental Hygiene, the Certificate of Incorporation was amended as of April 10th, 1975 to give the Association, in addition to all other powers, the following:

"To establish, own, operate and maintain non-residential facilities for the care, treatment, training, education and rehabilitation of the mentally retarded.

To establish, own, operate and maintain community facilities as hostels for the mentally retarded providing programs of care, services, habilitation, homelike environment and social activities for the mentally retarded or any combination of such programs.

To establish, own, operate and maintain a group home program (as defined in the Social Services Law) for mentally-retarded children; provided, however, that nothing herein shall authorize the group to care otherwise for, to board out or place out children or to act otherwise as a child-caring agency (as defined in the Social Services Law).

To establish, own, operate and maintain out-patient psychiatric clinics.

To establish, own, operate and maintain day-care centers or treatment centers, or both, in the State of New York; provided, however, that before each such center is opened the prior approval of the State Board of Social Welfare shall be obtained.

To establish, own, operate and maintain residential facilities providing 24-hour professional care, treatment and training programs, or any combination of such programs, for the mentally retarded.

Nothing herein contained shall authorize this corporation to establish or maintain a hospital as defined in Section 2801 of the Public Health Law or to undertake or carry on any of the activities specified in Section 404, subdivision (c) of the Not-for-Profit Corporation Law."

## Carey promises funds, not in budget

context of what is a very constrained statewide fiscal plan. As I am sure you are aware, New York State Government is facing a very difficult period with projected expenditures far above the level of revenues expected from the existing tax structure.

With this in mind, the 1975-76 Budget recommendations for Mental Hygiene programs represent very difficult priority decisions. We recognize the benefits of the hostel programs but a substantial addition of new dollars for this program was precluded by the general fiscal situation. However, the Executive Budget requests legislative approval for the Department of Mental Hygiene to further refine its priorities and if possible reallocate existing resources to fund the hostel program at an increased level. At this time, the Department is exploring alternatives to this end.

With regard to Chapter 620, although the Department requested \$8 million to fund

this portion of Local Assistance or Unified Services aid formulas it was determined that because of the lack of fiscal experience with this feature of the aid formula, a more conservative estimate of projected expenditures was required. The Budget bill sets forth the \$2 million as a separate item within the schedule of appropriations; therefore permitting the Division of the Budget to interchange funds and administratively expand the amount available if required. Furthermore, should expenditures exceed the level of appropriation, a deficiency appropriation would be considered.

This administration is committed to improving services and programs for the State's mentally disabled citizens despite the obvious difficulties imposed by the State's bleak fiscal picture. We trust that we will have your continued support during this period of critical and dynamic change for the Department of Mental Hygiene. Sincerely, Hugh L. Carey."



# The Special Olympics - What it's all about

By Jim Flanigan,  
State Director

During the weeks before the 1975 New York State Special Olympics Meet, the home of Sally and Bill Chilson, outside of Syracuse, was gradually buried in a sea of registration forms; the office of Dee DaBramo in Mamaroneck was constantly buzzing with efforts to recruit volunteers to run the games; people from almost every segment of the Brockport State University campus and the Village of Brockport became involved in preparing for over 2,000 visitors and, around the state, Area Coordinators were busy with area meets, wrapping up fund raising campaigns, ordering uniforms, assigning chaperones and arranging transportation for the State Meet. The telephone in my kitchen was constantly ringing with questions; "can we bring a camper and park on campus?" "we raised some more money, can we add two more athletes to our area delegation?" "can some parents obtain housing if they arrive late Friday night?" etc. etc.

## EXCITEMENT BEGINS

At times, it seemed like utter confusion and we wondered if everything would be done on time, but by Thursday evening, June 12th, an advance contingent from around the state had arrived and was busy with the details of pre-registration. Wrist bands and room keys were distributed, three telephone lines were open for calls with any last minute substitutions, participation medals, souvenir pins and bookbags were being counted to insure that every athlete would have one of each item.

On Friday afternoon the Brockport campus really came alive. Athletes arrived by bus, car, mini-van and even plane. Several area delegations from the western part of the state stopped for picnics at Letchworth State Park, sports clinics were in full swing. Thanks to pre-registration, most of the athletes were into their dormitory rooms within 15 minutes of arrival on campus, uniforms were proudly put on, new friends were made and, in the cafeterias, photographers from Kodak were taking pictures of each area delegation which would be given to each athlete as a souvenir of the weekend.

## OPENING CEREMONIES

By 5:00 p.m. all the areas had been registered and the athletes filled the dining halls with excitement. By 6:00 p.m. over 250 trained physical educators were meeting in the college gymnasium to plan work assignments, check equipment, make last minute scratches and prepare for the next day's events. By 7:00 p.m. over 1,000 athletes, with their chaperones had begun to assemble in the staging area next to the gymnasium. Finally, at 7:30 to the tune of two marching bands the athletes marched into the stadium for Opening Ceremonies. The ceremonies, complete with Olympic Oath, words of encouragement from Honorary Head Coach Bob Hyland of the New York Giants, lighting of the Olympic Torch and release of helium filled balloons lasted until sunset.

After Opening Ceremonies the athletes returned to their dorms where a special video tape program of cartoons was being shown in all the lounges. Several areas had pizza parties in an effort to satisfy the almost limitless appetites of their athletes. By 10:30 all the youngsters were in bed dreaming of the next day's glories.

Before most of the participants had even arrived at breakfast on Saturday morning, the Games Committee was already at work moving equipment into place, making sure each area had enough award medals, assigning volunteers and checking schedules. At 8:00 a.m. the gun went off for the first race of the day. Suddenly, two tracks, two swimming pools, two gymnasiums and eight bowling lanes were alive with activity.

Throughout the morning, the campus at Brockport State was buzzing as events were run and awards were made. Late in the morning the smell of cooking hamburgers reminded everybody that the lunchtime picnic would soon begin. Not even a sudden cloudburst during lunch could dampen the excitement of the day. Competition, sports clinics and award ceremonies all moved inside to await the end of the rain.

was ready for distribution 15 minutes after the end of Closing Ceremonies.

The huge Brockport State Gymnasium was crowded and the noise level was almost deafening for the Saturday night rock dance. However, these conditions didn't seem to bother the excited participants. Everybody got into the swing of things. As one college student, who had been working almost constantly since Thursday, observed; "the students who

## THE MEANING IS DEEP

As exciting as all this sounds, the State Meet is only a small, though very visible, part of what the Special Olympics is all about. The true impact of Special Olympics can be seen in the countless hours of training and preparation which takes place throughout the year. It can be seen in the increased awareness in communities throughout the state of the positive things that can be accomplished by mentally retarded people when they are given the support of their teachers, families and communities. It can be seen in the positive self concept Special Olympics has helped to develop in many retarded youngsters. It can be seen in the involvement of hundreds of physical education teachers and in the encouraging fact that a very large portion of the 250 people who ran our games are undergraduate physical education majors, who paid their own way to come and work on the meet and who represent the future physical education teachers of our state. Finally, it can be seen in the new appreciation many parents have for their retarded youngster.

There are, of course, other benefits of Special Olympics participation which relate directly to the big meets like our annual State Meet. For many youngsters a meet can represent their first time away from home, their first long trip without their parents, their first meals in a college dormitory or their first chance to meet a professional football player.

When you talk about the benefits of Special Olympics, however, you must always talk about the individual victories. The youngster who was afraid of the water, but went on to overcome that fear and win a race. The athletes who have moved on to school teams, regular classes or jobs in competitive employment. The boy or girl whose determination overcomes physical limitations. At this year's State Meet there were over 1,000 stories like these. Each one deserves to be told.

## WHAT HAPPENS NEXT

In the immediate future will be the 1975 International Meet at Central Michigan University in Mt. Pleasant, Michigan. This meet, involving over 3,000 young Olympians from the United States, Canada, France, Mexico, Brazil and several other countries, will be held August 7-11. Over 100 youngsters from New York State will be competing. One of the most exciting developments of this meet will be an "Exploration Day" to be held August 10th. On this day over 50 communities from around Michigan will "adopt" a state or foreign country. The host community will bring the adopted delegation to their town for picnics, parades, ceremonies, games and other activities. It promises to be a great people-to-people project that should do a great deal for the education of the people of Michigan with respect to mental retardation.

In the more distant future there are still a number of needs that must be met. There is a need for more year-long activities. We are already working on plans for a winter carnival, and tournaments in floor hockey, basketball, volleyball and bowling. There is a need to develop more adult-like programs for people over 21 years of age. At the other end of the age range there is a need to develop more non-competitive programs for younger children, families of retarded youngsters and multiply-handicapped youngsters.

A lot has been accomplished in the six short years of our existence in New York State, but a lot still needs to be done.

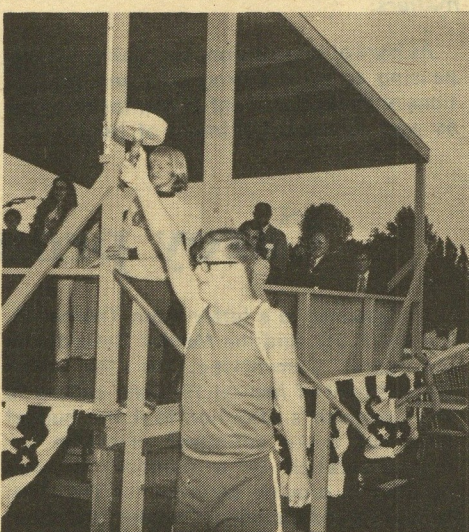
## Special Olympics '75 Opening Ceremonies



From left, Jim Flanigan, State Director of the N.Y.S. Olympics, Jim Cheyanski of the Buffalo Bills, Bob Hyland of the New York Giants and Kirk Lewis, representing the N.Y.S. Assn. Youth Board on the Executive Board of the Special Olympics.



Honorary Board member, Jerry Weingold and Kristin Krull, Miss New York State, at the reception before the ceremonies begin.



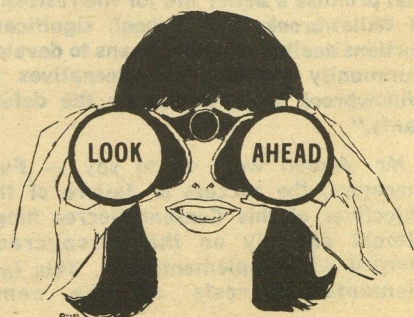
On the field at Brockport

## CLOSING CEREMONIES

As the 4:00 p.m. time for Closing Ceremonies approached, the sun broke through, permitting ceremonies to be held outdoors. The parade of athletes, extinguishing of the Olympic Flame, closing remarks and lowering of the flag were followed by the singing of Auld Lang Syne. The athletes then headed back to their dorms to freshen up for dinner and the big rock dance. While all this was going on, a group of volunteers was busy preparing a booklet with the results of the days activities. The booklet, 37 pages in length,

are here during the school year could learn a lot about their own inhibitions if they could go to a dance like this." For the younger athletes, not interested in dancing, a special show featuring a clown and a magician was also run. 11:00 p.m. found most of the weary athletes more than ready for bed.

Sunday morning started with breakfast, residence hall check-out, optional religious services, good-byes to newly made friends and departure for home.





# Bond bills peril hostels



## Nassau film award winner

Jose Ferrer, left, who donated his time and talent, listens to playback of his narration of the new Nassau Chapter film, "Like Everybody Else," with (l-r) Director Biff Boyle, Producer Julie Levy, Writer Harold Salemsen and Sound Engineer Paul Blank at the panel. Winner of two awards at the Long Island International Film Festival, which judged 200 films submitted from all over the United States and abroad, the 30 minute color film was awarded top honor as best documentary in its category — Social and Human Concerns and the most outstanding film made on Long Island. The film deals exclusively with adult retardates in the Nassau Chapter's programs — their vocational training center, hostels, boutique, greenhouse, occupational day training and recreation programs — and features the men and women engaged in their various daily activities. The title reflects the film's theme, that retarded people have the same needs as all of us and they are, in fact, "Like Everybody Else."

## Training grant for hostel staff

A grant of \$12,400 has been made by Social and Rehabilitation Service of HEW to the New York State Association for Retarded Children for training of personnel operating hostels for the mentally retarded.

This grant will cover personnel in region II which includes New Jersey, New York, Puerto Rico, and the Virgin Islands.

Lest some of our readers might be jealous that this will take place in Puerto Rico or the Virgin Islands, we hurry to assure them that the In-Service Training will take place in New York State, where most of the hostels exist.

The program will be under the direction and coordination of Meyer Schreiber, Associate Professor, Social Welfare, Keene College, N.J., once associated with the New York City Chapter, AHRC, director of Social Services. On the faculty as well will be Mrs. Edna J. Baer, formerly director, Division of Special Purpose Housing, Housing and Development Administration, New York City, Deputy Chief and Director, Social Planning Division, Neighborhood Conservation Bureau of Housing and Redevelopment, and for more than ten years, until 1961 executive director, Jewish Child Care Council, a council for all Jewish Family and Children's Agencies and institutions in the City of New York.

Also on the faculty will be John A. Gabriel, Ph.D., Professor and Chairman in Behavioral Sciences at Fordham University, School of Social Work, at one time assistant executive director at the New York Jewish Child Care Council and consultant on cost analysis, U.S. Children's Bureau, HEW.

The purpose of this In-Service Training Program will be to bring together per-

sonnel from the various hostels being operated for the mentally retarded in this region together with, we hope, at least one lay leader from each of the agencies and especially with the involvement of the residents themselves.

The program will seek to involve the major sub-systems of the social system — the staff, board members, policy makers, consumers or retarded adults; develop some increased awareness, understanding, insights into the basic and ongoing concerns flowing from the operation of a 24-hour, 7-day a week facility situated in a community settlement; delineate the role of the hostel worker through utilization of in-service training programs and, finally develop training materials for ongoing educational activities, particularly a manual for staff.

It is hoped also that we will try to innovate ways of peer help through a kind of peer review and evaluation. The program will be held sometime in October.

The steering committee, including John Conti of HEW, who was most helpful in processing this grant application, Peter Knauss of the Dept. of Mental Hygiene, Richard Bonelli, Executive Director of the Bergen-Passaic Unit, N.J. Association for Retarded Children; Maurice Kott, Director of Institutions and Agencies of the State of New Jersey, Harold Stein, Grants Manager and Specialist of Human Development of HEW; Robert Sansone, and of course the faculty of the In-Service Training Program, is now in the process of putting together the actual program of training.

Inquiries should be directed to the New York State Association for Retarded Children office.

The future construction of community mental health facilities, such as hostels, has been jeopardized by a series of bills, backed by state controller, Arthur Levitt, aimed at cutting down the use of "moral obligation" bonds.

"Moral obligation bonds" do not have to be approved by the state's voters in a public referendum. The whole mess came about through the failure of the Urban Development Corporation, a quite different agency from Housing Finance Agency which issues bonds for the mental retardation project.

### LEVITT INTRODUCES BILLS

Levitt has had introduced a group of bills in the state legislature that would effectively cut off the power of a variety of state agencies to issue moral obligation bonds. The ceiling on issuance of these bonds is limited essentially to the indebtedness already incurred or indebtedness that must be insured to finish existing projects. The effect in the case of mental hygiene facilities would be simply to erase about \$480 million in bonding authority.

Although it does not seem, at this moment, that there is much chance of these bills going through the legislature, their existence has effectively shut off the availability of bonding authority in the Housing Finance Agency which administers the two major programs affecting Mental Hygiene facilities.

"We'd have to say something in a prospectus for the sale of the bonds if these bills are pending," said Edward Bopp, Assistant Director of the agency. "Who would buy the bonds under these circumstances?"

Currently, HFA is authorized issue up to \$1,050,000,000 in bonds for the construction of mental health facilities and \$650 million has been committed. This leaves a bonding authority of \$450 million which could not be used if the bills were passed.

### SEPARATE PROGRAM ALLOWS \$100 MILLION

Under a separate program, HFA can issue \$100 million to provide state mortgages for construction of community facilities such as hostels. The agency has committed about \$20 million already, but that would be a ceiling, leaving \$80 million in unavailable bonding authority.

At the same time, the administration talks about a proliferation of hostels while its own controller effectively is killing off such a program.

### THREE AGENCIES AFFECTED

One of the immediate casualties is the construction of the 10 hostels in the Mid-Hudson Valley for which the New York State Association for Retarded Children received a \$480,000 federal grant. It is supposed to be a model for future home-style care, but now the financing is almost impossible with H.F.A. out of it. Attempts are being made by the Association to find more conventional financing. As part of this, the supplemental budget has included a request by the Department of Mental Hygiene for \$1 million to be a grant to the State Association for this purpose to leave the mortgage money far less than otherwise.

Other casualties appear to be the plan by the Nassau County Association to build 2 new buildings at a cost of \$2½ to \$3 million at its Brookville headquarters. Dr. Kolb, the new Commissioner, commented he hoped to advance the hostel program and half-way house program and day care program. "We are deeply concerned", said Dr. Kolb in a letter to Governor Carey's health advisor, Dr. Kevin Cahill.

Robert Laird, a spokesman for Carey said, "Carey has said publicly that he is not in total agreement with the controller. In a number of agencies, he thinks moral obligation bonds have been well handled. The Housing Finance Agency is one agency that has done a good job on that score." Nevertheless, we see no movement along this direction in spite of these welcome sentiments.

It is ironic that in the Mental Hygiene News of March an article appeared that the new design system for the hostels in the Mid-Hudson Valley would speed hostel development. Yet this system involves an

"elective component system for construction of hostels which we hope to test with the aid of Peter Knauss, Director of the Department's hostel program and the federal government."

"The elective component system offers the opportunity to create a very well designed hostel building at an economical cost, but of course if you can't build it all, then all this falls by the wayside."

## Membership lags

"It really never makes any difference," lamented Assistant Executive Director, John Bertrand, "no matter when we ask for memberships, everyone waits until the last minute to send them in."

He was hoping for a rush of memberships, since only 17 Chapters out of 58, including our new Yates County Chapter, had reported memberships by June 1. As usually is the case, there was a problem with consistency, with those Chapters who had shown an increase doing a fabulous job, and the remainder dropping off enough to show a decline in the comparative numbers of this same group of Chapters from 1974.

Comparing the June 1 reports to last year's final figures, this same group of Chapters shows a decrease of 447 memberships. Of those, two Chapters had individual reductions of approximately 500 and 375, respectively to offset our gains.

As always, however, there are a few "super gainers" and we want to give credit here to several outstanding efforts.

We must mention Erie County, which has sent an initial list of 184 memberships, after last year's disastrous low of 30; Columbia County under the Chairmanship of Mrs. William Young, which grew back to 300 from 247; the work of Montgomery County's Mrs. Joseph Tokarczyk who has sent in over 150 percent of last year's 81 members with a list of 128 and the two most outstanding to date, Georgia Sullivan, Chairman of Orange County's membership drive who increased her Chapters numbers from 203 memberships to 506 and Helen Donnelly of West Seneca State School Chapter who turned 1974's membership of 83 into a 1975 figure of 350.

We are hoping for such gains in many other localities.

## Joseph Stuckart dies

On April 18th, our dear friend, one of the early members of the New York State Association for Retarded Children and one of the founders of the Broome County Chapter, died after an extensive illness.

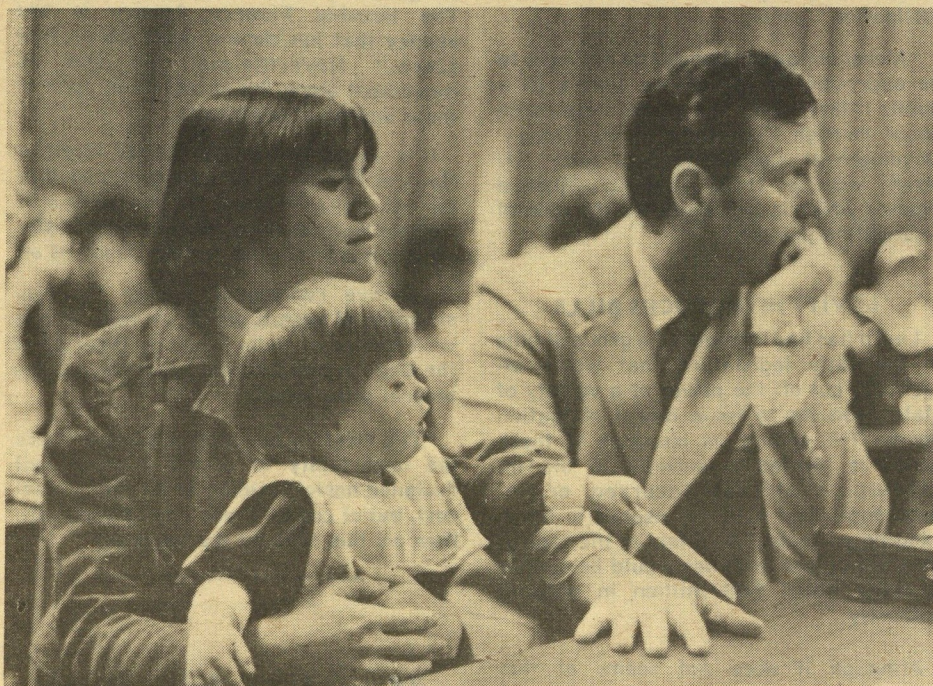
In addition to all these other duties he was also president of the Rome State School Chapter.

We do not know how to express our sorrow at the loss of this dear friend. He was one of our stalwarts, a member of the Board of Governors for many years, and one of the reasons for the success of the New York State Association for Retarded Children.



## Severely retarded

# In-service training draws over 250



Parents and real demonstration baby at early childhood intervention.

On April 23-25, at the Fallsview Hotel in Ellenville, more than 250 teachers and teacher aides gathered for an in-service training program dealing with young severely handicapped persons.

The participants came from agencies all over the State dealing with the mentally retarded, the cerebral palsied, autistic, physically handicapped and other developmentally disabled.

This was operated under a grant from the Department of Education under P.L. 89-313, Amendment to Title I, ESEA.

Under the direction of Robert Sansone, as it has been for a number of years in the past, the program was a concentration on early stimulation programs for preschool children. Participants in this were Robert Sansone, executive director of Suffolk County Chapter; Sheri Rabino, Registered Physical Therapist, Suffolk Rehabilitation Center; Charlotte Lafer, M.D., Pediatrician, Suffolk County Chapter; Marjorie Palmer, Speech Pathologist, Suffolk County Chapter; Barbro Salek, Registered Physical Therapist for the Suffolk Rehabilitation Center; Michael Osarchuk, Early Intervention Administrator of the Suffolk County Chapter.

## State lobbyists protested

In the halls of the capitol, there is always a group of lobbyists who operate mostly behind the scenes, never register, and receive their pay from the state's taxpayers.

These are the departmental lobbyists, employees in various state agencies and departments, who show up to defend or oppose legislation, but who lately have been offending more legislators than they have been persuading.

One of the legislators more than a little angry at them is Senator William T. Conklin (R-Brooklyn), who is trying to have his staff work out details of legislation to restrict departmental lobbying. Senator Conklin was especially disturbed at the efforts of the lobbyists of the Department of Mental Hygiene opposing S. 11B, the bill to create an Office of Mental Retardation, separating mental retardation from the Department of Mental Hygiene.

"The lobbyists for the Department are afraid the legislature will break up their \$880 million complex, but the (mentally retarded) kids are not treated right,"

Conklin said. According to Senator Conklin, departmental lobbyists tried hard to do in this bill.

Another legislator who has had his problems with state employees, although not departmental lobbyists in the usual sense, is Assemblyman Seymour Posner, (D-Bronx) chairman of the Assembly Labor Committee, who says that 150 state safety inspectors fearful of losing their jobs "stampeded" into his Capitol office, were unruly and hostile, and acted "irrationally", and "one guy wanted to take me outside and punch me in the nose."

It has been the experience of this Association that the various committees of the Senate and the Assembly have permitted the departmental lobbyists to be present at their committee hearings, not only to listen but also to give advice when others proponents or opponents of bills have been excluded. At present, such opponents or proponents are permitted to sit in on such hearings, but are not permitted to testify except by request.

Consultants were: Jay Schleichkorn, Association Professor at S.U.N.Y., Stony Brook; John Bryant, Speech Pathologist of the Suffolk County Chapter, and Sal Gullo, Program Director, Roosevelt United Cerebral Palsy Association.

The Assistant Coordinator was John W. Bertrand, Assistant to the Executive Director of the State Association and the Supervisor of the program was Joseph T. Weingold, Executive Director.

Almost three days of sessions dealt with organizing early stimulation programs, genetic counselling approaches to families, behavior modification and systematic teaching with preschoolers, feeding and speech and language approaches with young preschoolers, motoric approaches with young preschool children.

Proceedings will be printed and available to all those who desire them. Last year's proceedings and those of the year before are also available if this office is contacted.

More than 80 registrants could not be accommodated and we hope they will come to next year's session if the funds are available.



An eager group of participants, teachers and teacher aides.

## Dr. Giannini A.A.M.D. President

Margaret J. Giannini, M.D., Director of the Mental Retardation Institute of New York Medical College in Valhalla, has been elected President - elect of the American Association on Mental Deficiency, according to an announcement by James D. Clements, M.D., of Chamblee, Georgia, current President of the nationwide professional organization.

Dr. Giannini is a long time pioneer in the field of mental retardation, long known to the State Association. She is associated with the first clinic for the mentally retarded at Flower Fifth Avenue Hospital. From the small beginnings on Fifth Avenue, the facility has grown to a two-campus location, one in Manhattan and one in Westchester County, and is regarded as the world's largest and foremost treatment resource for the mentally retarded and other developmentally disabled.

As President of the 18,000 member AAMD, Dr. Giannini will head the country's leading professional organization devoted to improving standards of care and promoting research and new methods of patient treatment. The Association is based in Washington, D.C.

This Association joins with all others interested in this field in congratulating Peg Giannini on this signal recognition and honor.

## J.N. Adams to be closed

Although at first we thought that the reports were the reaction of uninformed parents, we are now convinced that it is the intention of the Dept. of Mental Hygiene to close down J. N. Adam, a small institution for the retarded and probably one of the best in the state, if not the country, and transfer the total population to Gowanda Psychiatric Center, a state institution for the mentally ill, whose population is rapidly dwindling. This proposed action by the Dept. of Mental Hygiene has been protested by the Association and brought to the attention of every legislator in the Western part of the state whose areas are served by J. N. Adam asking them to meet and make a common front against the Dept. of Mental Hygiene and the Division of the Budget. Letters have been written to the following legislators:

Senators Joseph A. Tauriello, James D. Griffin, Jess J. Present; Thomas F. McGowan; James T. McFarland; Lloyd H. Paterson; Assemblymen R. Stephen Hawley; John B. Daly; Matthew J. Murphy, Jr.; Harold H. Izard; G. James Fremming, Stephen R. Greco, Arthur O. Eve, William B. Hoyt, Francis J. Griffin, Dennis T. Gorski, Ronald H. Tills, Vincent J. Graber, Sr., Daniel B. Walsh, Rolland E. Kidder.

Apparently all of this is being dictated by so-called economy moves which will hit the residents of the institutions of the Dept. of Mental Hygiene very hard in spite of Governor Carey's promise that population will not be hurt.

In response to a mailgram sent to Dr. Kolb about the Wassaic Developmental Center transfers, we received a letter from him dated June 3rd which states in part:

"In accordance with the orders of the Director of the Budget, this Department was required to forward to his office successive plans for operation in case there was a serious reduction in state tax money to support our current operation. To comply with that directive, and the request for an urgent and immediate response, the Dept. has presented as its alternative a suggestion for the merging of a number of our institutions. One such merger would involve the Wassaic Developmental Center into the Harlem Valley Psychiatric Center. You should be advised that I am unsympathetic with the necessity of conceiving the proposed mergers, believing it more important to maintain our present institutional activities and increasing staffing through the process of patient attrition and community placement. This opinion of mine was conveyed verbally to the director of the Budget and to others. Hopefully we shall discover that there will not be a need to proceed with the several proposals made along these lines. I might mention that we also were required to provide other suggestions in regard to reduction in case the fiscal situation deteriorated further."

The letter concluded with the statement, "We shall indeed wish your participation and advice if forced to proceed along these lines."

We welcome Dr. Lawrence C. Kolb as an ally in this fight against government by budget which seems to understand the blue pencil only, but not human needs.

The alternative for cutting expenses lie in the development of community facilities.

"If the \$14 million now being contemplated to build a new institution in St. Lawrence Psychiatric Center was to be spent on the development of community facilities for the mentally retarded, there would be no necessity for those transfers from Wassaic or the closing of J.N. Adam," said Mr. Joseph T. Weingold, Executive Director of the State Association for Retarded Children.

We hope, he concluded, that there will be more consultation and planning together for this kind of thing and the reallocation of the money available rather than a blind following along traditional lines which have proved so disastrous to the operation of the Dept. of Mental Hygiene and to the reputation of government itself.



# Family care certification

In a bill introduced by Senator Donovan and others (S. 5260), various parts of the Mental Hygiene and Executive Law are proposed to be amended to prohibit a provider to persons no longer requiring institutional treatment from engaging in such activities on or after April 1, 1977, unless they possess an operating certificate issued by the commissioner. It further provides for the application for issuance of a certificate and requires the commissioner to prepare annually for the Governor and the Legislature a written evaluation report consisting of care and services in such homes and projected plans for providing and improving such family care. It also requires the Board of

Social Welfare to adopt rules governing operation of private proprietary homes for adults and provide residential care for such persons, with board. This bill passed the Senate on May 6th and still rests in the Assembly Mental Health Committee. The need for such a bill has long been recognized as family care homes have been operating, not only without any certification by any department, but with very little, if any, supervision.

There have been instances where persons have actually gone into the family care business, renting or buying a number of homes and carrying on a family care business without real supervision.

## A shambles

## How the State implements laws

In 1974, the Legislature passed legislation, at the request of the Dept. of Mental Hygiene, to enable community agencies to offer services to those mentally disabled persons who had been in institutions for more than 5 years and had been released after January 1, 1975. This legislation took the form of giving 100 per cent state aid for services to such persons.

One of these is chapter 620 of the Laws of 1974. One would think that this money would be funneled directly from the State of New York to the operating agency. How it works, however, is quite different. The local agency has to have a contract with the Community Mental Health Mental Retardation and Alcoholism Board. It must ascertain how many of these "620's" are on their rolls for services and then amend the contract with the Mental Health, Mental Retardation and Alcoholism Boards to segregate the 620's. The agency, therefore must send in a bill to the county treasurer for the 620's in the hope that they will get the full money back. This takes forever, if it is even understood, by most of the agencies.

Thus, although \$2 million has been appropriated, very little of this is siphoned

## Class actions

### possible now

On June 18th, Governor Hugh Carey signed into law (Chapter 207, Laws of 1975), a bill to amend the civil practice law to permit class actions without necessarily giving notice to all members of the class (S. 1309-B; Barclay; A. 1252-B, Fink). In his message accompanying his approval of this bill, Governor Carey said "This bill, modeled on similar federal law, will enable individuals, injured by the same pattern of conduct by another to pool their resources and collectively seek relief. By permitting common questions of law or fact affecting numerous persons to be litigated in one forum, the bill would result in greater conservation of judicial effort."

This bill, under a number of safeguards, would, in the opinion of the Association, permit class actions by parents of the mentally retarded, all of whom are claiming a service for an injury common to all. At present such actions were almost impossible to state courts, and a means had to be found to bring them in the federal courts.

This is an enormous step forward in protecting the rights of those who claim injury by the state common to many persons. An interesting section of the law is that if a judgment in an action is rendered in favor of the class, the court in its discretion may award attorneys fees to the representatives of the class based on the reasonable value of legal services rendered, and if justice requires, allow recovery of the amount awarded from the opponent of the class.

down to the various agencies even though more than six months have elapsed since January 1, 1975.

The editors of this newspaper have a suggestion: direct contracts should be entered into by the Dept. of Mental Hygiene with the agencies offering services to these persons to give them what's coming to them instead of having to siphon it through the local Mental Health Board, many of whom don't understand this whole procedure.

## Willowbrook director named

The Commissioner of Mental Hygiene has appointed Harold C. Piepenbrink, a mental health administrator in Illinois, to be director of Saten Island's Willowbrook Developmental Center for the mentally retarded, despite objections from the president of the Benevolent Society for Retarded Children an organization of parents of Willowbrook residents. Mr. Anthony Pinto, parent representative on the screening committee, and President of the Benevolent Society for Retarded Children, Willowbrook Chapter of the New York State Association for Retarded Children explained that the Society was not unalterably opposed to Mr. Piepenbrink, but felt that he had reservations because Mr. Piepenbrink had refused to

meet with a parent's committee in Illinois, withdrawing his application for a job as head of an Illinois facility for the retarded after learning that he would have to submit to an interview with a parent committee there.

At this office, Mr. Piepenbrink stated to the press that he had been considering applying for a job with the Downstate facility for mental retardation in Illinois, but after learning he would have to appear before a "screening committee" he decided not to apply.

He stated that he felt if the Department of Mental Health in Illinois did not know enough about his qualifications after 23 years, he did not want to work there.

## Weingold, Reville

## Scholarship winners named

Students at the State Colleges took the Joseph T. Weingold Scholarships for 1975, including the first male winner in four years, while the Capital District provided the winners of the James F. Reville Scholarships.

The Weingold Awards, which are limited to sophomore students at colleges offering an undergraduate degree in special education were granted to Mr. Jesse Kushner, a student at the State University College in Buffalo and Matilda Scuderi, who attends Genesee State.

Miss Scuderi, a Queens native whose work at Genesee has been almost straight "A" in nature, has worked at four different facilities for the mentally retarded, where she has developed a deep feeling for their needs.

Requirements for the James F. Reville Scholarships differ from the Weingolds, in that they are given to outstanding volunteers who are entering any field relating to mental retardation. Two Counties in our Northeast Region

recommended the outstanding young people who won these awards.

Leeann Shyne of Troy, Rensselaer County was one winner. Having just finished her second year at Hudson Valley Community College, Leeann hopes to become a student at SUC-Buffalo in September.

Kirk, a Schenectady resident, has been active in our State YOUTH organization ever since his Chapter had a YOUTH group. His qualities of leadership have been recognized by his peers who have voted him as N.E. Region Vice President. He is one of the very active Board members who always carries out assignments. Kirk has served as an officer, including the office of President, in his local YOUTH group. Kirk's father, Dave, has served for several years as a member of the Board of Governors of the Association, and, we are sure, is justly proud of Kirk's accomplishment.

All of the scholarships are in the amount of \$500.



## Tennis pro hosts retarded

Members of the New York City Chapter's AHRC Adult Recreation Program were given a free two hour tennis clinic at Randall's Island Indoor Tennis Courts, as guests of Proprietor and Senior Pro, George Hariy. Also pictured is group leader Meredith Anderson.

## Westchester facility

Governor Hugh Carey's proposed budget has set aside planning money for the construction of a facility in White Plains to house up to 102 severely retarded and multiple handicapped persons, all from the Westchester area.

The facility would be built on a small part of the 27 acres at North Street and Bryant Avenue, White Plains, that the state acquired from the city in 1970 through condemnation proceedings.

From 75 to 90 per cent of the persons who would use the facility are Westchester people now in large institutions. The rest are county residents now in the community who cannot be cared for adequately in their own homes. Some will be adults, and some children. The construction of 17 small houses, each with 6 bedrooms is contemplated. Persons who would be assisted would live in a home and take part in functional school, work or social activities in other facilities in the county.

Carey's budget proposed \$413,000 towards the Westchester Developmental Center, \$100,000 of which is to be used for planning the facilities in the fiscal year beginning April 1st.

In the 1960's, the state had planned to build a school for the retarded to handle about 750. They were pushed from pillar to post by the various community pressures until settling on the White Plains facility. This was supposed to have been completed in 1975 to provide jobs for 700 professionals and nonprofessional persons.

## Donation acknowledged

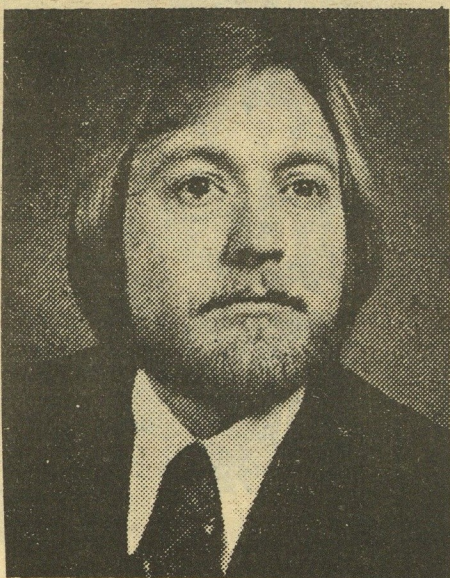
The Association acknowledges, with thanks, the donation by the Executive Directors of New York State Agencies (314(B) in memory of Norma Aronson, Ph.D. who passed away on May 8, 1975. Dr. Aronson was the executive director of the Comprehensive Health Planning Agency for the City of New York.

The donation came through Deborah A. Revels, Project Coordinator for the Genesee Region Health Planning Council.





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



## Tom asks?

**Has Your Chapter Reaffiliated?** The form is simple and must be in by July 31st to insure your chapter's voting rights at the Convention.

**Have you seen our new Membership Manual?** Your President has received one by now and should have brought it to the attention of all YARC members. There is a new advisor's manual also!

**Do you know** of a group of young people who might be interested in forming a new Chapter? If so, be sure you get in touch with me, so I can zip them out our new manual to aid them in organization.

**Are you aware** of the YOUTH NYS-ARC Convention dates? August 14th-15th-16th-17th holds an exciting experience in store for you if you attend.

**Did you hear** about YARC pins? The man from the pin company will be at the Convention to present them for your evaluation.

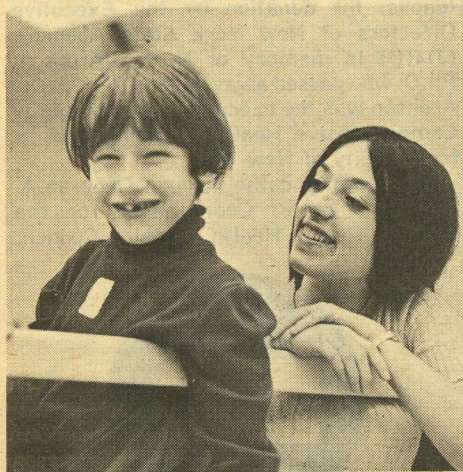
**Have you heard?** Camp Wilton will again be run by NYS-ARC during the last two weeks in August. If you'll be available for both of those weeks, send for your application now.

**Did your group** actively recruit new members during the March Membership Drive? There's a prize for the group that has the largest increase during reaffiliation. The prize will be awarded during the convention.

**Do you wonder** why your group's activities aren't included in this issue? Maybe it's because nothing was sent in. Make sure your chapter is included next time!

**Have you gotten** the name of a Pen Pal yet? A card once a month and a letter certainly would make some institutionalized person happy.

**Is your advisor** or one of your officers doing a super job? Well, if so, keep them in mind. As the State Y-ARC Awards Committee will be contacting Chapters for Special Awards recommendations.



Niagara YOUTH volunteer enjoys the smile of a happy child in their program.

August 14-17

## 1975 YOUTH CONFERENCE

### Dowling College, Oakdale, N.Y.

Plans for the 1975 N.Y. State YOUTH ARC Conference are really beginning to shape up. Things are starting to fall into place and it looks like it's going to be a great experience for all involved. The registration cost will be \$45.00. This fee includes all meals, lodging, workshops and special programs. Day registration will be \$30.00, this includes everything except lodging. The least expensive plan is the straight registration which will be \$15.00 and includes all workshops and special programs.

The conference starts Thursday, Aug. 14. For those arriving early on Thursday, there will be several early sessions of short information and instructional workshops. The convention committee has condensed their list of 50 workshops down to 11 major workshops, each 2 1/2-3 hours long. All of the original 50 topics will be covered in depth! Some of these workshops include: Employment, family life, advocacy,

careers, institutional living and many others. Each workshop will be presented twice.

The convention will have 4 major special events planned: a square dance, a semi-formal dance, and a special speaker — workshop type program. One special event that is being planned, but is not yet definite, is a sail around Long Island on a Ferry Boat.

If anyone has any questions, comments, suggestions, **Anything** — please send any correspondence to: Hilarie Seifert, P.O. Box 4, Port Jefferson, N.Y. 11777.

#### MONROE COUNTY YOUTH

Another 30-mile-long "Bike-Hike" in and around Rochester was the event for Sunday, June 1, with 3,772 supporting the fund-raising effort in behalf of the area's physically, mentally and emotionally handicapped. Again, the event was sponsored by the Monroe County Chapter of Youth Organized and United to Help the

## Letters mean alot

This year, the YOUTH-ARC Board of Directors began sponsoring a **Statewide Pen-Pal Program** whereby members of the community could write to residents in State Developmental Centers. As a part of this program, the Board felt it would be a good idea to give the opportunity to inmates of State prisons to write to the retarded residents. Who, after all, would have more available time or be happier to receive replies? How is the program working? The article below, reprinted from the Auburn Citizen Advertiser speaks for itself.

By Kevin Hiemel

Letters are an important part of an inmate's life — representing in many cases the only contact with the outside world. Consequently, I've written many letters to many different people, and received at least an equal number in return.

But the other day I received a letter so wonderful it relegated all others to some dark file in my mind. The emotion Nadine's letter evoked was a mixture — an odd mixture that warms the heart and brings a smile and tears at the same time.

The letter was written on light green paper with lines ruled lengthwise over an inch apart. Between these huge spaces were printed letters of various sizes, with the shaky lines of an untrained hand; and in my mind I visualized the pencil gripped in her small fist as she drew each line with the concentration of an artist, her tongue pressed into the corner of her mouth and her long shiny hair flowing past her frail shoulders. She probably paused frequently as her mind struggled for the right word.

DEAR KEVIN,  
THANK YOU FOR YOUR NICE LETTER.

I WAS HAPPY.

After she wrote the word "happy" she stopped to draw a sort of circle, very uneven, with little triangular lines in it and wavy lines scribbled across the top. I realized this was meant to be her smiling face, an expression of the happiness she had no other way to convey.

HOW ARE YOU TODAY?  
I AM FINE.  
I LIKE TO PLAY BASEBALL,  
LISTEN TO RECORDS,  
DANCE AND GO SHOPPING.

My mind brought the image of a matronly nurse standing by her side, softly smiling as she spelled the words too big for Nadine to know. (Yes, it would be a nurse. You see, Nadine is in a hospital.)

I ALSO LIKE TO WRITE LETTERS.  
PLEASE WRITE AGAIN.

YOUR FRIEND  
NADINE

So ended Nadine's first letter. Her name printed in slightly smaller and straighter letters at the bottom, apparently having had more practice writing it. When she was finished the nurse would have given her a blank envelope and stamp, watching as Nadine methodically folded her letter and placed it inside. Nadine probably made a face as she licked the envelope and stamp, tasting the glue, then giggled as the corners of her mouth turned up in a smile. After the nurse addressed it (as I could see when I received the letter), Nadine probably mailed it herself, if there was a mailbox in the hospital. I can imagine how proud she must have felt, doing this grownup thing, just like a big girl. All I can do is imagine, though, because I have never seen her. Nadine and I met through a third party. All I know of her is that she will be twenty years old soon, and will forever have a child's mind. But that's all I need to know. And if she painstakingly draws her words in huge letters then they are that much more dear to me. And if I wipe tears from my eyes, well then, it just means she has done something no amount of punishment could do.

And what of Nadine? Does her face light up when she receives a letter? Does she cherish in her innocence the word friend, happy in the knowledge that others care for her, and accept her as a person, as a friend? I like to think so. I like to think the prison of her mind is somehow ameliorated when she knows that she is a very special girl.

I guess in some strange way we need each other. Don't we, Nadine?

Kevin Hiemel is currently serving a sentence at Auburn Correctional Facility.

If you or anyone you know would like to correspond with one of our Pen Pals, please contact: Carolyn Fetter, 304 East 4th Street, Brooklyn, N.Y. 11218.

Association for Retarded Children (Y.O.U.T.H.-ARC). The local group of teenagers volunteered its services to the Association for Retarded Children located at the Al Sigl Center.

All proceeds go to local organizations and agencies serving the handicapped.

Last year \$92,000 was raised, with funds disseminated to all agencies located at the Al Sigl Center, Rotary Sunshine Camp, Camp Haccamo, Birth Defects Center at Strong Memorial Hospital, Crippled Children's Society, Rochester Wheels, Boys Club and several others. This year \$100,000 was pledged.

Between 5,000 and 10,000 young people were expected to ride in this year's "Bike-Hike" covering 30 miles in and around Rochester, however foreboding weather caused a smaller turnout.

#### COLUMBIA COUNTY CHAPTER

On April 5th, LARC participated in the indoor Olympics in Albany. Later in the month, a new idea in fund raising, a children's Film Fest, was held which raised \$16.00.

In May, raffle tickets provided the means by which this active Chapter was able to participate in their regional Special Olympics. Four from their weekly swimming program and bi-monthly workshop program, will go on to the State Olympics.

On the 17th of May, LARC held a dance for adult clients from the workshop in Hudson. It was so successful that LARC members have made it a part of their monthly program.

May 31st was the date for the annual Walk-A-Thon. Their goal was \$6,000.00.

Now they are planning a program in which clients will be accompanied to the public library on a weekly basis.

Love Association, you've got the right name!

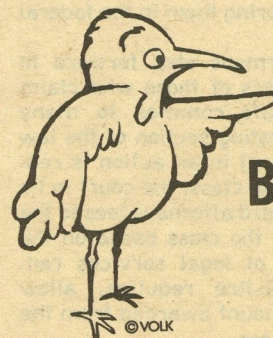
#### NORTHERN BROOKHAVEN JR. AUXILIARY — SUFFOLK CHAPTER

This group's biggest event was a super fund raiser. They sold raffles to raise funds for their own summer camping trip program. The prizes were a 10 speed Peugeot bicycle, an AM-FM radio and Basket of Cheer. They made about \$500! The drawing took place at a dance. All raffle tickets were sold in 3 weeks in local shopping centers.

Apart from fund raising, Northern Brookhaven has been participating in their regular programs of taking groups to bowl parties, plays, and concerts, field trips, etc. They have 8 activities a month. During the summer, this active Chapter will plan 6 camping trips for their older friends. The trips will be every other week with local field trips for children to such places as Long Island Game Farm, local stables for pony rides, movie matinees, etc. on alternate weeks.

May's big event was a beach party Bar-B-Q. The day was filled with softball, songs, games, frisbee tossing, kite flying and fishing topped off with hamburgers and hotdogs.

Northern Brookhaven, how lucky your retarded friends are to have you!



TO  
BUFFALO



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



Joe Killeen, President of Rensselaer ARC, congratulates Walkathon workers, King Gee, Bill Rogers, and Bob Sieffert, Walkathon Chairman.

### SUFFOLK YOUTH COUNCIL

Anne Brewster of Brentwood Junior Auxiliary has been elected to succeed Jay Klein as the 6th President of the Suffolk YOUTH Council. Anne was most actively involved in reorganizing the Brentwood Chapter which now has a membership of 35 — up from 5! Congratulations Anne.

### NIAGARA YOUTH

Niagara YOUTH is again as busy as ever. They recently began a twice a month physical activity training program for the retarded adults in their programs. On May 10, their Special Olympics team was again victorious at the local meet in Albion, NY. They came in first in the 440 yard relay and many other events.

On May 17th, they provided a program for 24 children whose parents were attending an in-service meeting. In the morning, they went to the Aquarium.

Niagara also started a "Birthday Club." A list of each client's birthday was obtained from the local workshop. From this list, Niagara YOUTH birthday cards were sent out each month, signed by all of Niagara YOUTH members.

Locally, Niagara YOUTH are putting together their own packet of information. This packet will include information on YOUTH-ARC, the mentally retarded, career opportunities, New York State schools and scholarships available.

This packet will then be distributed to guidance counselors and placed in agencies that handle volunteers. Great idea, huh?

### GREENE COUNTY

June 14 marked the beginning of a new event for Greene County, a Bike-A-Thon. The chapter designated the Day, "Greene County A.R.C. Day" and invited Assemblyman Larry Lane to be on hand to send the bikers off. Funds from this event will aid the chapter as they move to their new Work Activity Center July 1st.

In May H.A.R.P. (Help A Retarded Person) Youth organized a dance contest and awarded trophies to the 3 best couples. The dance was the first social evening for residents of Alfonsus Manor and clients of the various work programs.

### HOPE JUNIOR AUXILIARY OF SUFFOLK COUNTY

Hope Junior Auxiliary of Suffolk County planned a fresh outlook for the Spring by aiding in the Suffolk County Special Olympics. This year's events as in the past, were exciting. Everything was well organized and everyone was a fan-tastically happy winner.

Suffolk Developmental Center also found HOPE members hosting a Spring picnic for all the lucky kids they see every Sunday.

Lorraine Perez, HOPE's energetic President, also made sure auxiliary members got together socially simply to relax and enjoy themselves. A good President, like Lorraine, knows how to keep membership and morale strong. Thanks for sharing your good works with us, HOPE!

### SCHENECTADY COUNTY YOUTH

One of the most active groups in our State is the Schenectady Chapter. They babysit at O.D. Heck Developmental Center during parent counseling sessions as well as run programs for the adult living unit, Habitat.

A one day Rummage Sale in May netted them \$175.00.

In June they held a talent show with participants from O.D. Heck and ARC hostels. The script was written by YOUTH group members and the public was invited. The end-of-the-year Picnic is a feature for June. YOUTH group members and their friends are invited.

Monthly, Schenectady Youth hold dances for all retarded adults.

After Membership Month, this Chapter has 120 members!

### RENSSELAER COUNTY

One of the highlights of this year for Rensselaer County Chapter was the Walkathon sponsored by Alpha Phi Omega, a service fraternity of Rensselaer Polytechnic Institute which has provided them with both physical and material support previously.

Through the untiring efforts of many young people during months of planning and publicizing and the equally untiring efforts of the walkers, Rensselaer County Chapter will be \$8,000 richer. But even more, the mentally retarded, ever touched by these young people will reap the greatest awards — an involved and committed community.



Dance Contest at Greene County YOUTH party.

## Scholarships

### announced

The State YOUTH Scholarships Committee headed by John Dempsey of Chemung County selected the two winners of this year's YOUTH Scholarship at the Spring Board Meeting June 7th.

Selection of two out of an outstanding group of applicants was far from a simple task. The criteria was based heavily on service to youth groups, financial need, along with grade point average.

We're proud to announce that the 1975-76 winners are Jay Klein of Suffolk County and Debbi Firestein of Queens. Both of these young people have been dynamic leaders in their chapter and their communities for many years. We wish them and all the candidates our best in their continuing education in the field of Mental Retardation.

## YARC spotlights Hilarie Siefert



HILARIE SIEFERT

### YARC SPOTLIGHT

The job of Chairing a convention generally falls to the most capable and dynamic leader of the sponsor chapter. This year is far from an exception. For Suffolk County YOUTH, Hilarie Seifert was the logical choice.

Hilarie is 18 years old and a senior at Port Jefferson High School. She will be attending Syracuse University in the fall to study sociology. Hilarie's desire is to work with retarded people and their families as a social worker. She was awarded the Suffolk County Scholarship in May to aid her financially toward this goal.

Hilarie's leadership abilities took her to the Suffolk County YOUTH Council where she now holds the office of 1st Vice-President. She Chaired the 1974 Salvation Drive to aid local institutions and was also in charge of publicity for this event. She also served on the Suffolk State School Committee.

As a counselor at the Maryhaven School for Exceptional Children Summer Camp and the Northern Brookhaven Summer Camp, Hilarie gained further experiences and expertise in work with retarded children. Along with camp, she volunteered at the Special Olympics for four years, One to One Day, Be A Friend Day, and participated in both NARC and State ARC conventions plus several other annual county and state events.

## Schenectady hosts conference

The Maple Ridge Center was the scene of the second regional YOUTH Conference held on February 28th through March 2nd. Representatives came from Rensselaer, Genesee, Suffolk, Greene, Clinton, Warren - Washington, Erie, Saratoga, and Queens. Approximately 70 people attended.

The program was highlighted by a tour of O.D. Heck Developmental Center and the Schenectady County ARC Hostel. Workshops included Behavior Modification by Mr. John Jacobson, Recreational Therapy by Dorie MacArthur and Phil Glogawski, and Sensitivity - awareness by Michele Clarke. All instructors were from Eleanor Roosevelt Developmental Services. Ms. Clarke will present her excellent Workshop again at the State Convention.

The Schenectady YOUTH group presented their Saturday Morning Recreation Program as an integral part of the conference.

A meeting of the Northeast region and a general open forum were conducted by Kirk Lewis, Senior V.P. of the State YOUTH board.

Saturday evening a banquet was provided by parents of Schenectady County YOUTH members. All other meals at the conference were provided free by merchants of Schenectady County. Following the Saturday evening banquet, everyone participated in decorating the Maple Ridge Center for a special dance with retarded adults of Schenectady County.

## Federal education laws extended

Two major provisions have been made by the Congress which are of significance to the mentally retarded. The first is (P.L. 93-380), an extension of the current adult education programs for four years, and establishing a new 15 percent set aside for State funds for innovative programs and teacher training. It also specifies that up to 20 percent of State allocations may be used for the education of institutionalized adults.

The Education of the Handicapped Act is extended through fiscal year 1977. It does, among other things, the following:

1. Authorizes the Commissioner of Education to make payments to the state to assist in initiation, expansion and improvement of programs and projects for the education of handicapped children in preschool, elementary school and secondary school levels. On an entitlement basis, fully funded, it could result in grants totalling \$630 million for fiscal 1975.
2. Authorizes the use of funds to states for identification and treatment of handicapped children under age 3.
3. Requires States to provide procedures for insuring that handicapped children and their parents are granted procedural safeguards in decisions regarding identification, evaluation, and educational placement.
4. Requires procedures to insure that to the maximum extent appropriate, handicapped children are educated with children who are not handicapped.

5. Establishes, as the goal, provision of full educational opportunities for all handicapped children.

6. Requires that the states submit, to the Commissioner, an amendment to the state plan setting forth policies to insure the education of all handicapped children, and to insure that all handicapped children in the state in need of special education are identified and evaluated, that a detailed timetable for providing full educational opportunity for all handicapped children be established and that such amendment to the state plan will be available to parents and members of the general public.

7. Authorizes appropriations for experimental preschool and early education programs of 25.5 million dollars for fiscal 1975, \$36,000,000 for fiscal 1976, and \$38,000,000 for fiscal 1977.

8. Authorizes appropriations for training special education personnel (except for physical educators and recreational personnel) of \$45 million for fiscal 1975.

Other significant provisions are that the Congress be afforded the opportunity to disapprove the regulations or any federal aid program for education.

The new law affords parents of students and students attending educational institutions the right to inspect student school files and challenge their content. The release of documents to third parties is restricted.



# Your child in public school

Betty Pendler, Chairperson

Quote from Letter from Education Chairman of Schenectady County, Marilyn Wessels:

"Within the City of Schenectady we have formed a parent advisory council, representing 600 children; we meet monthly with school administrators and work usually collectively toward improving services. Much of the time the council has spent this year has been focused on the program for the trainable mentally retarded. The Schenectady ARC is seeking quite earnestly to make the school districts live up to their responsibility. It will be the job of the Education Committee to advise parents of their rights, and how to approach their own school districts for the kinds of services their children should have". Go to it, Schenectady — keep us posted on your progress so other chapters can get rolling in their area."

Quote from Patricia Myers of Steuben County:

"We have succeeded in placing parents of handicapped children on the Committee of the Handicapped in three school districts. Two more committees have promised positions . . . communication channels are opening, and in Corning particularly, parents opinions and wishes are openly consulted . . . In the districts where our people serve on handicapped committees, the best placement for the child, regardless of district, BOCES or ARC control, is being more frequently achieved."

So you see folks, things are happening — and it can be done — let's not give up the fight!

Other movements in chapters: Jean Black of Middletown being named to the Committee on the Handicapped — and also goes around addressing local meetings of Council for Exceptional Children, nearby colleges with Departments of Special Education — to help heighten "awareness". It's a good example to follow. Judy Shalvey and Georgia Sullivan in Orange County, in their "ombudsman" role discovered some districts dismissing trainable children at 1:30 p.m. They did some investigating — sent letters to the appropriate authorities, and now have it in writing that next year, there'll be a 3 o'clock dismissal. What time does your child get dismissed?

Anne Klinger, also of Orange County convinced the Valley Central School District to provide a school bus aide — she used the technique mentioned in our column in the last issue of Our Children's Voice on how to move bureaucracies by sending carbon copies of her letter to the school superintendent, various members of the Board, politicians, N.Y. State ARC, etc. — and got it in writing from the Superintendent of schools in her district, that it will be included in the upcoming budget. This shows that knowing our rights and speaking up can pay off!

Joan Mayer of Steuben County while pleased with her successes, deplors the fact that often some parents resist the move to integrate our students in non-academic areas, and having them be part of the total school, with the same hours as everyone else, participating in the same activities. How about some feedback from your parents on the subject of isolation vs. integration within the public school.

**New Programs under ESEA Title III** — if you are on any committees or have any input into suggestions for funded programs, there is an excellent pamphlet you can send for. Free — National Advisory Council on Supplementary Centers and Services, Suite 529, 425 13th Street, N.W., Washington, D.C. called "Innovative Educational Practices, ESEA Title III". "Title III projects are exploring ways to train aides, tutors and parents in working with handicapped children and to develop learning packages and materials for home and school use". For example, they describe an interest project "speech and language Development for Trainable Mentally Retarded with teachers guide and 16 curriculum packets — write to Michaela Nelson, Project Director, Educational Service Unit, No. 14, 1114 Toledo Street, Box 414, Sidney Nebraska 69162.

**A great magazine . . . The Exceptional Parent.** . . . excellent articles on a wide range of subjects, I.Q. testing, curriculum, siblings, sex education, reading lists, etc. — Subscription is \$10.00 per year. Be sure and mention AHRC when subscribing, as the State Office gets \$2.00 commission on every subscription. Write: Dept. 84 PO Box 964, Manchester, N.H. 03105.

**SEIMC — Special Educational Instructions Material Center** — has educational materials available for loan to parents — there is one in your area and you can borrow kits, films, books, tapes, teaching materials for use in your own home. Write to the N.Y. State Educational Department, Regional SEIMC Office, 55 Elk Street, Albany, N.Y. and ask for the address nearest you. Also ask to be put on their mailing list for their very interesting newsletter.

**Report from Mary Miller of Rockland County** — who attended a conference "Special Education Day" at Dominican College, Blauvelt on April 12, 1974 — quoting speakers Drs. Bilken and Bogdan, of the Center on Human Policy at Syracuse University, who stressed the need for attitude changes in society before human services will be provided as a right instead of a charity — and that all of us should be working towards the goal of making our children "highly visible". Thanks for writing, Mary — Have any of you out there attended an interesting conference — let us in on it! Have you read an interesting article of interest? Write the State Office about it so we can share it through this column — won't you please?

**Do you have a child just about to enter public school?** An excellent free pamphlet from Berkley Unified School District, 1414 Walnut Street, Berkley, California 94709 called "A Handbook to Help Parents" with interesting tips on helping your child develop language skill, a kindergarten readiness checklist, etc. Worth sending for!

Speaking about suggestions — when was the last time any of us parents heard some of the good things that happen to our children in school? A suggestion from the New Jersey Education Association, 180 West State Street, Trenton, N.J. 08608 is to have your school system pass out what they call a "Success Card" where the teacher would stop and think about two or three highlights when children achieved in ways that otherwise might never come to the attention of their parents, and urges the teachers to drop a "success card" in the mail to the parents. You can send for a sample of this card at the address mentioned above and show it to your school administrator.

**Parents of children in the public school . . . this is your column . . . we want suggestions and news items to help make this a meaningful column for you and your child in the public school, so let's communicate!** Betty Pendler.



## Charitable gesture

Camilla Gusman, 4½, presents invitation to Senator Jacob K. Javits, for the 26th annual dinner of the Association for the Help of Retarded Children, New York City Chapter, at which the Senator received the organization's highest yearly honor, the Humanitarian award. The dinner was held at the Americana Hotel.

## Senate confirms Kolb 39-19

The confirmation of Dr. Lawrence C. Kolb as Commissioner of Mental Hygiene is complete.

At his swearing in ceremony, Governor Hugh L. Carey pledged that New York will have the finest Mental Hygiene Department and programming in the country. He did not, however, give a timetable. Carey added at the ceremonies that the conditions pointed out in the Times Union series about the problem "will not exist when my work and Dr. Kolb's work is completed."

Carey said that he hoped that the Consent Agreement to thin out the population of the Willowbrook Developmental Center on Staten Island from 3,250 can be made "statewide in its application."

A spokesman for the New York State Association for Retarded Children, Inc., the major plaintiff in the action against the state in the Willowbrook Case pointed out that the thinning out of Willowbrook is but one facet of the Consent Decree. The major thrust of the action was to establish the right to treatment in the least restrictive environment for the residents of Willowbrook. This involved a completely different structure of staffing so that those who are in Willowbrook will get the best possible treatment, care and education. To talk about the thinning out of Willowbrook alone is to ignore the major thrust of the legislation. It will take years, six years, according to the Decree, to "thin out" Willowbrook. How many more years it will take for the other institutions for the mentally retarded in the Dept. of Mental Hygiene is anyone's guess.

"What will happen," asked Mr. Weingold, executive director of the New York State Association for Retarded Children, "to those who remain in the institutions and those, who under the most optimum conditions, will need highly supervised, therapeutic milieu because they are unable to live or cope in the general community?" One of the first appointments by Dr. Kolb was that of Dr. Hugh Butts, a psychiatrist and director of the Bronx Psychiatric Center as the Department's first deputy director.

Dr. Kolb said he did not know how much money Dr. Butts was making from his affiliation with the Albert Einstein Medical College in New York City nor how many hours Dr. Butts taught there weekly.

## SOAR story in press

In a byline article in the Buffalo Courier Express, Martha Jewell, Board Member and former Secretary of the State Association, described the business of advocacy as a "system developed to nag officials".

Stating that information being collected by SOAR, and now being distributed to local chapters by the State Association, would be of interest to any advocacy group, she added "It's timely too". Her theme states there is the "generalized quilt" excuse (why agencies don't act), wherein the agency says that all agencies or levels of government are at fault. High level State and Federal agencies, said Miss Jewell, urge starting at the grass-roots level; local ones say the bottleneck is at the top.

The "prematurity of request" ploy is common. Officials state plans are being formulated to solve the problem. Or they promise "further study" and suggest a committee or commission approach.

Another response of officials, says Mrs. Jewell, is "confession and avoidance". Overriding considerations are cited. Sometimes the need for action and the agency's responsibility — is conceded, but, unfortunately, there is "no funding available."

All of these attitudes, and more, on the part of public servants can be countered, say SOAR leaders, by demonstration that the community will favor correction of the injustices, or meet the real needs of minority groups, such as the handicapped.

Under this system, responsibilities can be pinned down, if advocates do their homework. The buck can be made to stop, the bell can be put on the cat, as Mrs. Jewell says, the loudly squeaking wheel will be oiled. It takes persistence, courage, and the refusal of be intimidated.

## Apology

In the last issue of OCV an article was printed "Plato Had a Word For It." Unfortunately, no reference in that article was made to the fact that Mr. Leopold Lippman and Dr. Ignacy Goldberg had written it.

We now wish to correct this omission and let everyone know that these two fine persons were the authors of that article.





## Review Board bill introduced

A bill was introduced by Senator Donovan and Assemblyman McCabe (s. 3876A. - A.5153) to establish a mental hygiene medical review board of four appointees by the Governor, with the advice of the Senate, to investigate and review circumstances surrounding deaths of patients of department facilities, to cause the body of the deceased to undergo necessary examination to determine the cause of death and, that upon review thereof, to transmit a report to the Commissioner and, when appropriate, make

recommendations to prevent recurrence.

This bill was introduced as a result of the unexplained deaths that have been occurring in various institutions, especially at Rome and Willowbrook. It was proposed by the State Association for Retarded Children. The bill passed the Senate June 6th and was referred to the Assembly Ways Committee where at this time it still languishes.

### Willowbrook dismissal testimony allowed

The state's highest court has reversed the Appellate Division, 2nd Depart., and reinstated an order of dismissal against the Willowbrook ward attendant, Joan Brown, who had been charged with striking a patient with a broom handle.

The case gained interest in legal circles because the person bringing the charge and her principal witness, were both residents of the institution and were found by a hearing officer to be incapable of understanding the nature of an oath.

Their testimony thus had to be taken unsworn, which gave ground for an immediate appeal by counsel for Ms. Brown, who argued that his client's rights to a fair hearing had been damaged by the unsworn statements. The Appellate Division of the State Supreme Court agreed and reversed the original order of dismissal.

However, the Court of Appeals ordered the dismissal reinstated, holding that even though unable to understand an oath, the victim and witness knew enough of what happened to testify against the accused attendant. Together with other circumstantial evidence as to the laceration received, the absence from the ward of other supervisory personnel, the fact that the injured inmate went elsewhere for help, Judge Dominick Gabrielli, writing for the unanimous Court concluded:

"We today hold that in an administrative proceeding such as this where the administration of an oath would be unavailing for the purpose of which an oath is normally administered, unsworn testimony may be received provided a sufficient foundation exists to support the hearing officer's determination that the witness possesses rudimentary testimonial capacity."

### Who pays?

A mentally retarded child placed in family care home out of Willowbrook, under the jurisdiction of the Cooperstown Board of Education, was deprived of education for at least six months because the Cooperstown Board of Education refused to enroll this child because they did not know who was going to pay for her and they didn't want to do so.

After much negotiation and the involvement of the New York State Association for Retarded Children through SOAR, the child was finally placed in a school program in Cooperstown awaiting the final decision as to who was to pay for her.

The general rule is that the school district in which the institution was originally located and where the child has resided was responsible for such education. In this case it was New York City which has refused to pay. By this time the situation is probably resolved, with New York City paying for this, as it must under the law pay for any resident of New York City placed in a foster or other family care home in another jurisdiction.

In any case, free public education is the responsibility of the State of New York and this should have been resolved by the commissioner of education immediately, without this child having to wait six months before receiving his just and Constitutional right, a free public education.

Do we need advocacy — (editor?)

### Human approach

The Governor's office has announced that the Governor's Committee to Employ the Handicapped has been eliminated because it is a "luxury."

## Catskill continues

## MR summer camps opened by state

The Dept. of Mental Hygiene has received funds to open its summer camps for the mentally retarded this vacation season. Two will be operated directly by the Department; a third will be opened in conjunction with the State Association for Retarded Children, Camp Catskill, as it has for the past three years.

Camp Wilton is on the grounds of the Wilton Developmental Center; Camp Seneca will be operated by the West Seneca Developmental Center on the shores of Lake Erie.

Camp Catskill, in Liberty, began its fourth season under the direction of the ARC on June 27th. It offers three sessions of three weeks each.

Camp Wilton, accommodating 120 campers a session, serves campers from Wilton, Rome, Sunmount and Syracuse Developmental Centers and Eleanor Roosevelt Developmental Services as well as the communities those facilities serve.

### ARC protests

### mass movements

In telegrams to Governor Carey and the Dept. of Mental Hygiene, the State Association for Retarded Children has protested the reported intention of the Dept. of Mental Hygiene to remove residents from Wassaic to the Harlem Valley psychiatric Center, a highrise Center with bars on the windows, a most inappropriate placement. Furthermore, this is in violation of the Dept. of Mental Hygiene Law itself that parental consent is needed for those under 18 and informed consent for those over 18.

In spite of the fact that we called for a conference on this, all we received in reply was an answer from Associate Commissioner Robert Hayes that did not answer these questions directly.

The possible movement of 100 residents en masse from Willowbrook to a new unit at Rockland S. H. was also protested as it cannot possibly take place without approval of the review committee under the Consent Decree in the Willowbrook case.

"The Dept. of Mental Hygiene seems to be moving along lines dictated by the Division of the Budget rather than human consideration," said Mr. Aronin of the New York State Association. "We look to Governor Carey for leadership in matters such as this to avoid the mistakes of the past and not create economies at the expense of the retarded."

"If, indeed, economies are to be effected, then we should look to the \$14 million that has been appropriated to build a new psychiatric unit at St. Lawrence Psychiatric Center where the population is diminishing rapidly; we should look to the phasing out of Harlem Valley Psychiatric Center where the population is also diminishing rapidly; closing down of that institution rather than comingling of the mentally retarded with the mentally ill to dictate a budget."

### TAPE from Page 2

work together in the formulation of parents and community advisory committees in the development of programs, in the monitoring of programs and the improvement of programs. I know this is a goal that dedicated people, such as Dr. Tesse, believe in.

These most vulnerable individuals deserve the commitment, the support, the financing, and the recognition, of those of us in our society who are fortunate enough, now, to be given the opportunity to help them."

Camp Seneca can accommodate 150 campers a session for a total of 600 over the season. It provides summer recreation to residents of West Seneca, Newark, Craig, Broome, Monroe and J. N. Adam Developmental Centers.

Camp Catskill has slightly longer sessions of three weeks with 150 campers attending each session. The camp is open to residents of the Mid-Hudson Region, New York City and Long Island. About 60 Catskill campers during each of the three sessions come from the department's residential facilities in those areas.

## Budget cut

Although, in general, the legislature passed almost all the requests of the Governor for budget purposes, one cut particularly rubbed the Governor the wrong way in his memorandum filed with the signing of A. 2400—A. which was the act to make appropriations for the support of government — state purposes budget.

He characterized the action of the legislature, in cutting the request of \$16.7 million to meet the potential cost of pending litigation in the Willowbrook case to \$5 million, as "irresponsible and inexplicable." He stated further, that he would submit a supplemental budget request asking that the full \$16.7 million originally requested be included.

It is doubtful, at this point, that the state, within this current fiscal year, could spend the whole \$16.7 million requested to implement the decree. Time will tell whether the \$5 million was adequate for this year's budget.

More important, is the failure of the Governor to request enough money for the development of community services, limiting himself to only \$2 million for full payment for services for the residents who have been released after being in institutions for more than five years. The estimated cost of such services, on the basis of those already released, is some \$8 million, which will force the state to go back to the legislature for a deficiency appropriation, a doubtful procedure. This is under Chapter 620 of the Laws of 1974 and is discussed in an editorial in this issue. Furthermore, the \$90 million appropriated, only \$10 million less than what the Governor asked for for local assistance is a pittance in the light of the needs of the community for the development of services that are going to be meaningful for the mentally retarded and other developmentally disabled.

### Memory gifts

The Association is in receipt of a gift from Hobart College signed by The Rev. Durstan R. McDonald, in memory of one of their students, Nick Shields, who was shot to death in San Francisco in one of a series of random murders that occurred.

As part of the memorial for Nick, students have planted two trees on the campus with an appropriate marker. The other part of the memorial is a contribution by the students to the New York State Association for Retarded Children since Nick had become involved and worked with retarded children the summer before.

The Association acknowledges this gift with deep emotion.



### Letters to the Editor

"Dear Jerry: I want to react to the article in the April issue 'To label or not to label' and confess that this issue confuses me and re-enforces my ambivalent point of view.

In order to get grant money from governmental agencies, in order to get special recreation, camping or other programs from local governmental agencies, we have to highlight the nature of the handicap, almost exploit it, plan on the unmet needs of this "category". Then in my crusade to raise the consciousness of the general public, I urge them not to think of the "retarded" in a group — they are people, who happen to be retarded.

I do, indeed, believe that often the label imposed on our children produces the self-fulfilling prophecy effect, within the school system, within many of the professions, but I also confess that often, for clinical or other reasons, the use of the label is necessary. I think the only answer is a phrase I heard you use some time ago, which I have openly plagiarized and use whenever I have occasion to speak to people ... "we cannot deny that our children are different — realists that we are, but that let us make sure that their difference will not make any difference in treatment, service, et al." Have I succeeded in confusing anyone else? Sincerely, Betty Pendler."



# CHAPTER NEWS

What our chapters are doing and saying for our children.

Congratulations to our ESSEX COUNTY CHAPTER which has moved rapidly into new programs. The Chapter began operating its Sheltered Workshop and hostel on May 1. . . DUTCHESS COUNTY CHAPTER recently held its Grand Ball. This big fund raising event was followed by a cannister drive throughout the county. The Chapter's work activities center has grown so rapidly in 2 years, that the center moved in May, to larger quarters, to accommodate more clients. . . Speaking of moving to larger quarters CHENANGO COUNTY CHAPTER has moved for the 2nd time in the last year in order to accommodate the many new clients that are coming into their new program and the Valley Players of Hudson Valley Community College presented "Flowers for Algernon" in the Campus Student Union Theater recently. . . RENSSELAER COUNTY CHAPTER was the recipient of the proceeds of one of the performances. Judi Mazza, a former bookkeeper, turned student in Special Education, assumed this as a new challenge — her first theatrical directing job. . . ST. LAWRENCE COUNTY CHAPTER just completed a long proposal to the Office of Vocational Rehabilitation for satellite Sheltered Workshops. In addition, they sent us this good news under heading of "No April Fool" "On April 1, 1975, Richard L. Laurin, Executive Director of the St. Lawrence County Chapter of the New York State Association for Retarded Children, Inc., accepted the keys to the Agency's first Hostel at 2 State Street, Potsdam, New York, on behalf of the Chapter's Board of Directors and the Department of Mental Hygiene. The Hostel has been purchased through negotiations with the Department of Mental Hygiene. Since Oct. 1972, the Chapter Board has been designing a plan to establish homes in St. Lawrence County as an alternative to having persons placed in sometimes costly and highly dehumanizing institutions. . . WAYNE COUNTY CHAPTER seems to be bubbling over with new things. One of their newsletters pointed out that in September they will have two new programs. One of the programs will be an early intervention program for children from birth to 3 years of age and sometime during the course of the year, WAYNE COUNTY CHAPTER expects to see its first hostel. . . Our thanks to the Bishop of Albany who presented a check to our MONTGOMERY COUNTY CHAPTER from the Bishop's fund. MONTGOMERY COUNTY CHAPTER is extending its programming rapidly, pointing up that their contract figures increased by some 50 per cent in March over February. Executive Director Frank M. Capone coins an interesting phrase when discussing the expansion of community services to former institutional residences when he said, "All Roads do not Lead to Rome, yet a great number do lead out of there." . . . CAYUGA COUNTY CHAPTER is enthusiastic with the dedication of their new center. We enjoy the spirit in their recent newsletter in which they said the State Association has set a membership goal of 300 for us, our self imposed goal is 500. . . FRANKLIN COUNTY CHAPTER writes to announce "The appointment of Paul A. Kendall as their new Executive Director, succeeding W. Michael Robson who resigned May 1. Paul begins his new job at a busy time. The County Board of Legislators has invited A.R.C. to submit by August 1, 1975, a proposal showing how A.R.C. could take over the existing county operated Charles Bartlett Rehabilitation Facility and Hostel, detailing benefits thereof to the clinics and to the county. This year, for the first time, five (5) scholarships (full tuition) are being awarded to Franklin County children attending Camp Catskill. . . SUFFOLK



Orange County Chapter held an educational seminar at their Newburgh Center on March 9. Mrs. Jerome Sullivan (L) who chaired the event, and Chapter President John McManus are

pictured listening to a few words from John Bertrand, State Association Assistance Executive.

COUNTY CHAPTER having a very interesting race. This one to see which of their two hostels, Riverhead or Bayshore, will be open first. That's the right kind of problem. SUFFOLK COUNTY CHAPTER recently co-sponsored a joint meeting with the Society for Goodwill to Retarded Children, the parents group at Suffolk Developmental Center, featuring Robert Hodgson and Leo Fixler of the Association in a full blown discussion of Guardianship. . . Speaking of a new program, a recent edition of the MONROE COUNTY CHAPTER newsletter discussed 6 new programs that have begun in their Chapter. These include a Men's Club, Fun Co-Ed Groups, Grooming Class, Craft Co-Ed Sewing Class, Co-Ed Socialization Group and Big-Little Sisters. . . NIAGARA COUNTY CHAPTER very happy to have the former Sunshine School in Lockport opening as a workshop. . . SULLIVAN COUNTY CHAPTER, getting the most mileage out of one program, reports that they have started an activities of daily living program for children in their three major facilities. A model apartment has been constructed consisting of bedroom, living room, kitchen, dining room, and bathroom. The program, in addition to providing ADL skills, will be used to help in the process of normalization for the many post institutionalized retarded that the Chapter is now servicing. In addition to providing the ADL service, the Chapter will use the model apartment for Emergency Respite Care. . . THE BENEVOLENT SOCIETY - WILLOWBROOK CHAPTER celebrated its 25th anniversary this year. On May 10th, a luncheon was held at the New York Hilton with over 800 in attendance. The luncheon honored the lawyers who participated in the Consent Decree Judgment. One of the featured speakers was Senator William Conklin who worked so hard for the bill to create an independent office of

Mental Retardation. . . ONONDAGA COUNTY CHAPTER extending thanks to the General Electronettes, who recently contributed \$600 to the Chapter. Also receiving thanks of the ONONDAGA COUNTY CHAPTER for the contribution that is made available to the Chapter from the sale of spring plants. . . NEW YORK CITY CHAPTER presented its 1975 Humanitarian Award to Senator Jacob K. Javits at its annual dinner, May 17th. Gary Essex of WABC-TV's Eyewitness News was master of ceremonies for the affair. . .

COLUMBIA COUNTY CHAPTER writes to tell us that they have instituted several new programs in their workshop including clerical training and nurses aide training programs for their clients. In a team effort they are placing groups of 3 of their clients and 2 senior citizens in a roving team in the community. They provide housekeeping services for families referred by public agencies. They will again be providing their summer day camp program. . .

(Continued on page 15)



The Sullivan County Special Olympics team marching in the parade at West Point April 26.



## Attitude survey toward retarded

A Gallup Poll, commissioned by the President's Committee on Mental Retardation, has found that most Americans express accepting attitudes toward their fellow citizens who are retarded, but some fear and lack of confidence persists.

On the positive side, 85 percent would not object to six mildly or moderately retarded persons occupying a home on their block, and 91 percent would not object to having such a person employed where they work. (In the first case, the retarded persons were described as "educated to live in the general community," and in the second as a "trained worker.")

The Committee also found it encouraging that 94 percent of the respondents thought that only some retarded people have to live in institutions compared with 1 percent who believe that all do.

If saw as unfavorable, the belief reported by 49 per cent, that most mentally retarded people are not able to support themselves and lead independent lives, and the fact that 14 per cent thought

there is reason to fear mentally retarded people.

Testing people's knowledge about the causes of retardation, the poll found that 76 percent believed that only some forms of mental retardation are inherited, 21 percent didn't know, and 3 percent said all forms are inherited.

In analyzing the responses, the Gallup Organization noted that the more the concept of special training is introduced, the more are people likely to accept retarded persons as fellow workers. Thus, while 14 percent think there is reason to fear mentally retarded people, only 5 percent would object to working with mildly or moderately retarded people who are trained for the job.

It also points out that although "it is almost universally recognized that institutionalization is not required for all mentally retarded people," only 33 percent think that most mentally retarded people are able to support themselves." The Committee has stated that most retarded adults can, with training work in competitive employment and lead independent lives.

## Transportation for NYS-ARC

The State Department of Transportation has recommended the New York State Association for Retarded Children, Inc. for a Federal grant of \$101,920 to purchase equipment to provide transportation for the retarded and handicapped in areas outside New York City. The Association also has been recommended to receive \$35,672 for use in New York City.

State Transportation Commissioner Raymond T. Schuler announced April 29th, that this Association has applied for the Federal funds to purchase 20 15-passenger vehicles to be used in counties outside New York City.

The buses to be operated by the Association are to be assigned by counties as follows:

Chenango, 1; Clinton, 1; Columbia, 1; Dutchess, 1; Erie, 2; Greene, 1; Herkimer, 1; Montgomery, 1; Niagara, 1; Oneida, 1; Ontario, 1; Rensselaer, 1; Rockland, 1; Saratoga, 1; Ulster, 3; and Wayne, 2.

The aid will come from \$1.3 million allocated by the Federal Urban Mass

Transportation Administration for use in New York State and is being distributed among 51 organizations. At the direction of Governor Carey, the State Department of Transportation is recommending the award of the grants which are subject to final approval by UMTA. The funds must be distributed by June 30, the end of the current Federal fiscal year.

"Governor Carey and I are pleased to implement this program to provide transportation for the elderly and handicapped," Commissioner Schuler said. "Their plight is particularly acute if they do not live near public transportation or do not have the physical or financial capability of operating an automobile."

The Federal funds are being provided under an amendment authored by Rep. Bella S. Abzug (D-N.Y.) to the Urban Mass Transportation Act. The amendment permits aid for transportation of the elderly and handicapped where public transportation is "unavailable, insufficient or inappropriate."

The grant is approximately half of that requested by the State Association.

## United Way cuts

The weight of the United Way's fiscal ax will fall with unequal impact on local services in Erie County, according to agency officials. The United Way announced that it was cutting its allocations to all member agencies by 14½ percent for the rest of the year, effective March 1st. Rising unemployment has caused payroll deductions to diminish the funds that were coming into United Way.

Since the 63 member agencies receive widely differing percentages of their total funding from United Way, the 14½ percent cut is hitting with varying severity.

According to Executive Director, Michael Trowbridge of our Erie County Chapter, the Association for Retarded Children stands to lose \$45,460, about 5 percent of its total operating budget.

"We're in a double whammy because every dollar the Association spends is matched on a one-for-one basis by the State. So, they take away a buck and we lose two bucks." Cuts that are made will probably be in the Association's so-called "Family Services," Trowbridge said. Those are services which help a family care for a retarded child in a home.

## Yates welcome

All Chapters of the Association join in welcoming our newest addition, Yates County Chapter, N.Y.S.A.R.C. Yates was one of the last four Counties in the State without an A.R.C. and has now beaten its Finger Lakes neighbors Seneca and Schuyler Counties, plus North Country Hamilton, into the fold.

The Board of Governors unanimously accepted Yates application at its May 24th meeting. Under the Presidency of Jerry Manley of Penn Yan, the new Chapter had adopted all necessary by-laws, etc. and submitted an initial list of 24 memberships.

Having completed the necessary paper work, the Chapter is moving toward its stated goal of a workshop in the County.

The Association expresses its sincere thanks to Ontario County Chapter for being a helpful neighbor during this formative period, and Assistant Executive Director John Bertrand expressed special thanks to Bob Rosenberg, Executive Director of Ontario County Chapter and Carol Ahrensbarck, of the Ontario County Chapter staff who handled all of the details of setting up the formative meetings. We all say "Welcome - Yates County", and good luck as you grow.

## What price complaint?

In addition to the unexplained deaths at Rome State School, which this Association and others protested, we also protested to Governor Carey the death of an 18-year old blind youth who died at Willowbrook, killed by an infection caused by a table knife lodged in his rectum.

Even more shocking (than the statement of his death) is the statement of the new director Harold Piepenbrink that preliminary inquiry produced no indication anyone other than the boy was involved.

A telegram sent by the ARC to Gov. Carey, asked for the immediate appointment of a committee of panel physicians, none of them connected with state service to look into the medical procedures and investigate the causes of these deaths at the facilities of the Department of Mental Hygiene and to lay the blame wherever it must be.

In response to this telegram, we received a letter from Mr. David W. Burke, Secretary to the Governor as follows,

## Employment regulations issued

The U.S. Department of Labor, Wage and Hour Division, has published regulations regarding the employment of patients and residents in the institutions of the Department of Mental Hygiene.

These regulations require the institutions employing patients or residents to apply for special wage certificates. They allow a facility to pay less than minimum wage rates to clients in specified work programs. The new regulations were necessitated by the decision of the U.S. District Court in "Souder vs. Brennan", reached October 1973.

That decision required strict interpretation of the amended Fair Labor Standards Act in regard to the payment of wages to patient - employees. It said, in effect, that a patient or other mentally disabled resident of an institution must be paid wages for work performed in the facility. The decision also affects other handicapped persons in a variety of work situations.

Certificates for less than the minimum wage may be granted in four basic categories. They may apply to a training and evaluation program, which is instruction designed to determine a working patient's potential and to teach him or her to adjust to a work environment. The regulations limit such a program to no more than 12 months.

Certificates may also cover an individual exception for a person whose earning or productive capacity is severely impaired. This kind of exception allows a wage rate less than that of a third category, the special group minimum wage. This covers patients and residents who have completed training and evaluation and entered an employment relationship with the institution.

The fourth category of wage exception is for clients of a "work activities center", a program of work activities for patients who physical or mental impairments are so severe as to render their productive capacity inconsequential.

For this category the Labor Department will determine "commensurate pay", a wage related to a patient worker's productivity. These rates will be based upon minimum wages and work standards in the facility and the general area in which it is located.

If any of our readers are confused by all this, questions concerning this implementation should be referred to the appropriate regional director, says the Mental Hygiene News of April 1975.

"Dear Mr. Weingold: The Governor has asked me to respond to your recent telegram concerning a death at Willowbrook. I have directed Dr. Lawrence Kolb, Commissioner of the Department of Mental Hygiene, to send the Governor the results of the current investigations being undertaken by the Department and to respond to the recommendations made in your telegram. The Governor appreciates your expression of concern in this matter. Sincerely, David W. Burke."

Since April 24, 1975 we have heard nothing further from the Department of Mental Hygiene, Mr. Burke, or the Governor on this matter. We do know, however, that the bills to create independent medical review panels have been introduced and reported elsewhere in this issue.

From the Governor's Office and from the Department — nothing.

## Assn. honors top employees

For the 10th year, the New York State A.R.C. has honored an Outstanding Employee within the institutions of the Department of Mental Hygiene serving the mentally retarded. The award consists of a certificate of appreciation to the employee, a nameplate to be placed on the plaque at each Developmental Center and a check in the amount of \$100.

A feature of the 1975 awards will be the expansion of the Awards from the large, "older" Centers, to include the following new facilities, Broome, Manhattan, Bronx, Queens, Brooklyn, Monroe and O.D. Heck.

In a departure from prior years, the nameplates and checks are being awarded by the parents group at each Developmental Center, or the Community Chapter closest to the facility, rather than at our State Convention.

The certificates were presented by the Association to the employees at the Department of Mental Hygiene "Employee Recognition Day", which was held in Albany on June 26.

Outstanding Employees for 1975, as announced by Edward B. Licence, Chairman of the Scholarship and Awards Committee are:

Broome Developmental Center - Betty D. Rannings; Bronx Developmental Center - Joan Lake; Brooklyn Developmental Center - Agatha Hopkins; Craig Developmental Center - Eileen Kline; O.D. Heck Developmental Center - Denise Sartoris; J. N. Adam Developmental Center - Charles Stewart; Letchworth Village Developmental Center - Lucinda Lanier; Manhattan Developmental Center - David Marrero; Monroe Developmental Center - Penny Barnes; Newark Developmental Center - Josephine Marsh; Queens Developmental Center - Cora Walker; Rome Developmental Center - JoAnn Bowers; Suffolk Developmental Center - Joseph Siele; Sunmount Developmental Center - Emma L. Helak; Syracuse Developmental Center - Betty J. Thater; Wassaic Developmental Center - Rabbi Harry Zwick; West Seneca Developmental Center - Rev. John R. Aurelio; Willowbrook Developmental Center - Charlotte Zinicola; Wilton Developmental Center - Irv Collins.



SEPT. 25-28



# Brandt on Medicaid

The following article on Medicaid for the retarded was submitted to O.C.V. by Marc Brandt, executive director of the Sullivan County Chapter. We think it important enough to reproduce in full.

"In a recent issue of Our Children's Voice (April 1975), Robert Sansone, executive director of the Suffolk County Chapter had sections of an article he wrote reprinted from the December, 1974 issue of the "AHRC Lamplighter" discussing Medicaid. Bob has been one of the pioneers for obtaining Medicaid for Programs for the mentally retarded. We, of the Sullivan County Chapter, have had our difficulties in obtaining this source of funding but urge all Chapters to apply, where called for, for Medicaid services.

Although most ARC's do not use or have even applied for Medicaid funding, the implications and difficulties surrounding the Department of Mental Hygiene's refusal to acknowledge ARC Chapters right to this funding has ramifications for every ARC in N.Y.S. and every retarded individual residing in our State. The confusion and discrimination against ARC's to be eligible and to receive proper licensing is another prime example of the Department of Mental Hygiene's inability to provide clear cut standards and a humane philosophy relating to the overall mental health and well being of the retarded of New York State.

We of the Sullivan County Chapter feel that the Medicaid issue deserves a great deal of attention by our corresponding Chapters. It is a known fact among professionals in New York State that the traditional psychiatric day care center programs provide little more than a brief encounter with a Psychiatrist. Our medical assistance tax dollars are paying for little more than an elaborate arts and crafts program. This is not to say that all day care centers operate in this manner. However, programs operated by local mental health centers often have non-certified persons with little in the way of proper day care, Day Treatment assistance.

Although the Department of Mental Hygiene appears to be constantly changing the standards, the day treatment definition, as defined by the Department, has basically remained the same: "A program offering treatment including a planned program of recreational, social and vocational activities in a therapeutic environment. Treatment services may be provided by a staff which may include psychiatrists, psychologists, social workers, nurses, educators, occupational and recreational therapists, psychiatric aides and volunteers. Treatment may include individual or group therapy, patient-staff meetings, drug therapy, occupational therapy, recreational therapy and other activity."

The New York State Association for Retarded Children, through its local chapters throughout the State, has demonstrated their ability to operate community based "developmental" programs. The ARC's programs in New York State are based on an attempt to provide developmental, educational and rehabilitation services which to our mind and satisfaction, reinforces the goals and objectives of the Department of Mental Hygiene through its stated purposes of Day Treatment: "the prevention of the need of in-patient care and treatment or the reduction of in-patient care and treatment or the reduction of in-patient stay through the provision of intensive multi-activity services for the reduction of disabilities."

Local chapters are now being required to apply for a Day Treatment license from the Department of Mental Hygiene in order to be eligible for Medicaid funding. Although we would be the first to insist upon professional standards, it appears that the Department is quite reluctant to give ARC's Day Treatment Certification.

In all fairness to the Division of Standards, Inspection and Program Evaluation, they are indeed tremendously understaffed for the assignments they are charged with. However, if the medical model insists upon not building up their staff in accordance with their own standards, we in the communities should not be penalized for their lack of abilities in certifying our programs. We should not nor should our retarded clients, be put to task because of the Departments inability to organize themselves.

If one looks at the real value of a Day Treatment Program, one sees that, under such a program, one really has a vested interest in the total concern for the total person. This is quite different from the Office of Vocational Rehabilitation's prime concern and vested interest in the area of vocation. This point needs to be emphasized as many of our Local Chapters programs are under criticism that they are too vocationally oriented and thereby ineligible for Day Treatment.

This is a belief that holds little water with the majority of ARC programs. Many ARC's throughout the State are providing "planned programs of recreation, socialization and vocational activities in a therapeutic environment" to hundreds of post institutionalized residents residing in family care homes throughout the State. These retarded citizens are the state's failure to provide proper and humane treatment. We of ARC only ask for the proper funding mechanism as stated by the Department of Mental Hygiene so that we might provide proper professional programs and humane treatment which is the retarded's right to be served.

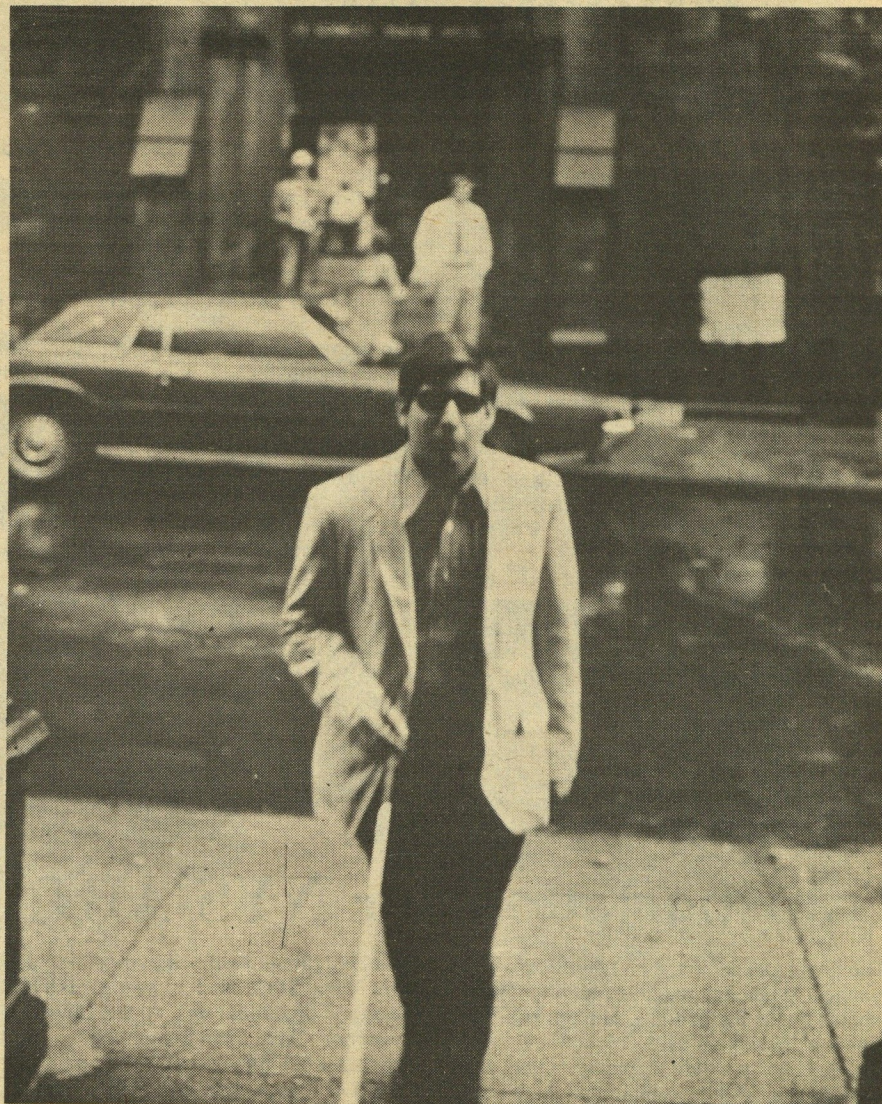
The Sullivan County ARC is one of the first chapters to have received a Day Treatment license from the Department of Mental Hygiene. We, indeed, hope we will not be the last and urge all chapters that have legitimate Day Treatment Programs to apply. Our local regional office, the Mid-Hudson Regional Office of the Department of Mental Hygiene, has been most helpful and has certainly cooperated and guided us to obtain the license. The law is the law and rules and regulations should not be established for only one disability group, but for every program and every disability that the Department of Mental Hygiene has jurisdiction over.

Since the Governor refuses to allow for separation and a separate Office of Mental Retardation, of which the Department of Mental Hygiene argues would fragment services and — if the Department is to have jurisdiction over the retarded of our State, then we as the professionals and parents involved with the retarded in the communities must insure through our local chapters and State Association, that at the very least, we will be reimbursed in the same manner as the other disabilities — **To do less is not ARC.**

## Where are services?

People sometimes wonder what our grant for the program coordinator, Tom McCarley, is supposed to accomplish. One of the things it has accomplished is that he is discovering people placed in the community, especially family care by the Dept. of Mental Hygiene, where they just sit with no services. As an example of this, we cite 34 such residents in 13 family care homes with no services beyond family care. These family care homes are in Ogdensburg, Dexter, Mooers Forks, Star Lake, Cadyville, Champlain, Watertown, St. Regis Falls, Ellenburg Depot, and Redwood.

This matter has been called to the attention of Mr. Robert Hayes, Deputy Commissioner, Division of Mental Retardation and Children's Services on April 28th. To date, we can locate no reply.



Daniel Rodriguez Returning "home" to Fineson House.

## Hostel resident awarded degree

### FINESON HOUSE RESIDENT GETS DEGREE

An outstanding study in determination may be all wrapped up in the person of Daniel Rodriguez. Although legally blind, Daniel, a resident of Fineson House, New York City Chapter's hostel, has kept working on a high school equivalency exam. His hard work was rewarded when on May 13, 1975 a letter was received by Mrs. Phyllis Levy, Supervisor of Instructors at the New York Association for the Blind, which contained the following paragraph, "I am happy to report that he (Daniel) achieved the recommended requirements for issuance of a New York State Department of Education high school equivalency certificate".

## OVR and DMH cooperate at Willowbrook

In the New York City area, according to information received from Joseph Palevsky, Regional Director of the OVR-DMH Program, the Office of Vocational Rehabilitation of the New York State Education Department has established services at the Willowbrook Developmental Center and at developmental centers in all boroughs as part of the joint OVR-DMH Program. This program has resulted in a number of individuals participating in training programs in a variety of community facilities and settings. The goal for the individual has been placement at the completion of evaluation and training, either in competitive employment or in long-term sheltered employment in a community rehabilitation facility.

Under the Vocational Rehabilitation Act of 1973, this proposal sets up an extended evaluation program for those whose vocational potential is doubtful and needs longer periods of time to determine. The Dept. of Mental Hygiene has asked the Office of Vocational Rehabilitation to organize such a program for the profoundly retarded Willowbrook residents now served by developmental centers.

It is planned to serve approximately 100 in the early stages of extended evaluation. They would be drawn mainly from Willowbrook prior to transfer to Manhattan, Brooklyn and Queens

Developmental Centers with a small proportion of the 100 from the Bronx Center.

The Dept. of Mental Hygiene, as the grantee agency, will be accountable and responsible for the total program. However, the program will be operated by the Office of Vocational Rehabilitation which will provide extended evaluation services to the target population.

This program, it is hoped, will be a prototype for the state in the development of services for the more severely retarded to return to and retain them in the community and assist them in attaining their maximum potential. As this is a similar problem in other states, it will have national implications for replication. If possible, research projects will be developed from some of the preliminary findings.

The community agencies that are involved in this evaluation program are the AHRC, Bronx location; Massive Economic Neighborhood Development (MEND); Federation of the Handicapped; Young Adult Institute; Association for Children with Retarded Mental Development; Brooklyn and Queens locations; United Cerebral Palsy of Queens and the Brooklyn School for Special Children.

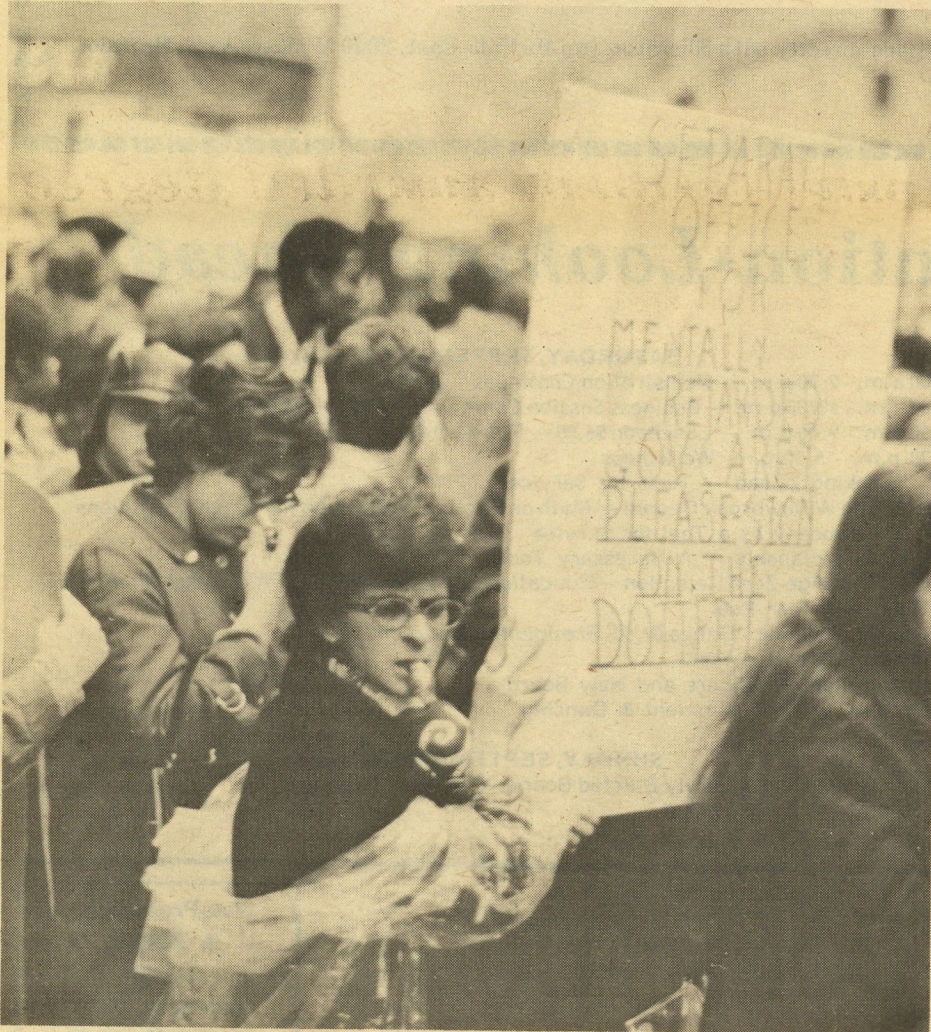
Nothing is mentioned in this about living arrangements for those who are receiving, or after they have received, extensive evaluation.



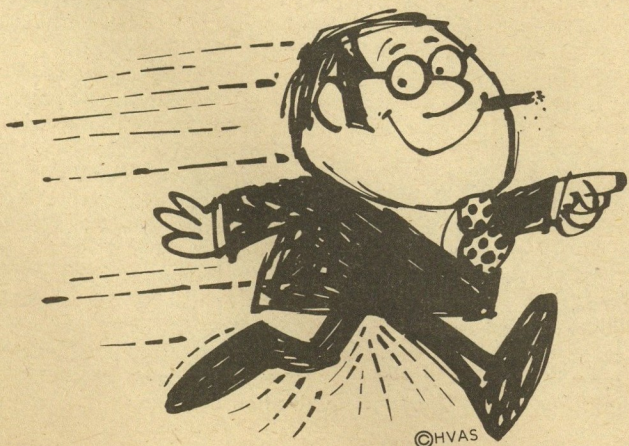
# Demonstrate for Bill



Thousands of retarded and other developmentally disabled and parents demonstrate May 2nd before Governor Carey's New York City office.



Retarded and professionals speak for themselves.



**BUFFALO OR BUST!**

## More Chapter News

From GREENE COUNTY CHAPTER comes the following word "The Chapter will be moving its Work Activity Center to a new building on July 1st, so they need additional equipment to get the building ready. The Work Activity Center is in full swing, with 32 clients enrolled. The new building will provide more opportunity to develop a total program. Everyone is looking forward to the move . . . I can't resist repeating an article found in ULSTER COUNTY CHAPTER'S newsletter indicating that in figures just released by the Reynolds Aluminum Company, the ULSTER COUNTY CHAPTER of the New York State ARC is a leading participant in recycling. In the one year they had their own community recycling center they have collected more than 2,603,275 pounds of recyclable material . . . Many thanks to Paul Nigra,

Executive Director of FULTON COUNTY CHAPTER for sending us the very complete schedule of The Lexington Center Weekend. This event, which is operated annually with the cooperation of the Fulton

Montgomery County's Community College is one of the most outstanding fund raising events, and public education events, within the State Association. If you are interested in knowing how something like this really should be run, why don't you drop a note to Paul at FULTON COUNTY CHAPTER and ask for a copy of the schedule. . . BROOME COUNTY CHAPTER has been functioning within their present center for some time, however they finally were able to have a dedication on Saturday June 7th. We continue to be impressed with the fantastic work being done in their workshop, particularly in the food services area. This is not in any way to de-emphasize the fine work being done in the other areas of the shop, it is just that the food services area is really unusual in its goals. Here's my inspiration for this month. How about all the Chapters of the ARC that have gardens making an arrangement to sell their produce to BROOME COUNTY CHAPTER . . . No one has to tell WELFARE LEAGUE - LETCHWORTH VILLAGE CHAPTER to think ahead. Their April newsletter contains a wealth of information about their 36th Anniversary Luncheon which will be held November 22, at the New York Hilton . . . from SARATOGA COUNTY CHAPTER comes word that their Capital Fund drive has reached the \$93,000 mark. Hope that will translate into a new building soon . . . MADISON COUNTY CHAPTER has moved its Administrative Offices from Canastota, New York to Oneida New York. The workshop, of course, went with it. We are sure this means help for many clients of the shop.

### Committee named to check DMH

Assemblyman Perry Duryea has asked Robert Wertz, R-Commack, ranking minority member of the Mental Health Committee of the Assembly, to head up a committee to investigate the operations of the Dept. of Mental Hygiene and make recommendations to the legislature.

Almost at the same time, Assemblyman Stanley Steingut, Speaker of the Assembly, appointed Assemblyman James W. McCabe a member of this committee and Assemblyman Burton G. Hecht, Chairman of the Ways and Means Committee as co-chairmen of a Democrat committee to make the same investigation.

In letters to Assemblyman Duryea and Steingut, the Association expressed the opinion that there should be public involvement on such committees; that in fact such committees, if they are to be as effective as they could be to duplicate the Moreland Commission type action.

Furthermore, there are no similar committees in the Senate.

### Pilgrim Accreditation loss pending

Pilgrim State Psychiatric Center, the largest mental hospital in the state, has been notified of pending loss of its accreditation.

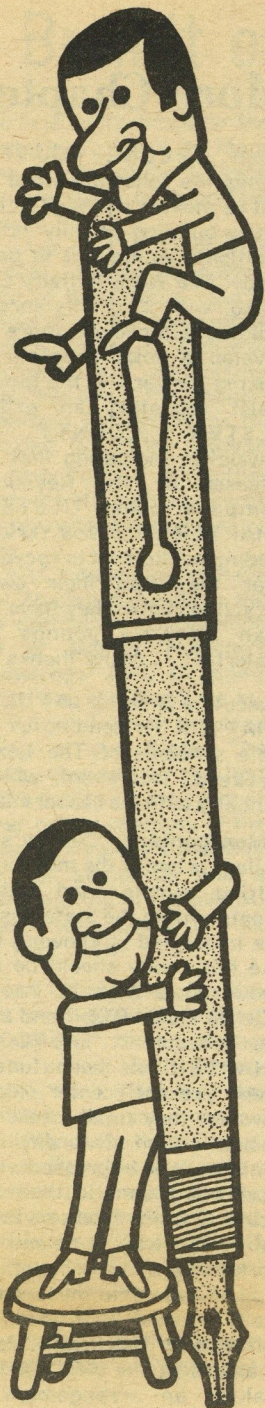
The reasons cited are: too small a staff and lack of privacy and other amenities for patients. Also critics of the hospital have charged brutality toward patients at a public hearing held by the Joint Commission on Accreditation in February of this year. The move to strip away accreditation does not include such charges.

Loss of accreditation would jeopardize \$22.4 million a year in federal, state and local funding for Medicaid and Medicare patients among the 6200 hospitalized at the West Brentwood, L.I. institution. The current annual budget for the hospital is \$52 million, almost all of the balance from state funds. This is the first time in the hospital's 44 year history that it has not received unqualified accreditation.

The Council on Accreditation is recognized by the Federal Department of Health, Education and Welfare which only gives Medicare, Medicaid benefits to accredited institutions.

The Joint Commission is a Chicago — based professional agency which sets standards for and inspects all hospitals in the nation. It is a private agency which has gained official status because its accreditation is required for eligibility to treat patients whose care is paid for by federal funding. Dr. Henry Brill, regional director of the State Department of Mental Hygiene conceded deficiencies but said that efforts would be made to get further resources in the institution to make up its deficiencies. He said that Pilgrim has always had full accreditation and "while this threatened loss is painful," it may prove helpful with improved conditions at Pilgrim.





**ADVANCE REGISTRATION—CONVENTION  
NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.  
BUFFALO, N.Y. SEPTEMBER 25-28, 1975**

To: Charles J. Kerrigan, Chairman  
Erie County Chapter NYS ARC Inc.  
470 Franklin St.  
Buffalo, N.Y. 14202

I wish to register in advance for the following events. My check/money order for \$ \_\_\_\_\_  
is enclosed (Please make checks payable to Erie County Chapter, A.R.C.)

Registration \$5.00 \_\_\_\_\_ (name)

\_\_\_\_\_ (address)

Tour — (check one) \$2.50: \_\_\_\_\_ (city)

A. West Seneca Developmental Center \_\_\_\_\_ ☐

B. Erie Co. A.R.C. Programs \_\_\_\_\_ ☐

Luncheon — Sat., Sept. 27	\$6.00
Banquet — Sat., Sept. 27	\$7.50
<b>Total — \$21.00</b>	

NOTE: All hotel reservations should be made directly with Sheraton Inn-Buffalo East, 2040 Walden Ave., Buffalo, N.Y. 14225

**SIGN UP  
TODAY!**

## 1975 Convention-Looking Ahead

**THURSDAY, SEPTEMBER 25, 1975**

Noon - 9 p.m. — Registration \$5.00 . . . Main Lobby  
8:00 p.m. — Meeting of the Board of Governors — Cleveland Room

**FRIDAY, SEPTEMBER 26, 1975**

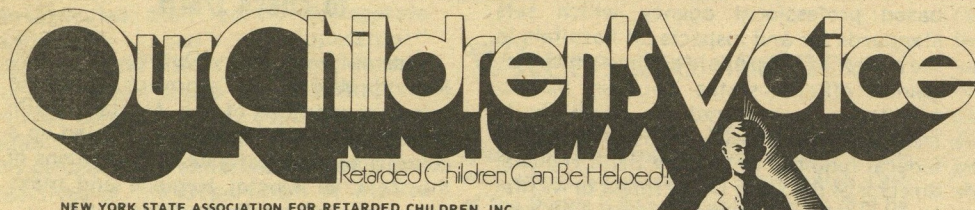
9:00 a.m. — All Day — Registration, Lobby  
9:00 a.m. - 12:30 p.m. — Board of Governors Meeting Continues  
12:30 p.m. — Luncheon — Open  
2:00 p.m. - 6:00 p.m. — Tours \$2.50  
    A. West Seneca Developmental Center  
    B. Erie County Chapter Programs  
    C. M. R. Computer Center — Univ. of Buffalo  
2:30 - 4:30 p.m. — General Session  
    "The Legislative Process"  
6:00 p.m. — Dinner — Open  
8:00 p.m. — Convention Convenes, Roosevelt Room. Greetings — Charles Kerrigan,  
Convention Chairman. Welcome — David Esserow, President, Erie County Chapter  
Convention Opened by State President — Elliot L. Aronin.

**SATURDAY, SEPTEMBER 27, 1975**

9:00 a.m. - 2:00 p.m. — Registration Continues — Lobby  
9:00 a.m. - 12:30 p.m. — Business Session Continues — Roosevelt Room  
1:00 p.m. - 2:00 p.m. — Luncheon \$6.00 — Fillmore Room  
2:30 p.m. - 5:30 p.m. Workshops  
    "Looking Ahead — Tools for Service"  
    A. The Willowbrook Decree — Myth or Fact — Its Meaning for Other Institutions  
    B. Advocacy as a Tool for Service  
    C. Guardianship — A Necessary Tool  
    D. Zero Age-Zero Rejection — Education for all 6:15-7:15 p.m. — Dutch Treat Social  
    Hour — Indoor Pool  
7:15 p.m. — Dinner - Dance \$7.50, Presidential Ballroom.  
    Presentation of Awards  
    Installation of Officers and New Board  
10:30 p.m. — Entertainment & Dancing

**SUNDAY, SEPTEMBER 28, 1975**

10 a.m. — Meeting of Newly Elected Board — Roosevelt Room  
12:30 p.m. — Adjournment.



NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

175 Fifth Avenue  
New York, New York 10010

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