



Our Children's Voice

Retarded Children Can Be Helped

Vol. XXVIII No. 3

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

September, 1976

SOAR in leading role

ARC sues NYS on Wassaic

Willowbrook standards must apply

On June 29, 1976, the New York State Association for Retarded Children filed a Class Action in the Federal Court, Southern District to:

A. Stop impending transfer of 200 Wassaic residents into a unit for the mentally retarded on the grounds of Harlem Valley Psychiatric Center.

B. Extend the conditions of the Willowbrook Consent Decree to the residents of Wassaic.

The defendants in the action are Governor Hugh L. Carey, the Department of Mental Hygiene and its Commissioner, Lawrence C. Kolb; Regional Director James Forde; Deputy Commissioner for Mental Retardation Thomas A. Coughlin, III; Director of Wassaic Developmental Center Richard Merges; Department of Education and its Commissioner, Ewald B. Nyquist.

The action is on behalf of the ARC and all the residents of Wassaic Developmental Center.

RESTRAINING ORDER ISSUED

Even though imminent transfers from Wassaic to Harlem Valley created the environment for necessary legal action, a temporary restraining order, issued by Judge Knapp and preventing the transfers, has been vacated by Judge Pollack.

A major reason for NYSARC's opposition to the transfers is that Harlem Valley Psychiatric Center could not conceivably qualify as the least restrictive alternative for the residents in question. The 200 persons to be moved will eventually be capable of living in their home

county of Westchester in hostels or family care situations. These persons will, in fact, be moved to such settings as the necessary facilities become operative. NYS ARC's position is that the monies being spent for renovation of Harlem Valley could be better spent on less restrictive alternatives to institutionalization such as the hostels and family care settings that will be necessary if a goal of true community placement is to be realized.

\$800,000 FOR RENOVATION

A total of \$800,000 was funneled into the renovation of Harlem Valley Psychiatric Center so it could take a portion of the 600 residents who must be moved out of Wassaic by March 1977 if Wassaic is to meet the HEW standards for Intermediate Care Facilities. If Wassaic does not meet the deadline, it loses the ability to generate \$10 million in Federal monies.

Even if Wassaic does meet the HEW standards, it would not necessarily meet the standards of the Willowbrook Consent Decree. At the same time, Harlem Valley, even with the influx of renovation monies, is still in direct violation of many of the standards of care granted to the Willowbrook residents. For example, if Wassaic residents were protected by the Consent Decree, they would have a "right to the least restrictive and most normal living conditions possible." In addition, staff would be required to "prepare and help residents to move from group to individual residences and from 'segregated from community' to 'integrated with community' living and programming."

Only one ARC victory in 1976 legislative results

The 1976 Session of the New York State Legislature was characterized by an almost total disregard of the program advanced by the New York State Association for Retarded Children.

Only one bill, part of the ARC program for years, was passed by the Legislature and signed by the Governor on July 29th. This bill (S-2235A) deals with the inclusion in family health and accident policies of children regardless of age, who because of mental or physical handicap are incapable of self sustaining employment as dependents. The bill introduced by Senator Dunne (R. Nassau) has been pursued by the Association for years, since a similar bill mandating the inclusion of these persons in policies written by nonprofit insurance companies such as the Blues was passed a number of years ago. The rationale for the bill is that these persons are dependents for life as evidenced by the Social Security Act where such persons may receive Social Security beyond the age of 18 on the basis they are and will

remain dependents for life. It is an enormous step forward in the delivery of services to retarded and other handicapped. When the question, "Do you have a handicapped child" is answered in the affirmative, insurance companies have excluded the child from such family policies. Other than this, the total ARC program failed to pass.

These measures include:

A bill to create a separate office of Mental Retardation. This never came out of committee. As a substitute for this, Speaker Steingut offered a measure to create a Mental Hygiene Planning Council which will be discussed elsewhere.

A bill to prevent local subdivisions of the state from passing or enforcing zoning restrictions on the use of property for group homes for the mentally disabled. The Association could not get an assembly sponsor for such a bill. It was introduced in the Senate by Senator Conklin.

A bill to remove parental liability for



An earnest demonstration on Wassaic. Left to right, Judy Gilman, James Hanifer, members of Wassaic Chapter board of directors; Joseph T. Weingold, NYSARC Executive Director; Doris Hosmer, President, Westchester Chapter.

NYSARC POSITION TAKEN

NYSARC has taken the position that the State has voluntarily entered into an agreement, the Willowbrook Consent Decree, which has set up a two-tiered delivery system for services to the retarded resulting in a lower standard of care for retarded persons in institutions that are not protected by the Decree. This is seen by NYSARC as a direct violation of the Constitutional right to equal protection, and if successful, the class action would insure that the State would end this

discrimination and provide the same standard of care of the Willowbrook class.

Attorneys for the plaintiff are Jack Bernstein, Director - General Counsel, and George Heymann, Associate Attorney, SOAR, System of Advocacy for the Retarded; Hyman Clurfield, Augustus M. Jacobs, and Walter C. Redfield.

OCTOBER MEETING PLANNED

At this time, the plaintiff's attorneys have explained to Judge Pollack they will need 3 months to assemble expert testimony on the conditions at Wassaic. Judge Pollack has agreed and the plaintiffs' and defendants' experts will meet before October, 1976, to attempt to agree on various standards, narrow their issues and review their positions. There will then be a pre-trial conference with Judge Pollack who will thereafter set a date for trial.

If successful, the decision for the plaintiff would set a legal precedent for extension of the Willowbrook Consent Decree standards to all other institutions for the retarded throughout New York State.

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Legislative Programs

Continued from Page 1 PERIODIC EVALUATION OF SERVICES

Chapter 328, to become effective immediately, amends the Mental Hygiene Law to provide that the Commissioner shall insure that all services for the mentally disabled, whether provided by the Department, by local governmental unit or by provider of services, are periodically evaluated and departmental budget requests reflect such evaluation.

COST BASIS FOR FEES

Chapter 329, provides that the Commissioner shall establish cost-based in-patient and non-inpatient fees with separate rates for each individual facility, no later than October 1, 1978. The act takes effect October 1976.

ADVANCE STATE AID PAYMENT

Chapter 330, provides that allocations for state aid for operating costs for local services be paid in advance no more than 10 days after the beginning of each quarter. Takes effect July 1978.

STATE CONFERENCE OF MENTAL HYGIENE DIRECTORS

Chapter 331, states the New York State Conference of Local Mental Hygiene Directors be composed of all the directors of community services. Its major power seems to be to review the comment upon the rules or regulations proposed by the Commissioner for the operation of local and unified services programs. These regulations must be submitted at least 21 days prior to the effective date to the conference, unless the health, welfare or safety of the residents and patients warrant prompt adoption of rules and regulations. This takes effect January 1, 1977. This interposes another bureaucracy between the state and the providers of services as the mental hygiene directors are politically appointed by local government without any input from the community.

WRITTEN TREATMENT PLANS

Chapter 332 deals with treatment plans and requires the development of written treatment plans. It requires the client or an authorized representative to include the parent or parents, if the client is a minor, to be interviewed and provided an opportunity to actively participate in such preparation or revision.

This must be done at least once a year. In addition, there must be consent for surgery, shock treatment, major medical treatment in the nature of surgery or the use of experimental drugs or procedures. It takes effect January 1977.

HOSTELS CHANGED TO "COMMUNITY RESIDENCES"

Chapter 333 eliminates the word hostels from the law and substitutes "community residences".

Up to one-half of the funds appropriated to "community mental health and mental retardation facilities development fund" shall be transferred to the state purposes fund for the purpose of expenditure made pursuant to this Act. It takes effect September 1, 1976.

MENTAL HEALTH INFORMATION SERVICE GIVEN ADDITIONAL POWERS

Chapter 334 gives the Mental Health Information Service the power to investigate cases of alleged patient abuse and initiate and take any legal action deemed necessary to safeguard the right of any patient to protection from such abuse and mistreatment. They act as the legal representative of such patient who has not obtained other legal representation or made provision for necessary legal services on a fee for service basis (not free). In addition, the Mental Health Information Service is mandated to examine the results of grievance and disciplinary procedures, and report to the Legislature with recommendations no later than January 1, 1977. The act takes effect September 1, 1976.

LOCAL PLANNING

Chapter 335 provides that each local governmental unit shall direct and administer local comprehensive planning process for a geographic area, with the providers of services of department facilities participating. This seems to be more of the same nothing. What is repealed in this Act is that the local governmental unit has to plan with the State Department of Mental Hygiene for the delivery of service to mentally disabled. Apparently the Mental Hygiene Department is now eliminated in this process. This takes effect immediately.

DEMONSTRATION PROGRAMS

Chapter 336, to take effect immediately, orders the Commissioner to develop plans for three or more "time-limited demonstration programs". The purpose of such demonstrations would be to test and evaluate new methods or arrangements for organizing, financing, staffing and providing services for the mentally disabled in order to determine the desirability of such methods or arrangements.

Such programs may include comprehensive organizational structures to service the mentally disabled with the purview of local government units, innovative financing and staffing as well as specific programs to serve the mentally disabled.

What we need at this point is more demonstration projects rather than implementation of what we already know. Anyone disagree?

CLIENT SERVICE REPORT SYSTEM

Chapter 337. This, in effect, is a duplication to some extent of one of the other bills. It requires the Commissioner to establish a client service report system to provide notification of services or treatment to individual patients or clients to them or their representatives, including parents, etc. or appropriate directors of community services and social services. This Act takes effect April 1978, except that part which provides for establishment of a client report system, which takes effect April 1, 1977.

BOARDS OF VISITORS

Chapter 338 is amended by Chapter 340 which deals with Boards of Visitors, and requires (a) directors shall notify immediately the Board of Visitors of any complaint of patient abuse, (b) Boards of Visitors shall include at least 3 parents or relatives of patients or of former patients, (c) the Board shall give notice of its meetings to the Mental Health Information Service, when they send a representative to the meeting, (d) the Board shall insure that a member or committee inspect the Department's facilities once every three months without prior notice and submit a report to the Governor or to the Commissioner, (e) if a member of the Board fails to visit and inspect a facility at least twice a year, he shall be considered to have vacated his office. The last part shall take effect January 1977. The rest of it in 90 days.

PRIVATE MORTGAGES FOR M.H. OR M.R. SERVICES COMPANIES

Chapter 339 amends that part of the Mental Hygiene Law which sets up Mental Health Services Companies. The purpose of setting up such companies originally was to insure a loan by HFA to such a company. Since HFA is now barely operating in this area, a lending institution now includes special lenders foundations, labor unions, employers associations, etc., etc. This enables the Commissioner to make seed money advances to such corporations where the lending institution for the purpose of developing a program for a hostel, for example, is a commercial lender instead of HFA. It takes effect immediately.

M.H. INFORMATION SERVICE TO TAKE LEGAL ACTION

Chapter 334 mandates the Mental Health Information Service to investigate and take any legal action necessary to safeguard the rights of the patient, act as legal representative for a patient who has not obtained other legal representation and make provision for necessary legal services on a fee for service basis. This is a power the Mental Health Information Service did not have before; the Act takes effect September 1, 1976.

COMPREHENSIVE PLANNING (AGAIN)

Chapter 335 emphasizes the obvious in other parts of the law, requiring each local governmental unit to direct and administer a local comprehensive planning process for each geographic area. Providers of services and department facilities shall participate in, and provide information for, this planning process. But, of course, they have nothing to do with the actual decision-making process.

DEFINITIONS OF RELEASE, CONDITIONAL RELEASE AND DISCHARGE

Chapter 433 amends the Mental Hygiene Law to include not only definitions of release, but also conditional release and discharge. Under discharge, (release and termination of any right to retain or treat the patient on an in-patient basis) the patient is not precluded from receiving necessary services on other than an in-patient basis nor shall it preclude subsequent re-admission on an in-patient basis.

DIRECTORS OF INSTITUTIONS IN "NON-COMPETITIVE CLASS"

Chapter 434 amends the Mental Hygiene Law so the director of a facility shall be "in a non-competitive class and designated as confidential". In other words, the Commissioner is now empowered to pick the best man for the job without regard to the Civil Service Law.

COUNCIL FOR MENTAL HYGIENE PLANNING

Chapter 441 creates a "Council for Mental Hygiene Planning" to establish statewide goals, objections and services for the mentally disabled. The council shall consist of a Commissioner and ten members to be appointed by the Governor, some of whom shall be appointed from recommendations by the temporary president of the Senate and some by recommendations of the Speaker of the Assembly. This is no more or less another planning gimmick. We cannot see what effect it will have on services in this state.

CONTINUING OF EXISTING INSTITUTIONS

Chapter 437 has in the seeds of it the dissolution of some of our institutions. The Legislature directs the Department of Mental Hygiene to survey and determine the immediate needs for continuing all state institutional operations and report to the Legislature by January 1, 1977.

It is noteworthy that in the bill which requires the Commissioner to submit a plan of consolidation, etc., of institutions, an amendment was passed, Chapter 438, which states the Department shall not "without approval of the Legislature initiate implementation of plans for regional consolidation of facilities and the associated reassignment of direct patient care functions, except as necessary to assure maintenance of hospital accreditation or federal funding."

Other laws of much more significance to the mentally disabled in the community will be dealt with elsewhere in this issue. An assessment of this package of laws leads to the conclusion that nothing much has been added to the amount or quality of services for the mentally disabled.

Editorial

No Exit

In relation to the Department of Mental Hygiene and its blind insistence on dumping the retarded into psychiatric centers, we seem like the characters in Sartre's "No Exit". We always think we are getting out of somewhere, but in reality we never will, given the circumstances of imprisonment.

Is the Department really so blind? Or, are they like the blind horse whose former owner told the purchaser when the horse went through a plateglass window, "it isn't that this horse is blind, it just doesn't give a damn."

Can we really say this Department gives a damn about what we the parents think?

Is it really concerned with the welfare of the retarded or the piddling bookkeeping of budget for the utilization of empty buildings in psychiatric centers that should be torn down?

No, this way there is no exit. There is an exit, however. That exit is to tear down the edifice, to remove the retarded from the Department of Mental Hygiene, build a new building, open windows, open doors, open minds, with vistas and vision instead of the tunnel vision, at the crummiest distance, at a begging stance, to which we are now condemned.

For God's Sake, let's get out of here.

Our Children's Voice

Retarded Children Can Be Helped

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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Education Law

Revisions include funds for special ed

Two bills were passed by this Legislature, one already signed by the Governor, the lottery bill (Chapter 92), and the other still on the Governor's desk which revise the whole system of special education to the handicapped in this state and provide more funds for it. The bill on the Governor's desk at this writing, (and we have every reason to suppose that he will sign it) is S. 9470A. (Giuffreda,) a bill which in many forms has been before the Legislature in the past two years. This bill completely rewrites Article 89 of the Education Law dealing with children with handicapping conditions. The bill does the following:

a. It defines handicapped children's special services operating and maintenance expenses, etc.

b. It provides for the establishment of local committees on the handicapped containing at least one parent to act as an advocate for the child, written notices to the parent when the child is being considered by the local committee, provision for consideration of objections to decisions of the local committees by the parents by an impartial arbitrator (who in our opinion isn't quite impartial, since he is being chosen by the superintendent of schools. The fact that he is supposed to be impartial and unbiased, etc. does not negate the fact he is being chosen by a person with special interests, the superintendent.)

Of great significance in this bill is the elimination of procedures under the Family Court Act for those between the ages of 5 and 21 to provide education for the handicapped. The school district must pay what it would ordinarily spend for the education of a normal child, with the state picking up the excess cost up to certain ceilings that would be set by the Commissioner and the Division of the Budget. This excess is to be borne by the county. In the case of the City of New York, by the city and the state on a 50 - 50 basis.

Maintenance expenses in residential schools are now included in the reim-

bursement factor. This negates the Court of Appeals decision in the Levy Case where such maintenance must be paid by the parent. This is in accordance with 94-142, the Federal Act for Education of all Handicapped. Maintenance expenses is defined as a dollar amount charged for room and board and allocable debt service for the living unit and such reasonable medical expenses incurred by a handicapped child when actually in attendance at a residential school. The dollar amount shall be approved by the Commissioner of Education and Director to the Division of the Budget. In the opinion of the ARC, this ceiling violates Federal Law and regulations as well as Supreme Court decisions (Mills vs. Bd. of Ed.).

Transportation, which has been a touchy subject all along, is being reimbursed as heretofore, but up to a distance of 50 miles. It is aided at 90 percent.

Under the grievance procedure, an aggrieved parent can request an impartial hearing on a local district level and then can appeal to the Commissioner of Education and finally may appeal to the Supreme Court under an Article 78 proceeding. The section also insures that the child will receive an education during the pending of any appeal proceeding. The Family Court Act is retained for the physically handicapped and for those children under 5.

There are still defects in this bill which we hope will be corrected later. In order to conform with the Federal Act, there must be mandatory education by 1978 or 1980 for children under 5. We are also not very sure whether Committees for the Handicapped having only one parent on them will be acceptable to the Federal government.

On the whole, however, this is a far advance on what we have had until now.

Combined with Chapter 92, the lottery law, this provides a system of delivery of services with a wide range of possibilities including residential schools and some additional funding out of the lottery law.

Money follows the child

In the field of education, through a ruling of the Office of Education of HEW, a start is being made on the principle of money following the child.

More than \$8 million can now go to local school districts to help educate 18,000 handicapped children who have transferred from state operated and supported schools for the handicapped, HEW's Office of Education recently announced.

Each year, the state agencies receive about \$96 million for state operated and state supported schools for handicapped children under Title I of the Elementary and Secondary Education Act as amended (P.L. 93-380). The state institution schools count the number of children in average

daily attendance and receive money based on this number. In the past, if a child moved to a local education agency, the money originally allocated to the state institution for the child stayed there.

Under regulations printed, if a school district can provide an education appropriate to a transferred child's needs, state agencies may make funds available for that child. In the past, local school districts have been reluctant to accept children they could not count in average daily attendance and for whom they could not receive assistance. But now, if the local education agency can provide an appropriate education, it is possible for the money to follow the child and not remain with the institution.

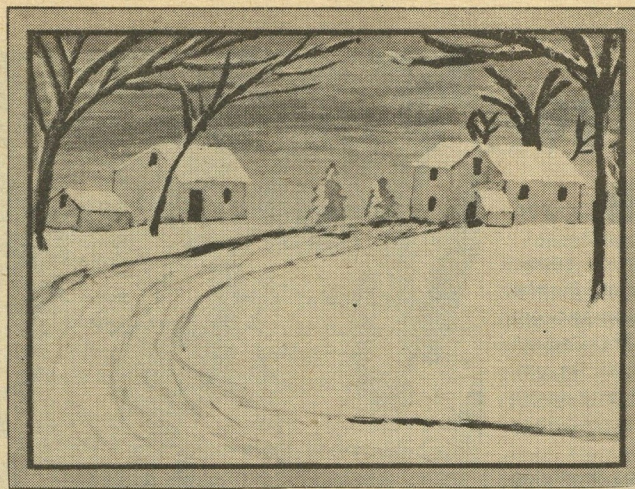
Property use restrictions

A bill introduced by Assemblyman Passannante (D.-N.Y.) (A 10110A) provides, in effect, that you cannot do anything with real property located in New York City for the handicapped and any others, for that matter, without giving notice to the local community board. They can then raise hell, even though the Commissioners don't have to pay any attention to them. This is just another

method of trying to impede facilities for the handicapped.

It stems from the community fear of drug rehabilitation centers which spills over into the mentally retarded.

If we need another indication of a separation of mental retardation from the rest of this nightmarish collection of laws, this is it. We have expressed our opinion to the Governor that he should not sign this restrictive bill.



409-6



408-6



407-6

1976 ARC holiday cards available now

Once again, chapters of the NYSARC will have the opportunity to do some fund raising and spread the word about the skill of the mentally retarded through the Association's annual holiday card sale. 1976 marks the fifth successive year chapters of the Association have the opportunity to offer cards designed by mentally retarded artists.

As in the past, the top designs will be on display at the Metropolitan Museum of Art during the holiday season.

This year's top three designers were **Roberto Hotchkiss** of Rome Developmental Center, who will receive a \$100 U.S. Savings Bond, **Bruce Gedney** of the Westchester County Chapter, who will receive a \$50 U.S. Savings Bond and **Albert Armino** of the West Seneca Developmental center, who will receive a \$25 U.S. Savings Bond.

We hope every chapter of the Association will have a local sale to make the cards available to its members and the public. For those who do not have the opportunity to purchase the cards through their local chapters, we are reproducing the three winners and an order blank.

Please support local chapters of the Association through the purchase of cards. 50 per cent of the purchase price will stay in the local chapters. Take advantage of greeting your friends during the holiday season with a design by one of our many talented retarded artists.

TO: NEW YORK STATE
ASSOCIATION FOR
RETARDED CHILDREN
175 Fifth Ave.
New York, New York 10010

Please send me the following cards
by mentally retarded artists:

No. Boxes	Style, Price & Message	Amt. Enclosed
.....	407-6: 25 Cards at \$4.00 May Every Joy and Blessing Be Yours at Christmas Time and Throughout the New Year.
.....	408-6: 25 Cards at \$4.00 Greeting You With Warm Good Wishes for Christmas and the New Year.
.....	409-6: 25 Cards at \$4.00 Season's Greetings With Peace, Health and Happiness Throughout the New Year.

TOTAL Enclosed:

Your Name

Address

Abuse charges increase

A two and one-half year study report made to the Commissioner of Mental Hygiene shows that patient abuse charges brought by the New York State Department of Mental Hygiene against its employees have increased tenfold as a result of changes in State disciplinary procedures.

The study showed the 594 cases involving patient abuse were brought by facility directors during the 30-month period since July 1973, when the new procedure went into effect. Only 61 cases were recorded during the two years previous to the change.

Slightly more than half the patient abuse cases reported involved physical assault upon the clients, according to the study. The remainder included sleeping on the job, abandonment of work station, failure to provide adequate client supervision, or sexual abuse.

The study showed that 115 employees were dismissed and this accounted for 33 percent of the requested terminations.

The DMH also showed definite reluctance by arbitrators to impose dismissal penalties in cases which reach arbitration. Only 18 percent of these cases resulted in firing, 24 percent in acquittal.

The study also showed that over a two and one-half out of every hundred clients is likely to be a victim of abuse resulting in initiation of disciplinary action against an employee. Incidents at developmental centers are four times those in psychiatric centers.

The report also noted the Department has unsuccessfully proposed legal services to be provided for the client who is victimized during the disciplinary proceedings and arbitration.

In a letter to Dr. Kolb (who had sent a copy of the report to Joseph Weingold), Weingold writes that the heart of the trouble lies in Article 33 of the contract with CSEA.

He also suggests the regulations provide that the residents or patients be represented by counsel. If unable to hire counsel, then the Department of Mental Hygiene, just as it pays for arbitration at \$250 a day, could well pay for counsel too, even if it means legislative action.

"I am disturbed by the fact that the directors of the institutions do not have power in the end to decide whether or not a worker should or should not remain in the facility," writes Weingold.

"The whole situation, it seems," Weingold continues, "is tainted with the proposition the rights of the employee are paramount to the rights of the patient or resident. Until this is resolved in some way, we will have, what I consider to be, an unhealthy and, certainly, a shocking situation with regard to the mistreatment, physical or otherwise, of patients and residents."

In sum, he concludes the state is not protecting the rights of the mentally disabled as it should and the report clearly indicates this.

Toni Parisi appointed

In listing in the last issue of OCV the appointments made by the Governor to various Boards of Visitors, we omitted the important name of Toni Parisi to the Board of Visitors of West Seneca Developmental Center.

Toni is the Chairman of the Institutions Committee of the State Association. Our apologies to you, Toni. The omission was inadvertent.



Left to right, Pat Collins, Dorothy Vine, Program Chairman, and Dr. June Christmas.

Community League honors Dr. Peg Giannini

The keynote speaker at the Community League Luncheon on April 10th was Dr. Margaret Giannini head of the Mental Retardation Institute, New York Medical College Valhalla, N.Y. Her work has earned her the respect of her colleagues and parents of the retarded. She was honored by the Community League at its annual luncheon in recognition of her work.

Pat Collins, art editor, WCBS-TV, served as Mistress of Ceremonies.

Another good friend of the retarded, Dr. June Jackson Christmas, Commissioner of the New York City's Department of Mental Health and Mental Retardation Services, also addressed the gathering of families and friends of the retarded.

Scholarship winners named

At the meeting of the Scholarship and Awards Committee of the New York State ARC held April 30, 1976, two new recipients were selected for both the Joseph T. Weingold and James F. Reville Scholarships.

The Weingold Scholarships, which are given to sophomore students studying for degrees to become teachers of special classes were awarded to **Clare Stritt** and **Kimberly Costanza**. Clare Stritt is a student at Mt. St. Mary College in Newburgh, New York, a school that has produced several winners in the past. Kimberly Costanza is the first student from the Dominican College of Blauvelt, New York to be named a scholarship winner.

The Reville winners are given to individuals working toward a degree in a field related to mental retardation and can be used at any time during the college career. The winners of the Reville Scholarships for 1976 are **Susan Melrose**, who will be entering school in the fall and **Teresa Hynes**, who will also be attending Mt. St. Mary. Teresa has long been active in the YOUTH group of the New York State ARC in Suffolk County.

The Association is delighted to have such outstanding young people as part of their program.

The program, under the able direction of Dorothy Vine, of Community League, included entertainment by residents of the Developmental Center. Their singing showed the many hours of work by the dedicated staff of Wassaic.

Bernice Feinberg, president of the Community League, presented a check to Richard Merges, Director of Wassaic, to provide a laboratory at the school in memory of the late Dr. Irving P. Aaron, in honor of his many years of service to the residents of Wassaic.

8th grade visits Westchester ARC

About 100 eighth graders from Blind Brook School in Port Chester toured the White Plains facility as part of their study of the book **Of Mice and Men**. It was the youngest group ever to visit the workshop, and the students were impressed by the general industry and the level of achievement of the clients. In the discussion which followed, most of the students said the visit had opened their eyes to the problems of the retarded and to their capabilities when given an opportunity to work.

The visit was the result of a phone call by teacher Peter Tarshis, who wanted a film about mental retardation to show to his class. Following the visit, Mr. Tarshis wrote: "I cannot thank you enough for the program you set up for us at Blind Brook High School. You can imagine the trepidation of a group of junior high school students over the prospect of visiting a workshop for exceptional people. Any fears or misunderstandings we might have harbored were certainly allayed. The warmth and humanity with which you at WARC opened your lives to us made a highly positive impression. Junior High being perhaps the most confusing and least sensitive stage in human development, the great impact of your program must have been obvious to you during the question and answer period. We left your facility with much, much more than a greater understanding and appreciation of Lennie Small (a character in the book) we left with a greater understanding and appreciation of ourselves and all humans."

State Board action

Forty-seven of the Association's 58 chapters and the State YOUTH organization were represented at the meeting of the State Board held in New York City on May 1. As is the Board's practice, reports were received from all of the Association's standing committees, the budget for the coming year was adopted, reports were received from our special projects, SOAR and Link-Up, and the usual business of the Association was also carried on.

Joseph T. Weingold, executive director, made special note of the new booklet, "Advocate's Guide to New York State Education Laws for the Mentally Retarded and other Developmental Disabilities," and he expressed special thanks to George Heymann of SOAR for his effort in compiling the book.

A number of the actions of the Board centered around properties for chapters. An action by the Executive Committee to assist St. Lawrence County Chapter with the acquisition of property was approved, Suffolk County was authorized to sell its Riverhead property, Chautauqua asked for authorization to form a holding company, Columbia County was given permission to enter into a long term lease of property and Niagara County was permitted to sell its Sunshine School in Lockport, New York.

An annual budget in the amount of \$290,650 was approved by the Board. The good news with the adoption of the budget was that the annual assessment rate of the chapters was decreased to 2 3/4 percent.

During the course of the meeting, the winners of our annual scholarships were announced (covered elsewhere in OCV), and it was also agreed by the Board that we could accept advertising in the state newspaper, Our Children's Voice (also covered elsewhere in this issue). The Board will meet again during the State Convention in October.

Court rules for group home

"It is our opinion that a group home for mentally retarded children constitutes a family for the purposes of a zoning ordinance." With these words, an appellate court in New York State upheld a Supreme Court decision that the Working Organization for Retarded Children (WORC) has a legal right to locate a family group home in a neighborhood zoned for single family homes in Queens.

The original suit was filed by the Little Neck Community Association, representing residents of the neighborhood. The Association expressed sympathy for the proposed group home residents but felt the home should be located in a residential zone rather than one restricted to single family homes.

The court rejected this argument, as well as those citing previous court decisions barring student groups living in zoned areas. The decision stated that the proposed group home "will neither provide accommodations for transients nor introduce a life style which is repugnant to traditional family values." The court added that changing houseparents on a rotating basis would not effect the home's status.

WORC plans to have the home, which will house eight youngsters, in operation within three months. The organization plans to make every effort to involve community representatives in planning and implementing activities for the residents of the home.

The group home, the court said, "will provide retarded children with a stable environment in a setting in which they will have a real opportunity to develop to their full potential."

Heymann answers L.I. Press

In a letter to the Editor of the Long Island Press, George Heymann, Associate Attorney of SOAR, took issue with the statement, "Under new state education regulations, the parents of handicapped children have expanded 'due process' procedures which allow them to challenge the appropriateness of the placement of their children."

Mr. Heymann stated that the amendments to the Commissioner's regulations, although a major step forward, do not come up to the criteria established by Federal legislation. The issue of burden of proof has not been dealt with. "Until it is clearly stated in the regulations that the burden of proof will ultimately lie with the agency making the placement, parents must continue to challenge school administrators on unequal footing."

Mr. Heymann challenges the impartiality of a hearing officer appointed by the chief school officer. "I find it difficult," he writes, "to see how an impartial hearing can be conducted when the individual making the placement objected to, can also preside at the hearing. In order to promote fairness to all the parties involved, an impartial hearing officer must be appointed for all hearings and agreeable to both sides."

"It is incumbent, concluded Mr. Heymann, that the State Education Department and the local school districts assist the parents in securing a sound education for their handicapped children and not to give them false hopes with 'due process' safeguards that fall far short of their goals."

HUD turns down ARC

The application of the New York State Association for Retarded Children for approximately \$1 million in Housing and Urban Development funds to supplement the \$480,000 grant to construct 10 hostels in the Mid-Hudson Region has been turned down categorically and without explanation by Housing and Urban Development.

In commenting on this, Mr. George Hirsch, President of the Association said, "It is absolutely inconceivable that the administration can talk about deinstitutionalization out of one side of its mouth, and turn us down for a mortgage loan from the other side of its mouth."

Efforts to get a meeting with Carla Hills Director of HUD, have been fruitless.

It is interesting to note, however, that HUD did approve application of the Pinellas Association for Retarded Children in St. Petersburg, Fla. for a 30-unit residential facility, and the Broward Association for Retarded Citizens, Ft. Lauderdale, Fla. for a \$325,000 loan for 36 units.

All the funds in New York State went to agencies that were going to build housing for the aged and so-called handicapped, whoever they may be.

The Association is now pursuing, with the Department of Mental Hygiene, the possibility that the Department of Mental Hygiene will build the 10 hostels in the Mid-Hudson area out of the \$6½ million appropriated for community residences for the Willowbrook Class and that these hostels will then be turned over to the ARC's in the various counties to operate.

One year later

"Wasted dollars - wasted lives"

A recent article in the Times-Union of Albany studied attitudes and conditions in the Department of Mental Hygiene as a follow up to the series it printed beginning May 4, 1975 on the Department of Mental Hygiene, called "Wasted Dollars-Wasted Lives."

The reaction of what has happened under Dr. Kolb's administration in the past year are varied and some of them quite contradictory.

QUESTIONS AND REACTIONS

DMH does not know — and is not attempting to find out — which of its facilities are well run and which are not ... there is little, if any, scrutiny of departmental spending once the budget is passed, and department officials admit to virtually no internal audit capacity. "Although information is the basis of evaluation and decision-making, yet systems for collecting and distributing data on programs and costs have been poorly managed according to Nelson M. Weinstock, DMH's new information specialist.

Weinstock told directors of DMH facilities at a Glens Falls conference in the Spring that information is not in a meaningful format; that retrieval is expensive and time consuming, collection is costly, and error prone." Because of these shortcomings, the systems have little effect on patient care. Promises were made that this will improve.

"The Department's billion-dollar budget is prepared each year with highly suspect spending projections and other data."

FISCAL INFORMATION LACKING

DMH directors at the Glens Falls conference complained that none of the

budget information they compiled this last fiscal year made its way into the final document.

Rochester Psychiatric Center Director, Dr. Russell Barton said the material they prepared, "has no relevance" to the budget they ultimately received.

Edward Skloot, Deputy Commissioner for Internal Management, acknowledged that the budgeting process was "haphazard, it was inefficient" because of the changing demands in the fiscal crisis. He promised, however, that this would change.

"DMH chooses to exercise virtually no control over its 72 hospitals and training schools."

The establishment of the regional offices in the past two years has robbed directors of some of their authority and caused confusion, according to some directors. "It's a system of triangular accountability," describes Dr. Yoosuf Haveliwala, director of Harlem Valley Psychiatric Center in Dutchess County. Dr. Kolb says the directors of the institutions see the regional director as cutting off their access to the commissioner and eroding their authority.

"It (DMH) has no control over its 63,000 employees."

Dr. Hagop Mashikian, director of Suffolk Developmental Center in L.I., claimed that administrators can't do their jobs because the Civil Service System forces them to hire incompetent employees.

Directors have complained in the past that they can't fire employees guilty of patient abuse because of the hearing procedures, which are stacked against them. In 1975, Dr. Kolb decided to allow patient advocates to appear at these hearings.

provide 75 percent instead of 50 percent of the cost of community mental health expenditures."

This, as we all know, has not happened. Such a bill never got out of Committee. Further, it was not part of the Governor's legislative program.

"...give the Commissioner of Mental Hygiene flexibility to reorder the existing array of state institutions."

This has been done and this means that the Commissioner of Mental Hygiene may not transfer the residents from the State schools to the psychiatric centers without regard to the psychological effects, the effects on the public or on the parents.

"...legal impediments to the improvement of institutional care of patients must be removed. Patients in Mental Hygiene facilities must be safeguarded from abuse."

An article in this issue of OCV shows that the cases of patient abuse have increased ten-fold in the last few years.

In addition, the Governor went into some detail on the investigation of alleged illegal activities by nursing home operators. Nevertheless, the Department continues to make contracts with proprietary homes of various kinds for services to the mentally retarded.

If anyone wishes a copy of this document called, "State of the Health Message — Special Message to the Legislature" it may be obtained from the Honorable Mario Cuomo, Secretary of State, 162 Washington Avenue, Albany, N.Y.

WEINGOLD CRITICAL OF EFFORTS

Joseph Weingold, Executive Director of the New York State Association for Retarded Children was critical of the Department of Mental Hygiene's statewide efforts to deinstitutionalize children, claiming that many of the residents have been moved into family care homes without proper back-up services. He says that the residents are not being moved out of the facilities "in any significant degree because the bureaucracy is so entrenched it is impossible to do it expeditiously."

The Department, according to Mr. Weingold, does not provide "front" money needed by organizations to develop programs and patient residences in the community. Kolb said such money is necessary and is being provided principally for Willowbrook residents.

Dr. Mashikian, the Suffolk director, was highly critical of the fact that many who like to enter the system are not getting any care because there has been no admission of anybody for a number of years.

The Harlem Valley director doesn't think "the department as a whole has done any major shifts in its operation or policy." Nevertheless, he believes the "system" will change.

LETTER QUOTED

The Willowbrook Decree has had a tremendous influence on the operations of the department, but now, more than a year after the Decree was signed, let us quote from a letter from Ann Nehrbauser of Hastings-on-Hudson. She writes,

"Dear Mr. Wingold, I could not resist writing these few lines along with the registration (to the convention) to comment that the first meeting I attended on the 'Willowbrook Decree — Where are we Now' was on June 20, 1975. Now, just a year later, June 26th, and after having attended at least four subsequent meetings all on the same subject, I must say that at least it's a popular title. Other than that I would answer, 'still up the creek'. The bureaucracy has grown, good intentions have been voiced, people have been shuffled and paper compliances have been made, and I imagine what you're thinking is 'What else is new?' Sincerely"

It is the contention of the Association that nothing radically will change in the delivery and development of services for the mentally retarded in this State unless a separate Office is created and it is divorced from the Department of Mental Hygiene and its myriad problems, other than mental retardation.

Supplement to

SOAR Guide

The pace of change in our education laws and regulations makes written documents obsolete in a very short time. It became necessary, with the advent of new regulations for education of the handicapped, for SOAR to issue a supplement to "Advocates Guide to New York State Education Laws for the Mentally Retarded and other Developmental Disabilities". It now includes the specific instructions for committees on the Handicapped. If you wish to receive a copy of this supplement, write to S.O.A.R., System of Advocacy for the Mentally Retarded, 175 Fifth Avenue, N.Y., N.Y. 10010, Room 1308.

Medical Review Board criticized

On May 19, 1976, Governor Hugh L. Carey issued an Executive Order creating a special board to investigate suspicious deaths in State Mental Hygiene institutions.

The Order establishes the Mental Hygiene Review Board, with powers to investigate the causes of unusual deaths, examine the deceased, and inspect the facility where the death occurred. The Board would report to Dr. Kevin M. Cahill, the special assistant to the Governor on Health Affairs.

The Board also may investigate and report on the adequacy and quality of medical care provided to the mentally disabled by the Mental Hygiene Department and its facilities. He directed that all reports of unusual deaths, or deaths from other than natural causes, be reported to the Board.

Senator James H. Donovan, (R-Chadwicks) criticized Governor Carey's Review Board as a "board of coroners with no consumer representation whatever."

Fed. regs. bar MR bias

Proposed regulations implementing section 504 of the Rehabilitation Act amendments of 1973 (PL93-112) affecting mentally handicapped persons were promulgated in the Federal Register May 17 and refined July 16. Section 504 establishes a government-wide policy against discrimination in federally-assisted programs and activities on the basis of handicap (including mental handicaps).

The legislation states, "no otherwise qualified handicapped individuals in the United States shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."

Of particular interest to us is Section 84.34 (Free Education) which states "A recipient to which this sub-part applies shall provide a free education to each qualified handicapped person who resides in the recipient's jurisdiction, regardless of the nature of severity of the person's handicap."

Of even greater significance is the statement, "If the program is residential, the provision of free education also includes the provision of non-medical care, room and board, and transportation."

In the opinion of a spokesman for the Association, this negates the Court of Appeals Decision in the Levy Case which required the parent to contribute for maintenance in a residential school. Although the proposed regulations require residential or day care programs and/or activities for institutionalized mental patients to provide suitable educational services, no provision is made for adequate and appropriate psychiatric care or safe inhuman living conditions in mental institutions.

This, however, is covered under the Developmental Disabilities Services Act.

Representative Edward Koch (D-N.Y.) May 19th introduced related legislation (HR 13900), which establishes hearing procedures for handicapped individuals discriminated against on the basis of disability by a federal department and/or agency.

Donovan said, "Rather than open the Department of Mental Hygiene to true independent investigations of institutional deaths, the governor has chosen to let members of the world's greatest mutual protection society investigate other members of the same society."

"Under the Governor's plan, it is the physician director of the institution who will be asking five other physicians to investigate deaths at his institution. Thus, the department would decide which deaths the board would investigate."

Donovan, the Chairman of the Senate Committee on Mental Hygiene and Addiction Control, added, "When a person chokes to death on peanut butter, the Governor's board, like the coroner, can determine that he choked to death on peanut butter."

What the relatives of the dead patients want to know is how the person got to have so much peanut butter that he choked on it, or, when he died of a broken skull, how he wound up at the bottom of the stairs,

It is my personal belief that the great majority of consumers would rather have a single policeman investigate how a skeleton wound up on the grounds of Pilgrim Psychiatric Center than have an investigation by all the pathologists in the state," he said.

Last year, the governor vetoed Donovan's bill creating a review board of two physicians, an attorney and another person.

The same governor who, in vetoing the review board bill last year, said the board would have a 'staggeringly broad mandate', now proposes to have his five-man board report on the quality of care in more than 50 institutions. That should speak for itself.

A penny saved; a penny earned

To help meet the legislative cut in the Department of Mental Hygiene's budget by \$1.5 million this year (and its express intention to make a similar cut in 1977), the Department of Mental Hygiene has increased its rent for employee housing and the rates charged for meals at Department facilities, as of June 3rd.

The increases were imposed by the Division of the Budget in response to a legislative mandate to bring these charges into line with "fair market value". A second increase in rent fees will be put into effect in June 1977.

The new monthly rent takes into account both the geographic location and condition of the housing. Adjustments are made for multi-unit apartments and other variations from the single room.

In addition, monthly meal rates have also been revised as of June 3d. Employees are now required to pay \$27 (we assume a month) for breakfast, \$37.50 for lunch, and \$43.50 for dinner, for a total of \$103 maximum monthly meal charge. Individual meal charges are 90 cents for breakfast, \$1.25 for lunch and \$1.45 for dinner.

We will not comment on whether this is high or low for the meals being served.

Mumps immunization required by bill

In a bill introduced by Senator Conklin (S.753), public health law is amended to include mumps in the immunization provisions. The bill passed in the last days of the Legislature and, at this writing, is on the Governor's desk.

ARC Director attacks Mental Hygiene Law

The State Mental Hygiene Law and the State's two-tiered system of delivery of mental health services came under strong attack at a meeting of the Association of Mental Health, Mental Retardation and Alcoholism Services Board held at the Ramada Inn in Niagara Falls in June.

Joseph T. Weingold, Executive Director, New York State Association for Retarded Children said, "We are committed to try to make whole lives for the 600,000 mentally retarded in this State but operate through an imperfect law, imperfectly administered, little understood and under-financed. Too frequently we see the services delivery subordinate to the bureaucracy, instead of the other way around." He criticized the state law for its failure to fix responsibility, for lumping very disparate disabilities into one, and for failing to put any financial obligation whatsoever on local government.

"It is a law that funds mental retardation services at less than almost any other kind of human service in the state."

Regional Dirs. have authority

In answer to a letter to Dr. Lawrence C. Kolb in which the Association protested transfers from Wassaic to Harlem Valley Psychiatric Center and questioned whether Mr. James Forde, Regional Director, had the final say, this was Commissioner Kolb's reply:

"We are attempting to provide the maximum authority to our Regional Directors to make all decision relating to the operations of the Departmental facilities within the geographic area of their responsibilities. The Regional Director reports directly to the First Deputy Commissioner who is the line authority for the relay of services to our clients and patients for the State at large. The Regional Directors' decisions are subject to review and modification at any time on the request of groups relating to or in employment by the Department. While the occasions have been few, there have been modifications, and even reversals, of decisions taken by individual Regional Directors during the 16 months of my tenure."

Any questions now about the authority of the Deputy Commissioner, especially the Deputy Commissioner for Mental Retardation?

ARC opposes new 'division'

The Association's opposition to Senator James H. Donovan's bill to create within the Department of Mental Hygiene a Division of Mental Retardation and Developmental Disabilities kept this bill from coming to the floor of the Senate. A telegram to every member of the Senate Mental Hygiene and Addiction Control Committee, as well as to Senator Anderson, President Pro-tem, and Senator Marchi, Chairman of the Finance Committee, stated, "This is a cosmetic approach to a deep seated illness. There already is a Division of Mental Retardation in the Department. Changing its name and giving duties to the Deputy Commissioner that he already can get by administrative action will cure nothing. The avalanche of bills introduced by Senator Donovan and others to amend the Mental Hygiene Law clearly results from inadequacy of the Department's dealings with mental retardation. We strongly urge support of separate Office for Developmental Disabilities and Mental Retardation (Conklin-Landes) rather than the present bill. Mental retardation can no longer live on half measures."

By this time it is also known that the Association's bill for a separate Office failed.

He charged that one-half of the state's mentally retarded are not receiving daily services.

"The problem has been complicated," said Mr. Weingold, by the 'state's obsession' with institutional care and an absolutely immoral imbalance of funds for institutions as compared to funds for the community."

He pointed out that, in State funding, a total of almost \$400 million goes to less than 3 percent of the mentally retarded in institutions and only \$27 million allocated to the more than 97 percent in the community.

This two-tiered system of services in institutions or in the community is "polarization of the worst kind" and may "Even be unconstitutional."

Mr. Weingold concluded that if all the programs that exist somewhere in the state were brought together in one place, and in depth, we would have a complete program for the retarded in New York State.

He concluded by suggesting a joint committee of the ARC and the Mental Health Boards to draw up a legislative program to benefit the retarded.

ARC Testifies

In preparation for the White House Conference in 1977, and a Statewide Conference in September 1976, the New York State Council on the Handicapped held a series of meetings, one of them in New York City, at which Joseph T. Weingold, Executive Director of the Association testified.

In his testimony, he urged that the past mistakes of White House Conferences not be repeated by lumping the mentally retarded with other handicapped whose needs may be quite different. He distinguished the mentally retarded from other handicapped by stating: "what other handicapped group has 3 percent of its population in institutions? What other group has most of the 97 percent of those in the community threatened with eventual institutionalization unless there are community services developed for them?"

The plea to the Council was that mental retardation be made a special topic of consideration. "It is a group funded and supported by less," said Mr. Weingold, "except in the institutions, than any handicapped group in the country."

He urged the examination of Federal failures, and our own New York State fiscal bureaucratic failures, to implement the hundreds of recommendations of other studies and reports cited in the testimony.

Half fare for retarded

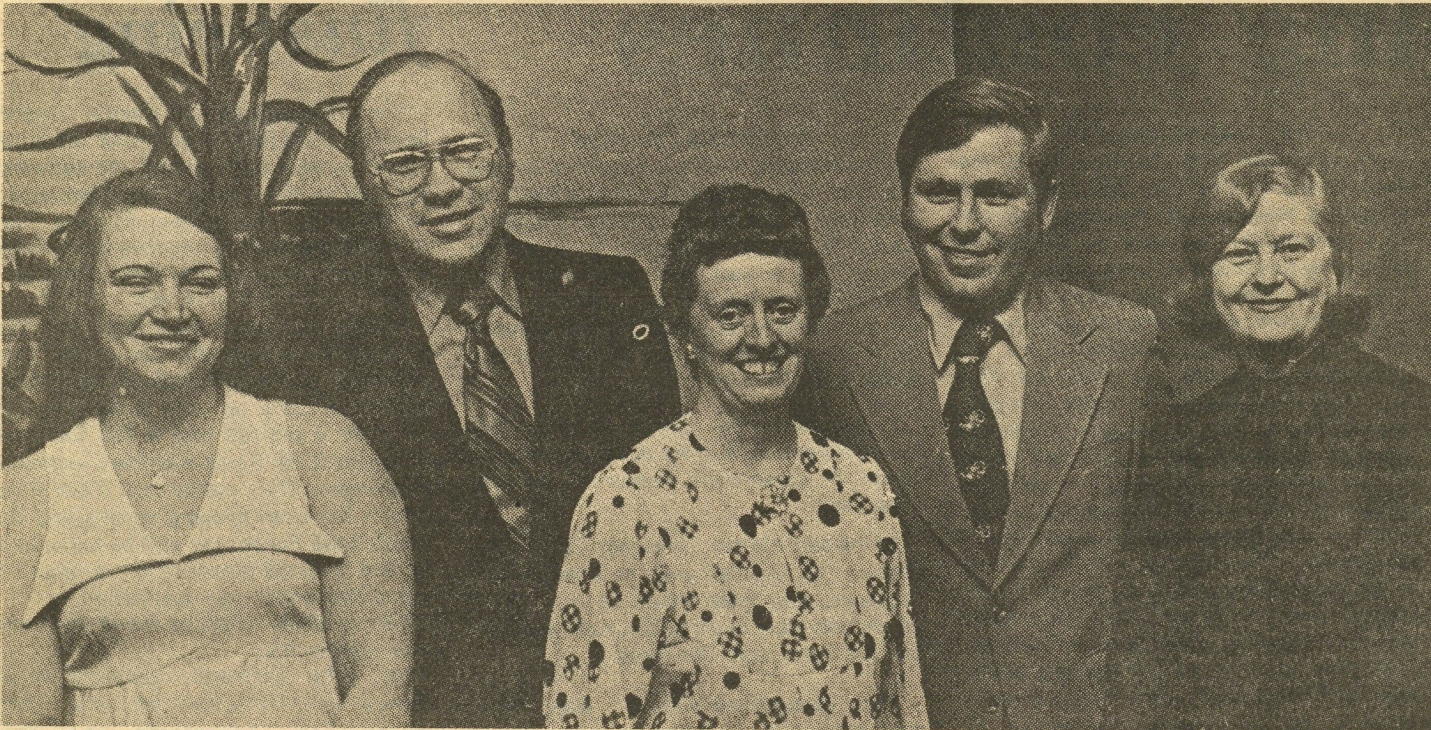
The Metropolitan Transportation Authority has broadened its criteria for the Half Fare Program to include those affected by mental retardation and brain damage. The definition for mental retardation in its upper limit is restricted to those with I.Q. of 69. The MTA is being urged by the Interagency Council for Mental Retardation in New York City to raise this limit to the acceptable figure of I.Q. 75 established by the state law by the Board of Education regulations.

Most of the mentally retarded persons in the City of New York will now have an opportunity to benefit from the program, although the hours when it is available are limited as follows: No half fare is permitted between the hours of 7 a.m. and 9 a.m., and 4:30 p.m. to 6:00 p.m. Further information may be obtained from the MTA, 1700 Broadway, N.Y., N.Y.

This program has been extended also to commuter services on the Long Island Railroad and The Harlem, Hudson and New Haven, for "off peak" hours.

CHAPTER NEWS

What our chapters are doing and saying for our children.



At Cortland County's Tenth Anniversary Dinner (l. to r.): Bonnie Barker, executive director, Cortland County Chapter; John Bertrand, assistant executive director of New York State ARC; Muriel Blett, president, Cortland County Chapter; George

Freebern, master of ceremonies and director of special education at BOCES, and Karin Burgess, past president of the local chapter and secretary of the New York State ARC.

WILLOWBROOK CHAPTER will begin our chapter news this issue. They welcome a new president, Genevieve Camen. The chapter's thanking persons who participated in a fund raising basketball game between the sports writers of the Staten Island Advance and the Education Department at Willowbrook which raised over \$1000 for educational materials. Congratulations to the chapter on its very successful May 15 luncheon, and thanks to them for hosting our Southeast Regional Conference ... **ONEIDA COUNTY CHAPTER** is distributing its new newsletter on a brightly colored sheet, the most cheerful we've seen among ARC newsletters. It tells of the chapter's move from their old school home to a new building at 14 Arnold Avenue in Utica, where they are gradually bringing all of their programs. We might add that the chapter hosted the annual convention of the ARC Executive Directors Association in March ... **CHAUTAUQUA COUNTY CHAPTER** writing excitedly about two trips. The first was a trip taken by a number of their clients to Disneyworld and all of the wonderful responses which were received from the clients who attended. The other was from the visit to Jamestown, by King Carl Gustaf of Sweden. The king visited Jamestown, and while he was there many of the flags that were waved during his stay were made by our ARC center.

Many persons in the Swedish press and the king himself commented later that Jamestown provided the warmest welcome he received in the United States. It must have been the ARC flags that did it ... **SUFFOLK COUNTY CHAPTER** accepted, with thanks, a contribution of \$1250 from the Society of Goodwill to Retarded Children, a gift to the chapter from the ninth annual dinner dance by the society.

Their new Bohemia facility going up right on schedule, and everyone hoping that the chapter will be able to begin programs there early in 1977 ... **NEW YORK CITY CHAPTER**'s annual dinner was held the evening of May 15. The Humanitarian Award was presented to former attorney general Ramsey Clark. The chapter's newsletter, the ARC Chronicle, coming out in fabulous new form put out by the chapter's very own workshop on a

Monolith printing press donated by the William Randolph Hearst Foundation ...

SCHENECTADY COUNTY CHAPTER making big plans for their summer day camp, expansion of their Boy Scout program and an interesting program from their long range planning committee, headed "Where we are as of now." ...

SARATOGA COUNTY CHAPTER, working hard to get themselves all certified, has opened the first workshop in the county. It opened officially in their new downtown facility on Monday, May 3. We certainly are looking forward to continued growth in this area. ... The following interesting item came from **ERIE COUNTY CHAPTER**. A fund-raising basketball game, which pitted the staff of the Erie County ARC and the disc jockeys from the Buffalo radio station, WYSL, was sponsored by the Grand Island Parent Association and the proceeds of \$1400 went into the development fund for an ARC children's group home. Not only was this event financially successful, but it was a fun-filled evening with many staff and volunteer groups participating. ARC staff members formed a cheerleading squad, a pep band and a coed team of 15 players.

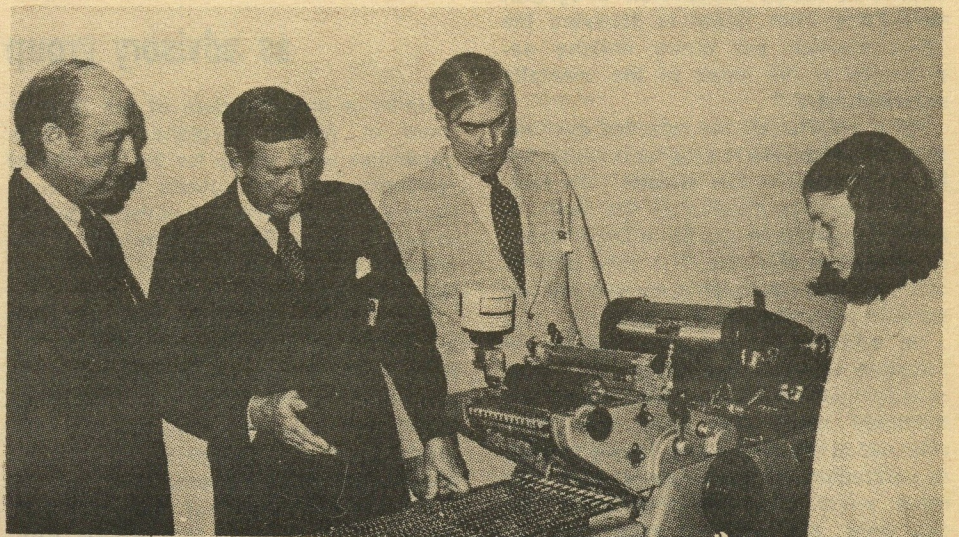
About 400 people attended the game. The star player was J. D. Hill of the Buffalo Bills football team. His prowess was so outstanding that it was quickly decided that he should alternate playing for both teams and switch sides each quarter. The proceeds formed the first major contribution to this development fund. The ARC staff is looking towards the end of this year for the opening of the first group home for children who are mentally retarded in Western New York ... **CORTLAND COUNTY CHAPTER** began a new adult program called, "Social Club" in June. Very pleased about adding this program to their regular recreational and summer camp programs. In early May this year the chapter celebrated its tenth anniversary with an anniversary dinner, bringing back John Bertrand from the state office who worked with the chapter on organizing, as their speaker. One change was noted, in that Sam Forcucci, a charter member and past president of the chapter is now the mayor of Cortland and graced the meeting with his presence. ...

We admire the spirit of **MADISON COUNTY CHAPTER** which in May held a get together for the staff and parents and friends of trainees of the agency for a "gripe night". Apparently it was a very worthwhile activity in give and take, and future meetings are planned. ... **NASSAU COUNTY**'s spectacular Rose Ball occurred on June 19. Deputy Majority Leader of the State Senate, William T. Conklin, was this year's Humanitarian Award winner, a well-deserved honor. The chapter's newsletter, *Nassau News*, continues to be one of the outstanding journalistic efforts in the state, so loaded with activities we cannot begin to select one over the others. Why not write and ask to get on their mailing list to pick up some ideas for what you can do? ... **CLINTON COUNTY CHAPTER**'s April newsletter received an interesting heading. It was suggested by the editor that, since winter had not yet left them and spring had not really set in, such an issue could be referred to as the "thaw" issue. Why not? ... **WELFARE LEAGUE LETCHWORTH VILLAGE CHAPTER** has moved its offices. Long located in New York City on 31st Street, the chapter has moved its offices to the grounds of Letchworth Village Developmental Center. ...

MONTGOMERY COUNTY CHAPTER's Liberty House really opened up at their open house on May 2. In addition to running the usual conducted tours, they had a bake sale, penny sale, food booth and craft fair. That's what you call stuffing a lot of activity into one day. ... Did you know, that **MONROE COUNTY CHAPTER** has 76 persons in hostels? They also had an interesting news article in a newsletter on how to avoid being fooled by "cosmetic quackery." **MONROE COUNTY CHAPTER** also has over 135 persons giving volunteer services on a regular basis. Maybe some of us should write them and find out how they do it. ... **BROOME COUNTY CHAPTER** newsletter had an interesting feature in their summer issue, discussing the fact that one of the projects being considered by the county rehabilitation council was a Bicentennial float dealing with the disabled and how they have been treated and perceived over the past 200 years. The article went on to discuss difficulties in researching the problem and in trying to portray what has happened. It was well summed up in the concluding paragraph which read, "What it all comes down to is that, in the next phase of our history, the retarded will need more support, encouragement, and better training than ever before, and the greatest thrust will have to come from the community. We will have to use the same kind of analysis we use as individuals and as a country in deciding what our retarded citizens will do in the future. ... **GREENE COUNTY CHAPTER** sends the following ambitious release: The Greene County Chapter has many activities planned. First on their list is to try and increase their total membership from less than 100 to at least 300 this year. They have enlisted the aid of a ladies auxillary to help them with their campaign this year and are sending out over three hundred special membership letters to people all over the county. The Greene County Hotel and Restaurant Liquor Dealer's Assoc. sponsored a dinner dance for the benefit of the Chapter on March 24. Over three hundred people attended this function. Fifty-fifty chances were sold, and there was anticipation that over 1000 tickets would be sold, thereby raising \$500 in funds for the chapter. Board Member Jack Griffin was in charge of the affair. A very special thanks to Jack for all his fine work!

The chapter also conducted their second annual Bike-a-thon on May 8. Last year, there were over 125 bikers that participated in the 25 mile route. This year,

Continued on Page 9



Inspecting New York City's New Printing Press (l. to r.): Mr. Robert Frehse, from the William Randolph Hearst Foundation; Mr. William F. May, Chairman of the Board of American Can Company, for whom the Bronx shop is named; James P. Murphy, A.H.R.C. President; and, trainee Christine Tobia, who ran the first words off this press.

Psychiatric Center dumping continues

Lest we think that the dumping of Wassaic residents from Wassaic Developmental Center into the Harlem Valley Psychiatric Center is unique, we are now confronted with the experience that the Department is dumping 16 adult residents out of Craig and West Seneca into the Elmira Psychiatric Center. In a special edition of the Chemung County ARC news, the entire story is related.

1975 BUDGET PLAN

Back in April 1975, a budget plan was submitted by Dr. Shah, Director of the Elmira Psychiatric Center for the funding of a developmental disabilities unit at that center. This proposed unit would have provided, primarily, "in-patient services" to mentally retarded people whom the state would "repatriate" from Newark and Craig Developmental Centers (state institutions for the mentally retarded). This plan was submitted with the input of only a few professionals and little or no input from parents or other consumers or the community.

Nevertheless, the 1975 plan fostered by the Elmira Psychiatric Center states, "The idea of establishing a small, short-term developmental disability unit at the Elmira Psychiatric Center may seem unusual to some. It is, however, consistent with regional and local planning (although not always explicitly) and addresses the needs of area consumers for comprehensive, accessible, least restrictive local services." This plan was submitted in April 1975 and reviewed by the Finger Lakes Regional Office.

Adult ed urged to include retarded

In a letter to Mr. Norman Kurland, Director, Study of Adult Education, in the State Education Department, Shirley J. Reynolds, United Cerebral Palsy Association of Western, New York and a member of the Education Committee of the New York State Association for Retarded Children protests the failure of the adult education program to include the mentally retarded.

"For example", she writes, "our own suburban school district offers a most extensive Adult Education program, everything from Ballet to Studying the Stock Market, yet offers nothing appropriate to the needs of the mentally retarded adult."

"It is unfortunate the retarded continue to be denied access to programs supported by public funds in this manner" she said.

She urges the director of the Study of Adult Education in the State Department of Education mandate that each district offering adult education programs include specific programs for this group.

"In addition to the large number of retarded adults residing in the community," writes Ms. Reynolds, "there are hundreds more that have now been returned to the community having resided in institutions for many years, and very often never had the opportunity for adequate educational programs as children. There are also thousands of other retarded adults currently residing in institutions not receiving any opportunities for participation in adult education

ARC AND SHAH MEET

In September 1975, Shah spoke to the ARC Board of Directors and some ARC members. He promised the establishment of a community advisory committee to determine needs and explore alternatives.

A task force, including broad representation, was formed to explore the alternatives involved in planning for expanded community services for the mentally retarded. It made recommendations to Dr. Yudashkin, Regional Director. Planning for repatriation of 25 people was included in the ARC's tentative budget for 1977 and it seemed that a true spirit of cooperative planning was being developed. An alternative plan to the use of the Elmira Psychiatric Center as an in-patient unit to house the repatriated mentally retarded was never presented.

On July 1st, 1976, the last meeting of the task force, proposals were included for a network of community residences to provide home-like living for the people who will be repatriated from Newark and Craig.

IN-PATIENT UNIT ANNOUNCED

Suddenly, Dr. Shah announced that he was going to submit a request to fund a 16 bed in-patient transitional unit for people returning from Newark and Craig in the building ARC will be vacating — Building 1-C.

"The ARC maintains that the only rational route for repatriation to take is from the institution to the community," writes Michael Lewis Gordon, executive director of Chemung County Chapter. "There is no reason why deinstitutionalization must mean re-institutionalization when there is an alternative available."

programs. For example, the West Seneca Developmental Center does not have any adult education for its 1100 adults. BOCES offers extensive adult training programs for vocational as well as citizenship training, but again excludes the retarded."

To date we have seen no reply from Mr. Kurland on this matter.

Welfare League approved as advisory group

Under a memorandum of the Department of Mental Hygiene, No. 75-10, guidelines were set up for the transfer of residents from institutions to the community or elsewhere. One of the guidelines included an advisory committee of the parents' group that would be involved in the decision-making process.

Although this does not always work out as we hoped and has not stopped the transfers from developmental centers to psychiatric centers, we are happy to report from the Welfare League that the group is now to be considered the advisory group under that memorandum.

"This organization has been acting in this capacity prior to this official confirmation," writes Dorothy Gasman, President of the Welfare League, "much to the satisfaction of the Regional Office, according to Mr. Forde."

CAREY'S RESPONSE

This action by the Department of Mental Hygiene is being taken in spite of the June 23rd 1976 letter from Governor Hugh L. Carey to Joseph Weingold in which he states, "I am aware of your strong opposition to the location of treatment units for the mentally retarded and the mentally ill on the grounds of the grounds of the same state facility."

It remains the policy of this administration to aid in the development of a range of community resources for the retarded."

In the same letter, Governor Carey says that he "co-located" units as a temporary measure, that these would be considered on an individual basis by Dr. Kolb who will discuss them with Weingold.

Such discussions with Dr. Kolb never took place and the dumping continues, as in Elmira and probably elsewhere.

"We can only say," states Weingold, "that this demonstrates the highest degree of insensitivity to the wishes and desires of the parents and professionals we have ever seen in the Department of Mental Hygiene."

We urge all our readers to protest this to the Governor or we will end up as we were 100 years ago with "idiots" and "insane" put together in the same institutions with the results that we all know.

Budget cuts hurt NYC special ed

The efforts of the New York City School system to accommodate a rapidly increasing enrollment of handicapped pupils in special education programs have been significantly hampered by the fiscal crisis.

After a five-year growth period, in which the special education budget rose to \$241 million from \$110 million, funds for these programs, which enroll some of those students most in need of educational services, were abruptly cut by \$39 million.

The cutbacks came in the fact of a 51 percent increase in enrollment of handicapped students — from 27,865 in 1970 to 39,553 in 1975 — and the passage of new state and Federal regulations that will require more spending. In 1973, the State Education Commissioner, Ewald B. Nyquist, ordered the "immediate" and "appropriate" placement of all handicapped pupils requesting it.

Cuts of \$21 million more have been proposed for the coming school year — when an additional 8000 pupils were to be placed — while the system's Division of Special Education and Pupil Personnel Services absorbs the impact of the loss of 1,050 of its teachers, and a third of its paraprofessionals, who were dropped during the year.

Executive director of the division, Dr. Helen M. Fuelner said, because of the money troubles "technically we are in non-compliance with the law."

The adverse impact of the cuts, which have also forced a large staff turnover, is in evidence throughout the schools, because special education is a central rather than a district program.

"We had three teachers for 18 brain injured kids, now we have two teachers for 15 children, and we are no longer testing retarded children," said Joan M. Kenny, superintendent of District 10 in the Bronx.

Task force studies M.H. financing

The Task Force on Mental Hygiene Service Delivery, which will study the State's system of financing and delivering services to the mentally disabled, and to recommend programs to the next legislative session to improve the system's effectiveness, held its first meeting in Albany in June of this year.

Noting the very short time the Task Force has to operate, Dr. Kolb, Commissioner of Mental Hygiene, said if they could not come up with a document on time, he would tell that to the Governor.

Several Task Force members expressed pessimism. They stated that Task Force efforts have not brought results and that such a Task Force may well be taken as an excuse to avoid planning which would be mandated under new legislation.

Mr. John Bertrand, Assistant to the Executive Director of the State Association, represents the State Association on this Task Force. At the meeting, he stated that he "hoped we have not been called to support a plan which is already made." Dr. Kolb told him there was no plan. "We will be sending you documents; they will not be final documents."

Dr. Bertram Pepper, Commissioner of Mental Hygiene for Rockland County, said that he hoped the effort would address the "serious inequities in funding" between state and local mental hygiene services.

Throughout the school system there has been an increasing tendency to place untrained teachers in special education positions.

The Division of Special Education and Pupil Personnel Services consists of nine bureaus, six of which concentrate on education for a particular handicap. They conduct 40 programs that serve 39,553 full time pupils and about 75,695 part-time pupils. Programs are conducted at 232 special school locations in 519 regular schools, and for 2,992 pupils on home instruction.

As programs and services are cut in the public schools, it is feared that any desired savings would be converted into only another type of expense, as parents, backed by new state legislation, seek private-school placement for their children. About 1500 children attended private schools last year at public expense.

And since 1973, two new regulations requiring more spending have come into force. For one, school districts have been ordered to establish committees for the handicapped. Also, parents have been assured the right of "due process" appeals in the diagnosis of a child as handicapped, which means the creation of a new office.

Last year, Commissioner Nyquist said he would not allow school authorities to cut back on programs because of the budget crisis.

Although the Commissioner has broad powers to enforce city compliance with the state mandate, including the withholding of essential state aid, it is not certain how far he intends to go in the current crisis.

So far this year, his only measure has been to allow school districts to legally increase class size for handicapped pupils. This was done by permitting a 20 percent class-size increase in cases where attendance is normally 80 percent of those registered.

SMITHTOWN

By T. N. Hyneshan

What started out as "We've Only Just Begun," has now turned into "We're only glad it's over." We are, of course, talking about our major fund raiser; the Big Fashion Show which was held on Friday, May twenty-first at St. Patrick's Church in Smithtown. To those seated in the audience, it appeared smooth and organized. But those of us who worked so hard during the last four months still can't believe it. Just to give you an idea of what went on...

Picking a theme should be a relatively minor detail; not so for the Smithtown Juniors. After many discussions, arguments and out and out battles, "We've Only Just Begun" was agreed upon. It seemed appropriate because, as each of our goals are reached, we realize there is so much more we can do and we set new goals and begin again.

Then, there was the all important decision of program and place-setting colors; which again caused many discussions, arguments and out and out battles. We finally decided on bright green programs, yellow table cloths and green paper goods to match. The outcome of course, was quite different. We had orange programs, white table cloths and green and gold paper goods. But beggars can't be choosy.

Again after much discussion, many arguments, and out and out battles, we picked a program cover. But, of course, something had to go wrong. An auxiliary member's mother thought our lovely program cover was an advertisement and it was thrown away. However, this would not set us back too long; we simply rushed through our stages of discussion, arguments, and battles and picked another.

The next heavy decision on the agenda was centerpieces. We discussed everything from shellacked bagel arrangements to bowls of goldfish. One of the most original ideas was a styrofoam ball with a stick in it and a sign reading "We've Only Just Begun." When our discussions, arguments and battles were over we agreed upon cloth flowers.

Our decorations committee had a great idea of making a tree filled with large, colorful paper flowers to dress up the stage. A few days before the show they finished the tree and left it outdoors. Naturally it had to rain, and our beautiful flowers looked like used tissues. We remade the tree Friday afternoon at set-up, and it really added a nice touch to the stage.

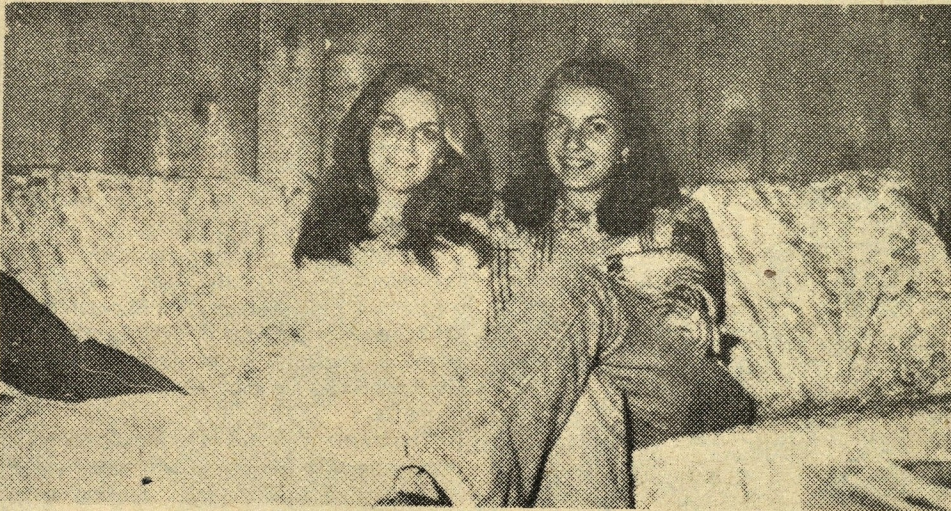
Our very enthusiastic publicity chairperson placed several calls to Geraldo Rivera, and the Channel 7 News, and was quite dismayed when he never returned her calls. However, she was informed that he might show up, and she stood outside anxiously awaiting his arrival all night. He never came though (she probably gave him the wrong directions).

Very seriously now, we've got an endless list of people to thank, from our fantastic chairpersons, to local stores, and to our audience. And of course Suffolk Chapter A.H.R.C.; especially Adam Strickland and the Printing Department for printing our attractive tickets. Over one thousand dollars was made, and it will be used to support our summer programs, including fifteen camping trips.

BABYLON

Babylon Auxiliary's Fifth Annual Chinese Auction was a huge success, netting a profit of \$2,282.90. Three hundred and eighty-two persons were at the Lindenhurst Senior High School on May 7, where over 300 prizes were auctioned. The uniqueness of this event is that it is run by a coordinated effort of the Babylon Auxiliary members, each volunteering for a committee of their choice and taking it on from there. The auction is the latest in a round of fund-raising projects of the auxiliary since the beginning of the year.

YOUTH Group News



Co-chairpeople Cindy Udasin and Julie Simkowitz relax back stage after months of preparation and a successful show.

Fashion Show a hit



Highlighting the evening, Terri Hines and John McClave model the latest in bridal attire for bride and groom.

Starting with a New Year's Eve Party, chairman Barbara Innes turned in a profit of over \$500. In February, Pat Parker and Emily Kandler hosted a small card party which netted \$188.87. On March 27, a "Luncheon is Served" was held at the Constantino Brumidi Sons of Italy Lodge in Deer Park and Fay Cantone, chairman, reported a \$322.25 profit. In April, \$37 was raised by having an Anticraft demonstration, and Easter candy sales totaled \$326. On June 11, a dance recital sponsored by the Betty Hyer School of Dance at the Robert Moses Junior High School, North Babylon was held for their benefit. The auxiliary held their Installation Dinner on June 11 at the Knights of Columbus Hall in Lindenhurst. The annual family picnic was held on the Phelps

Teen power was fully demonstrated when the Smithtown Junior Auxiliary members presented their Seventh Annual Spring Fashion show recently at St. Patrick's Church in Smithtown.

Chairpeople Cindy Udasin and Julie Simkowitz were assisted by other Junior Auxiliary members, and many of their retarded friends from A.H.R.C. workshops and special education classes.

Thirty-five members of the auxiliary and four of their mothers modeled a variety of clothing from sporting wear to full bridal attire for an audience of over five hundred guests.

The highlight of the show, themed "We've Only Just Begun," and moderated by Mrs. Udasin, was the bridal gown modeled by the lovely Terry Hines.

It was an evening of social and financial success; demonstrating the concern of many young people, as well as netting over one thousand dollars which will be used for summer camping trips, picnics and outings.

Lane Club House grounds on June 27, starting at 10 a.m.

ROCKLAND COUNTY CARNIVAL AIDS THE RETARDED

About 100 enthusiastic young teenagers from the Spring Valley and Pearl River areas of Rockland County held a carnival to raise money for the local ARC.

The event, held at the Fleetwood School in Spring Valley, featured a Chinese auction, a flea market, a baking contest and sale, handcraft items, a car wash and merchandise donated by area businesses. Games and refreshments were available. Betsey Cohen, president of the newly formed YOUTH group, was assisted by her officers, and Adult Adviser Mrs. Mary Miller.

Chapter News

Continued from Page 7

they hoped to increase that figure to at least 400 participants. A local automobile dealer has donated a 10 speed bike, which will be among the many prizes that will be in a special drawing for all who finish the entire route. There will be a celebration party at the end of the route, which will be at the chapter's Work Activity Center in Catskill. Proceeds of the event will be used to help carry on the chapter's work, including that of sending at least twenty children to the Special Olympics. ...

SULLIVAN COUNTY CHAPTER wraps up the news for this time with words that they have challenged themselves to a membership of 800 for 1976-77. If there is any chapter that will make it, we think Sullivan is the one. The chapter is operating a very successful bingo once a week, and incidentally, had five artists who were cited by the state association for outstanding entries in the Christmas Card Design Contest. Keep up the good work Sullivan.

Auxiliary aids AHRC

The Blue Feather Auxiliary, an organization of friends of the mentally retarded, has embarked on a new project for the New York City Chapter, AHRC.

The volunteers are financing the new program for 2-5 year olds to be housed in one of the public schools (P.S. 312) to the tune of \$41,000 annually. The acceptance of these children is remarkably demonstrated by the attitude of the so-called normal children in the school, two of whom submitted poems commenting on the presence of these severely retarded in their community:

PLEASE STAY

There are lots of people in the world that are handicapped in some way, And all these handicapped children are welcome to stay. Our school is wonderful,

And we understand how these people feel.

We understand now what is wrong with them.

What I am trying to say in a very nice way is,

Please stay.

Because we want you to be part of us in every day.

(Maria Rodino, 4th Grade, P.S. 312)

KIDS ARE ALL THE SAME

The handicapped kids on our first floor

Make us feel prouder more and more.

Don't make fun or call them a name, Because Kid's are all the same.

These kinds have feelings like yourself.

Make them feel proud of what they can do.

Because kids are the same, like me and you.

If they don't act or think exactly like you,

Help them in things that they can do.

If they seem different, they are not to blame,

Because you should know kids are all the SAME.

(Jay Silverman, 5th Grade, P.S. 312)

Youth advisor bids farewell

Mary Jo Iovino, President of the Suffolk County Chapter and Youth Advisor to the State Y.O.U.T.H., in a column in ARC Light, (the newspaper of the Suffolk County Chapter) bade farewell to her State Y.O.U.T.H. activities.

She wrote, "They (youth) will still have my personal support, as well as my efforts to continue to garner additional understanding and acceptance by others in our state. In addition, I shall always cherish the relationship it was my privilege to enjoy with so many dedicated, committed young people throughout our state working for and with the mentally retarded. They never failed to teach me something new and valuable in dealing with the retarded. They always raised my level of awareness and understanding."

Suzanne B. Crane, formerly a member of State Y.O.U.T.H. and now a teacher at the Al SIGL Day Care Center for retarded children in Rochester is the new Y.O.U.T.H. Advisor.

Social Welfare

OK not needed

Section 436 of the Laws of 1976 amends this section to state that the Board of Social Welfare shall not be required to give its approval before the filling of such a certificate of incorporation.

Further, it requires that any such certificate shall have on it the approval of the Commissioner of Mental Hygiene. At least this is one step forward in our struggle to get hostels off the ground (see the June issue of OCV article by Hy Clurfield). This Act takes effect September 1, 1976.



Shirley Stone (standing), Anne Palermo, Bonnie Joy Alperin, Karen Mihich (seated).

Four share M.R.I. award

For the first time in the Mental Retardation Institute's volunteer recognition program, four joint recipients have been named as Volunteer of the Month for August by the Institute, a department of New York Medical College at Valhalla. Anne Palermo, Bonnie Alperin, Karen Mihich and Shirley Stone, all residents of the Margaret Chapman Home, 5 Bradhurst Avenue in Hawthorne, were named by Dr. Margaret Giannini, Director of the Institute, as joint award winners.

"These dedicated young ladies have all worked so effectively and conscientiously that we could not single out one as being more deserving than the others," Dr.

Giannini announced. The August honorees, some of whom are former clients of the Institute's comprehensive services program, donate their efforts full time, five days each week.

Dr. Giannini pointed out that Anne, Bonnie, Karen and Shirley have done effective volunteer aide service in every division of the Institute — Out-Patient Clinic, In-Patient Hospital, the School, and in many administrative assignments.

"They are very reliable and productive, and they are all devoted to the thousands of developmentally disabled patients whom we serve," Dr. Giannini said.

Volunteers interested in contributing services to the Institute are invited to call (914) 347-5300.

Orrin Judd dies

On July 8th, the Honorable Orrin G. Judd, United States District Court Judge for the Eastern District of New York and judge in the Willowbrook Case, died suddenly of a heart attack while attending a conference in the mid-west.

We can only quote here the statement by Governor Hugh L. Carey on his death.

"The death of the Honorable Orrin G. Judd, United States District Court Judge for the Eastern District of New York, comes as a tragic blow to all those involved in the effort to provide quality services and dignified living conditions for the mentally retarded.

As the presiding judge in the Willowbrook Class Action proceeding throughout its four-year history, Judge Judd stood as a symbol of the most humane and worthy aspects of our judicial system. His commitment to these most vulnerable of our fellow citizens was constantly evident. He gave of his own time and energy to visit personally Willowbrook Developmental Center to listen and talk to its residents, their parents and friends, and to guide all parties in the case toward a common goal.

After supervising the negotiations which resulted in the historic Willowbrook Consent Judgment, Judge Judd continued his involvement by scheduling numerous informal meetings to personally monitor progress toward implementing the steps and standards contained in that document. During each of these meetings, the court room in which Judge Judd presided was transformed into an open forum where ideas and concerns could be freely expressed in an atmosphere of equality and respect.

His quiet patience, great ability as a mediator and unfailing willingness to give of himself will be sorely missed by all those who came before his court, confident that the decisions he rendered would embody the spirit of the law and the utmost equity.

Abzug introduces bill to aid retarded

AMENDS SSI

In response to a statement of the problem to every member of the New York State Delegation to the Congress, only Representative Bella Abzug took the time and trouble not only to answer, but to do something about a drastic situation.

Under SSI, administered by Social Security, the payments made by the parents for tuition for a mentally retarded person in a private school are considered income to the retarded person and, if over a certain amount, make that person ineligible for SSI. The consequence of this is that person loses the benefits, not only of SSI, but the supplemental amount allowed by the State of New York Department of Social Services which brings fees up to as high as \$685 a month to such private schools.

The reason for this is that SSI regards not only earned, but also unearned income as part of the assets of the retarded person in the determination of eligibility. These fees are declared to be unearned income. No matter what protests were lodged with Social Security agency, there was little understanding or response. Representative Abzug, however, came to the rescue with a bill (H.R. 12836) which amends Title XVI of the Social Security Act to provide that payments of tuition, fees or other training costs by any person for a mentally retarded adult individual attending a school for the retarded shall not be treated as income of such individual and determining his or her eligibility for supplemental security income benefits.

This is even better than the determination of Social Security that such payments shall not be considered any more than one-third of the income from SSI.

Our thanks, Bella.

Assn. Chapters in Regional Meetings

Members of the Association had an opportunity to participate in Regional Meetings in their respective areas throughout the state and obtain some insights into recent developments in education as well, in the four regional meetings recently completed.

Coordinated by the regional vice-president in each of the Association's four regions, groups were invited to participate at Schenectady on April 10, in Cortland on June 5, in Batavia on June 19 and at Willowbrook Developmental Center on June 26.

The format of the 1976 regional meetings was generally the same, with members of the Education Committee putting on a presentation at each meeting, and a separate time being set aside for a meeting of presidents and treasurers of local chapters with Association President George G. Hirsch and Southeast Regional Vice-President Evald Gasstrom, who was wearing his hat as chairman of the Association's Budget and Finance Committee.

The first session, scheduled in Schenectady, included only the chapters in the southern portion of our Northeast Region. At this meeting, Marilyn Wessells, of our Education Committee, put together a program of three sessions with the topics, "Helping the Parent Become an Advocate," Helping the Parent Evaluate Their Child's Program," Mainstreaming — What it Means for Your Child." A group of about 65 representing all of the Chapters who were contacted to be present for the meeting were in attendance, and this particular group was the only region to have every chapter represented at the meeting of presidents and treasurers.

The June 5 meeting in Cortland was arranged by Regional Vice-President Al Cappuccilli. Assisting Al by handling local arrangements was State Secretary Karin Burgess. The meeting was held at the Cortland-Madison Boces Building in Cortland where, under the leadership of Education Committee member Tom Scholl, a small but very enthusiastic group spent a good deal of time dealing with individual education problems. While the format for the meeting followed the same basic outline as in Schenectady, the fact that the group was small permitted the afternoon session to get into a real one-on-one question and answer session and the enthusiastic attendees kept Mr. Scholl a full hour beyond the scheduled ending time as they dealt with individual problems in the area of education.

The Association wants to give special thanks to Mr. George Freebern, who arranged for the building to be available for the Association for the day and also arranged for a magnificent luncheon which was prepared by members of the special classes in Cortland-Madison Boces. The young people who assisted in the kitchen that day were paid for their efforts, and certainly their efforts were very much appreciated as the excellent meal which was set out lured even the most careful eater back for seconds. While we were disappointed that only eight of the 17 chapters in the region were represented, those present were very enthusiastic about the content of the meeting.

Western Region Vice-President Winifred Rabbit worked with the members of the staff of the Genesee County Chapter and the members of the Education Committee in the Western Region to repeat the fine performance at the Western Regional Meeting, which was held in Genesee County Chapter's new center in Batavia on June 19. Marge Cervone of Genesee County Chapter and Shirley Reynolds from West Seneca Developmental Chapter headed up

the educational portion of this program and were aided by Board member Martha Speeth from Allegheny County who appeared on one panel and Ted Kurtz from the Education Department and Ellen Owen, a member of West Seneca Chapter. We were delighted to be joined in this meeting by a group of approximately 20 students from the State University College at Geneseo.

The long round of meetings finally drew to a close with the Southeast Regional Meeting at Willowbrook Developmental Center. Mr. Sherman P. McCoy, deputy director of administration, handled the arrangements for our space at the facility and Mrs. Genevieve Camen, new president of Willowbrook Chapter, handled the internal affairs. At this meeting, the educational portion was covered by Education Committee chairman Betty Pendler and her Southeast area committee member Georgia Sullivan. George Heymann of the SOAR staff also participated, not only on the educational panel, but with some discussion about what is taking place in the institutional realm, especially with regard to the transfers at Wassaic Developmental Center. The speakers at this meeting were augmented by the presence of our Executive Director, Joseph T. Weingold.

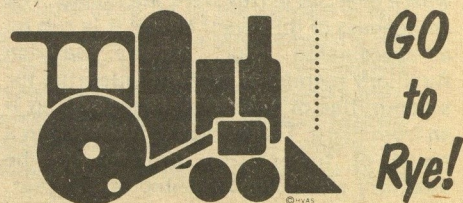
Probably the two people to whom greatest thanks for the success of the meetings should be given were State President George G. Hirsch and Southeast Regional Vice-President Evald Gasstrom who traveled to each of the meetings to review with chapter presidents and treasurers and activities of the chapters and some of the financial pitfalls they should try to avoid. These meetings were very enthusiastically received and it was the feeling of presidents and treasurers present that we should continue such meetings as a part of our regional meetings and hopefully also as a feature at the state convention. In response to this, another meeting for presidents and treasurers has been scheduled in the State Convention program.

There will be one further regional meeting for 1976. It will be in the North Country to take in those chapters in the Northeast Region for whom coming to Schenectady would have presented a distance problem. This meeting will be arranged by the Regional Vice-President Eleanor Pattison and Dr. James Johnson, the North Country representative of our Education Committee, and will probably be held sometime in September.

Budget restores MH funds

We are happy to report that the Supplemental Budget passed by the Legislature the last day of their session this year restored \$4,004,000 of the \$7½ million lopped off by the Legislature to extend the benefits of the Willowbrook Consent Decree to other institutions. Our efforts, up to now, to find out where this money is going and what positions are going to be added have not elicited a response.

In addition, the Department of Mental Hygiene also received \$40,000 more in local assistance, and \$4,567,000 in capital construction to bring the institutions up to ICF-MR standards.



Education Committee

FROM BETTY PENDLER, CHAIRMAN, EDUCATION COMMITTEE

Attention: Newsletter Editors ... Do you give some space to the subject of education in your newsletter? Just a short paragraph or two is enough to create the awareness the Education Committee is striving so hard to achieve!

Some items: from Blanche Clark, Education Committee, Schenectady Chapter — The formation of the Education Committee is one of the most exciting things to happen to the ARC. Our function as the Education Committee for this chapter is to keep the parents informed so they can make intelligent decisions concerning their child's educational placement. This newsletter is going to serve as the prime communicator between the committee and the Association. With this in mind, we offer the following information:

1. Parents have the right to act as advocates for theirs and other children. We must teach our parents to work with administrators cooperatively and not to be intimidated by them. They may be the professionals, but we are the experts.

2. We plan to teach parents how to evaluate programs run in our school district. We can no longer allow our children to be either fully or partially excluded because the school district says that they do not benefit from established programs.

3. Parents must begin to create and to organize community awareness. It is your duty as a parent to become more knowledgeable. We list the members in our chapter who are on the education committee and we will keep you informed of our progress and hope you will keep us informed of your needs.

From Oragne County Chapter: Anne Klingner, Editor — "The Torch" never fails to include a column called the Education Scene — listing publications of interest, items such as "Parents as advocates — Many school districts now have parents on Advisory Committees on the Handicapped and on the Actual Committee for the handicapped. "The Lamplighter-Suffolk County Chapter — with a special column called "Special Ed". So you editors of newsletters, get the education liaison of your chapter to give you information to fill a column in each issue — help spread awareness in the field of education.

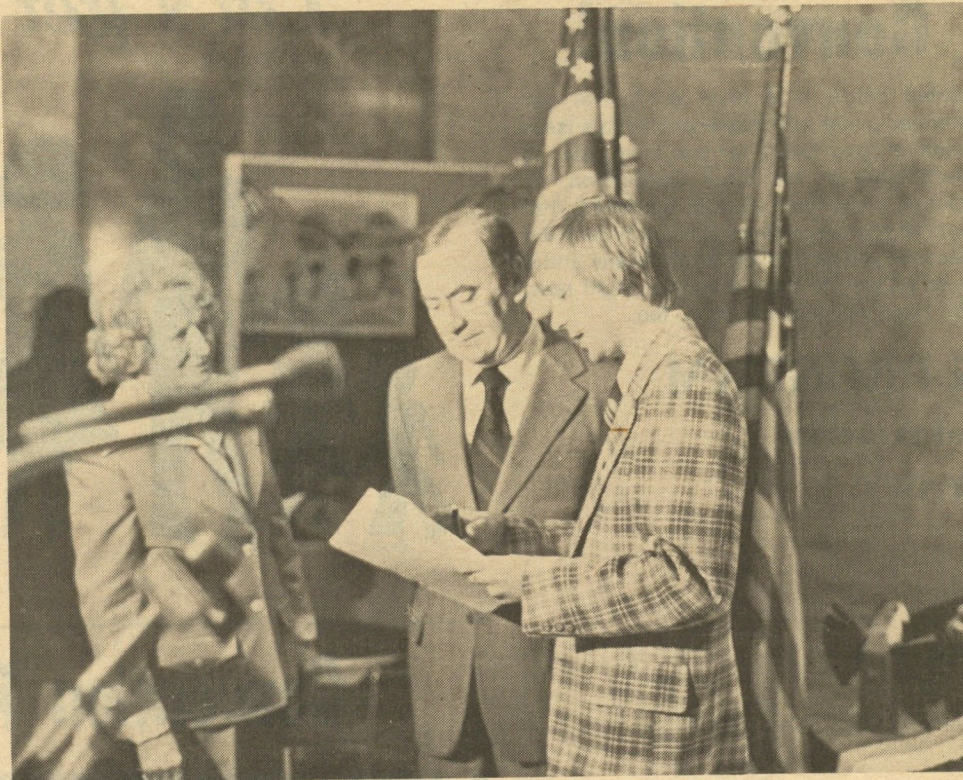
Regional Meetings — The Education Committee imparted information at all regional meetings — Northeast, Southeast, Central, and Western, where panels were held on the subjects of "Helping the Parent Become an Advocate"; "Helping the Parent Evaluate their Child's Program"; "Mainstreaming — What it Means for your Child"; "Due Process" — and stirred up lots of discussion.

The Education Committee attended the public meetings of the New York State Council of Handicapped, to make sure our input got "in" to the Governor; our Education Committee member Shirley Reynolds, representing the state schools, was busy attending meetings of County Mental Health Advisory Board, workshops on Early Education Programs by State Early Childhood Consortium, BOCES Advisory Council meetings; your chairperson, Betty Pender, addressed the Rockland County Chapter of Council for Exceptional Children on "The Parent Speaks."

We urge all chapters to send representatives to various professional groups to increase awareness and parent power by putting in PARENT INPUT wherever and whenever you can.

NEXT ISSUE: Sample letters to write to your school district asking for more services, tips on "How To Evaluate a Program", "How To Set Up Advisory Councils", and lots more.

Art & awards



Mrs. Dorothy Boehring (left), Governor Hugh L. Carey (center), and Eugene Maillard prepare for ceremony.

NYS Special Olympics

Governor Hugh L. Carey was an honored guest and speaker at the New York State Special Olympics Bicentennial Arts Showcase and Awards Ceremony held recently at the Legislative Office Building. The Governor, shown here prior to the opening of the ceremony with Mrs. Dorothy Buehring, Associate in the NYS Office of Education and Eugene Maillard, State Coordinator for the "Very Special Arts Festivals" dedicated to the creativity of the handicapped youngster.

Mrs. Dorothy Buehring, pioneer in these programs, announced the following winners:

First Place: Rebecca DelRio — St. Agatha's Home "Jones Beach Painting"

First Place: John Stepien — Westchester A.R.C. "Empire State Building Painting"

Second Place: Thomas Kline — Carondelet School — Latham — "Painting"

Second Place: John Pachulski — Con-

netquot — Central School — Bohemia "Sculpture"

Third Place: Martin Wasserman — Westchester A.R.C. "Bird Motif"

Third Place: Kathy Jeffords — Thomas Jefferson School — Utica — "Paintings"

Honorable mention was given to the following schools: New York State A.R.C. — Jefferson County; South Cortright Central School — South Cortright, New York; Allentown Elementary School in the Allegany BOCES; Buffalo School No. 42; and the Monroe BOCES No. 1 at the Foreman Center.

Governor Hugh L. Carey and Lt. Governor Mary Ann Krupsak were honored guests and speakers.

Mrs. Buehring also invited the following Co-sponsors of the event to present awards including: Senator William T. Conklin (R-Brooklyn); Senator James H. Donovan (R-Chadwick); Assemblyman Anthony G. DiFalco (D-New York) and Assemblyman Ronald H. Tills (R-Erie).

Outstanding employees honored by DMH & ARC

The Association was privileged to join with the Department of Mental Hygiene in honoring those persons selected as "Outstanding Employees" in each of the State's Developmental Centers, at a luncheon given by the Department, in Albany, on June 6. Each winner receives a certificate of appreciation from the Association and a check for \$100, and has a plate with their name on it, placed on a plaque in the Developmental Center.

Edward B. Licence, Chairman of the Scholarship and Awards Committee of the Association prefaced the award presentations with the remarks, "As parents of children in a Developmental Center, Mrs. Licence and I thank God every day for people like you."

John W. Bertrand, Assistant to the Executive Director, and Mrs. Shirley Licence, a member of the Scholarship and Awards Committee assisted in the

presentations. The Association was also represented by Northeast Regional Vice President Eleanor Pattison, State Board Member Tom Mingo and Matt Puleo, Executive Director of Schenectady Chapter.

The 1976 award winners were: Rodney Coleman, Bronx D.C.; Dorothy Decker, Broome D.C.; James Pilcher, Brooklyn D.C.; David Woolever, Craig D.C.; Judith Kearney, J.N. Adam D.C.; Roy Kelly, Letchworth Village; Dorothy Silvern, Manhattan D.C.; Reg McGill, Monroe D.C.; Leona Johnson, Newark D.C.; Roberta Hansen, O.D. Heck D.C.; Marie Marino, Queens D.C.; Warren Molo, Rome D.C.; Rae Schaefer, Suffolk D.C.; Dr. Wilbur Rose, Sunmount D.C.; Catherine Eckert, Syracuse D.C.; Gwendolyn Streeter, Wassaic D.C.; Raymond Boehm, West Seneca D.C.; Helen Keil, Willowbrook D.C.; and Paul Vogt, Wilton D.C.

Blatt named SU Dean

It is with great pleasure that we announce the appointment of our friend, Dr. Burton Blatt, of the Division of Special Education and Rehabilitation at Syracuse University, as Dean of Education at the University.

Dr. Blatt is known for his dedication to the education of the mentally retarded, his work in the public school system of New York City. He is the author of "Christmas in Purgatory," the famous photographic essay on institutions for the retarded. The book had a terrific impact on subsequent events leading to the Willowbrook lawsuit.

Dr. Blatt writes it would not be possible for him to diminish his interest in special education, especially in the field of mental retardation. Though he has received this prestigious appointment, we would not want to lose him.

In-Service Conf. features sight & hearing

The latest in-service training of teachers under a grant from the State Department of Education under P. L. 89-313 was held on Wednesday, Thursday and Friday, May 12th, 13th and 14th at the Fallsview Hotel.

The program consisted of training in techniques for visually or aurally impaired severely retarded children. It was under the direction again of Robert Sansone, executive director of our Suffolk County Chapter, assisted by John W. Bertrand, supervised by Jerry Weingold.

The first general session was an introduction to the Mid-Atlantic Deaf-Blind Program, data collection on behavioral techniques and rationale in behavior modification.

The evening social hour prepared participants to their group sessions the following day and communications and concept formation — discrimination and signing; discrimination training — prevocational training. The sessions were reversed and repeated with the final day taken up in conference reactions and comments.

More than 250, the maximum we were permitted to have participate under the grant, came to the hotel prepared for an interesting program which was certainly delivered.

A sample of the reaction to this is the following letter from Dorothy Buehring, Associate in Education of the Handicapped, who reacted to the program even before it took place.

"Dear Jerry: Thank you very much for forwarding a copy of the program for the In-Service of Teachers scheduled for May 12-14 at the Fallsview Hotel. As programs begin to be organized for severely handicapped and profoundly retarded children within the public schools in our State, there is a critical need for this kind of in-service training.

You and the members of the NYSARC, Inc. are to be commended for your effort to meet the needs of these classroom teachers and personnel and other disciplines who will be involved in these newer programs. I personally feel the need for this same type of in-service teacher training so I will try to schedule my field trip for that week so that I may be included in at least a part of this in-service session."

Hurry

to



the Convention!

Don't miss the Convention!

Why are you sitting reading this article? Why aren't you over at the table filling out a registration blank for the annual State Convention? Well, don't just sit here! Get registered!

There, now that we have taken care of that, we are looking forward to seeing you at the State Convention at the fabulous Ryetown Hilton in Westchester County.

Listed below is a brief outline of our planned event and elsewhere in this issue another opportunity for you to register to participate at the State Convention. Of course, if you have done as we asked, that part of your newspaper is already torn out because you have filled out the blank and it is on its way to the Convention right now. We hope you will be, soon, too.

CONVENTION PROGRAM

The Promise of America

THURSDAY, OCT. 7

4 p.m. - 9 p.m.
Registration \$5
8 p.m.
Meeting of the Board of Governors

FRIDAY, OCT. 8

10 a.m. - All Day
Registration
9 a.m. - 12 Noon
Board of Governors
Meeting Continues
12:30 p.m.
Luncheon — Open
1 p.m. - 4 p.m.
Tours
Westchester Co. Chapter Center
6 p.m.
Dinner — Open
8 p.m.
Convention Convenes.

BUSINESS SESSION

- A. Roll Call of Chapters
- B. Reports of President, Treasurer, Executive Director and Committee Chairmen
- C. Report of Board of Governors Meeting
- D. Appointment of Committees
 - 1. Resolutions
 - 2. Convention Site — 1978
 - 3. Others
- E. Election of Nominating Committee
- F. Election of State Officers and Governors
- G. Other business
- H. Good and Welfare

SATURDAY, OCT. 9

Breakfast — Open
9 a.m. - 5 p.m.
Registration
9 a.m. - 12:30 p.m.
Luncheon \$8
2:30 p.m. - 5:30 p.m.
Concurrent Workshops

- 1. Parent Aid Group
- 2. Education
- 3. Institutions
- 4. Guardianship

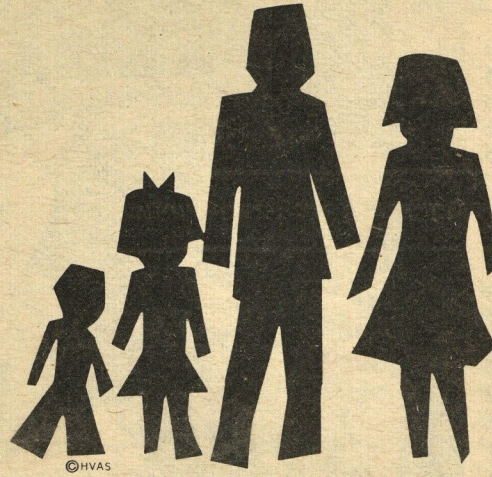
6:15 p.m. - 7:15 p.m.
Cocktail Hour
7:15 p.m.
Dinner \$12
10:30 p.m.
Entertainment & Dancing

SUNDAY, OCT. 10

8:30 a.m. - 10 a.m.
Breakfast — Open
10 a.m.
Meeting of Newly Elected Board
12:30 p.m.
Adjournment

REGISTER NOW

Let's get together



in Rye!

Convention Registration

TO: Westchester County A.R.C.

121 Westmoreland Ave.
White Plains, N.Y. 10606
Attn: Mary Kallet

Please accept my pre-registration for the following Convention events:

Registration	\$ 5
Luncheon — Saturday, Oct. 9	\$ 8
Dinner — Saturday, Oct. 9	\$12
Total	\$25

Name: _____

Address: _____

Phone: _____

TO: Rye Town Hilton Inn

699 Westchester Ave.
Port Chester, N.Y. 10573

Gentlemen:

Please reserve the following accommodations for me for the Convention of the New York State A.R.C. Oct. 1976

Single at \$39 per day _____

Double/Twin at \$47 per day _____

Date of Arrival _____ Departure _____

Name: _____

Address: _____

Our Children's Voice

Retarded Children Can Be Helped

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.
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