

# Our Children's Voice

Retarded Children Can Be Helped

Vol. XXXI No. 1

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

January, 1979

## State Convention

# Delegates demand parity for community services

## 100% community funding pressed

The 1978 Convention of the State Association in Rochester, New York, October 26 to the 29th, brought forth a record attendance and highlighted unanimous decision of the delegates and the Board of Governors to press for equality of treatment of the mentally retarded who have never been in institutions with the treatment accorded those who had been in institutions and deinstitutionalized.

### WORKSHOPS HIGHLIGHT NEED

The Workshops, all highlighting the need for quality services and staff training, clearly brought out the handicaps under which the Chapters and community agencies are operating in delivering services funded at only 50 percent by the State.

The battlecry was "parity", 100 percent funding for all in the community.

Workshops brought out that other states, such as Pennsylvania, Michigan and Illinois, were funding services in the community at 90 percent and California at this time at 100 percent, in spite of Proposition 13.

### PROGRAM FAR RANGING

The Legislative Program presented to the Convention covered a wide-range of social needs: repeal of discrimination against the mentally retarded in obtaining life insurance, elimination of parental liability for fees incurred before the 1977 law was enacted eliminating such fees, that Community Service Boards hold public hearings on their plans and education of the handicapped to be mandatory from age 3 to 21.

Considerable discussion developed in the Legal and Legislative Committee concerning admission practices to the Developmental Centers. A resolution was adopted to change this in accordance with the recommendation that there be an admissions Committee for each Developmental Center.

In addition to the election of Eleanor Pattison of Rensselaer County as President, the following were elected as Officers and Members of the Executive Committee: Hy Clurfeld, Senior Vice President and Vice President of the Southeast Region; Ellen Maroun, Vice President of the Northeast Region; Al Cappuccilli, Vice President of the Central Region; Shirley Reynolds, Vice President of the Western Region; Mrs. James Reville re-elected as Treasurer; Irving

Caminsky, Ph.D. re-elected as Assistant Treasurer; Vicki Friel re-elected as Secretary and Arthur Gasman, Robert Horn and Al Turk as members of the Executive Committee.

This Legislative Program was adopted by the Convention:

### A. STATE INSTITUTIONS AND SERVICES

1. Continued support of the bill (passed by the Senate) to clarify the provisions of Chapter 777 of the Laws of 1977 by explicitly stating that the abolition of the parental liability for fees in Mental Hygiene and Social Services Laws is retroactive in effect.
2. Provision that decisions on admission to developmental centers shall be made by a committee appointed by the Commissioner of Mental Retardation and Developmental Disabilities in each Center, to consist of: the director of the center, a representative of the Department of Social Services, a representative of a not-for-profit corporation providing services in the field of mental retardation, a representative of an agency providing advocacy but not other services in the same field and a "citizen advocate," that is, a member of the community interested in the same field but not representing any agency, and that a decision of such committee in favor of admission shall not be appealable but a contrary decision may be contested by an Article 78 proceeding.

### B. COMMUNITY MENTAL HEALTH SERVICES

1. Provision that funding of community services for the non-institutionalized mentally retarded be on a basis of parity with the funding of such services for those deinstitutionalized, 100 percent for all.
2. Provision that interest on any mortgage for the acquisition, construction or remodeling of a facility to serve the mentally retarded and interest on monies borrowed to fund services pending receipt of state funds be reimbursable expenses under contracts with mental health boards.
3. Provisions that community mental health boards or other appropriate agencies must hold public hearings on their proposed programs at least 30 days before submitting them to the Commissioner.
4. Provision that state funding of con-

struction or acquisition of facilities for the mentally retarded by voluntary agencies be on the basis of 2-3rds of the cost, instead of the present 1-3rd, or on parity with facilities for the deinstitutionalized, whichever is greater.

### C. EDUCATION

1. Provision that education of the handicapped be mandatory from ages 3 to 21.
  2. Provision that school districts be per-
- Continued on Page 13

## Mrs. Pattison is new ARC president



ELEANOR PATTISON

A long career of voluntary effort on behalf of mentally retarded persons reached its culmination on October 28th, when Mrs. Edward Pattison of Sand Lake was elected President of the New York State Association for Retarded Children.

Mrs. Pattison, known as Ellie, began as a volunteer with the Rensselaer County Chapter of the Association for Retarded Children (ARC) in 1959. As time went on, her involvement with the Association grew. "The more work you did, the more you would realize how much was still to be accomplished," she stated.

Ellie, wife of the former 29th District Congressman Ned Pattison, became a member of the Board of Directors of the Rensselaer County Chapter ARC, even-

tually serving as President for 3 years. For the last 3 years she has served as Northeast Regional Vice President of the State Association.

On the eve of her election, Mrs. Pattison recalled some of the growth and changes she has seen during her involvement with the Association for Retarded Children. When she first started as a volunteer with the agency, much of the organization's effort was directed toward providing classes for retarded children who had been excluded from attending public schools. The agency also operated a small adult training class, but much of the effort of the state in the field was directed toward large isolated institutions, such as Rome and Willowbrook.

During her years as President of the Chapter, the agency opened its first community residence, obtained a grant for a pre-school program, initiated plans for an expanded adult services program and began working with area school districts to provide a public education for all handicapped children of school age.

As State President of the Association for Retarded Children, Ellie Pattison will direct an organization that has, in its 28 year history, grown to 60 chapters with over 32,000 members and over \$37 million in annual budgets.

In addition to her activities with the Association for Retarded Children, Mrs. Pattison has served on the Rensselaer County Unified Services Executive Committee, as Co-Chairperson of the Unified Services Adult Mental Retardation Program Center, on the Board of Visitors of the Oswald D. Heck Developmental Center and on the Council on Citizen Participation and Advisory Committee on Recodification of the New York State Department of Mental Hygiene.



# LETTERS

## Letter of praise

Arthur L. Schwartz, Acting Director, Consolation & Education, Principal Associate in Psychiatry, Albert Einstein College of Medicine of Yeshiva University wrote a letter to Jerry Weingold regarding his interest in our Children's Voice.

This letter of praise is long overdue. I have been the recipient of "Our Children's Voice" for a number of years and continue to find it informative. Anyone who seeks vital information about what is happening in the field of mental retardation, whether it be related to legislation, service delivery or what have you, your most excellent publication is the answer.

Keep up the high level of the publication — it is an activity that is most needed and helpful.

Best wishes.

## CARC News editor comments on OCV

Eric Sandahl, Editor of the Connecticut ARC News, wrote to Jerry Weingold about his impressions of the new OCV.

Today I saw, for the first time in several months, a copy of *Our Children's Voice*.

As I have been moved to do many times over the past 27 years, I want to congratulate you again for the high level of creative and constructive activity being carried out by the New York ARC's chapters under your inspiring leadership and guidance. My only critical comment re OCV is that you should publish it more often.

To assure that I won't miss any future issues, I'm enclosing my subscription fee, which should be at least three times what you're charging non-members.

I'm still turning out *CARC News* as a labor of love. I'm not satisfied with the contents, but until I get a little help, there's not much I can do about it.

## Weingold Responds

In response to Mr. Sandahl's letter Jerry Weingold commented on his observations.

I cannot begin to tell you how pleased I was to get your November 9th letter.

You have been our fairest and severest critic through the years.

Since I have a few other duties to perform, my latest being Chairman of an Advisory Committee on the writing of a new MR and DD Law, we just cannot get OCV out more than three times a year, interestingly provocative as it is.

I am going to deposit your subscription check, because we never return a check from here, but I assure you within our capabilities, you should be getting every copy of CCV (incidentally, we are charging non-members \$1.00).

*CARC News* comes here regularly, and read it with interest and sometimes envy.

## Rights of disabled are civil rights

In a move of great significance, Senator John E. Flynn (Republican-Westchester) last year introduced S.10470 amending the Executive Law in relation to recognizing and declaring equality of opportunity and freedom from discrimination, **because of a disability**, to be a civil right.

Senator Flynn is the author of numerous bills against discrimination of the handicapped in housing, employment and many other areas.

This bill would pin it all down to give the agencies a leverage for action where these discriminations exist. This bill is heavily supported by Harold Unterberg, Director of the Office of Advocate for the Disabled and many others, but failed to clear the Senate Finance Committee (Marchi-Republican-Staten Island) Chairman.

## About a sister in Wassaic

Mrs. Dora G. Foley of Florida writes this poignant letter about her sister in Wassaic Developmental Center.

I read your magazine as usual. But this time it was very interesting and pathetic at the same time because I know there are a great many changes going on in Wassaic.

I have a dear sister in Wassaic Developmental Center in Wingdale. She's past 65 years and I saw her last year. I am 80 years old and fell and I am walking with a quad cane for 2 years so I have this cross to bear for her. I love her very dearly and I have no one else who cares as I do. I do have a sister-in-law who writes to her. I send her a couple of dollars monthly as I know she does some little work in O building in Wingdale. And when I visited with her last year I was told she folds paper bags and not to send her clothes as I did at one time because she has loads.

All I hope is that they keep her in O building. She is happy there but originally came from Wassaic Building C. And I hated it there. So all I hope is that she stays where she is.

According to the magazine, there are an awful lot of changes going on and she is not a young woman. Neither am I.

Thank you for your magazine. It has been gratifying to me in spite of the misery. I'm afraid my dear sister will be moved. I hope not. But I am not a privileged character and, for that matter, neither is she.

You will excuse my writing. I have arthritis very bad in my right hand. It's a struggle to be alone, a widow.

Thank you again and may all the children be taken care of.

## Thank you

Senator William T. Conklin writes to thank Jerry Weingold for the coverage on his retirement in the last issue of OCV.

I was pleased to read in your recent publication of "Our Children's Voice" your statement on my decision not to seek reelection this year.

I am glad that my friends in the Association for Retarded Children have been made aware of my decision and that I will always be supportive and involved with their goals and activities in the coming years.

Once again, thank you for the kind words.

With kindest personal regards.

## Apostolate name change

Brother Joseph Moloney, O.S.F., Executive Director of the former National Apostolate for the Mentally Retarded has announced the group has changed its name to the National Apostolate with Mentally Retarded Persons. The change was made during the Eighth Annual Conference of the National Organization.

"The addition of the word 'persons' is based on a wish to affirm the dignity and personhood of our brothers and sisters with whom God has invited us to share ministry. Our previous title fell short of expressing this human dignity."

The name change is consistent with the major goal of the organization: "To foster full participation of mentally retarded persons in the life of the Church." Barriers to this are most often unconscious.

Brother Moloney states, "We therefore urge your continued support in your own diocese toward overcoming the conscious and unconscious barriers which prevent mentally retarded persons and, indeed all handicapped individuals, from full participation in the life of the Church."

# Magna Carta for retarded

The declaration of the President's Committee on Mental Retardation is a Magna Carta for the mentally retarded, who have been too long submerged since their initial burst sponsored in 1963 under President Kennedy, under the overlay concern for other handicaps, most of whom are served well under many other provisions of Federal laws.

The President's Committee is to be commended for coming out, once and for all, that the mentally retarded are deserving of consideration as mentally retarded, not to be watered down by cries of, "what about other handicaps?"

The physically handicapped have been served for years and years through the Crippled Children's Act and many other provisions for the deaf, the blind, stroke victims, heart institutes, etc., etc. It is only the mentally retarded who, if not also afflicted by some of the other handicaps, that had to stand alone until 1963 and the

formation of the President's Committee.

We welcome this statement of the President's Committee. It confirms and reinforces our commitment to the mentally retarded, as the commitment of other organizations are to the handicaps they serve.

There must be an end to this watering down of services by saying "what about this or that" in consideration of what is happening to our children, young and adult.

Year after year we have seen services for them on a national level fused, altered and even eliminated to further this approach.

It must stop and we must take as our beacon and our battle-cry the statement of the President's Committee on Mental Retardation.

We congratulate them; we offer them our full support. The hopes of the retarded ride on this.

## MEMBERS, FRIENDS:

It must be obvious to all, at this point, that the State is funding services for the retarded in the community at a starvation rate — 50 percent.

But this starvation rate is limited only to those who have never been in institutions.

For those who have been in institutions and who are deinstitutionalized, the State pays 100 percent for community facilities.

This is an inequity to which the State Convention addressed itself, calling for **PARITY** for the funding of all community services.

The Governor, in a release dated October 31, 1978, recognized this but says he will do nothing for the present funding and

may take up to two years for future funding.

**WE ASK YOU TO WRITE TO YOUR STATE SENATOR AND ASSEMBLYMAN IMMEDIATELY, CALLING THIS SITUATION TO HIS OR HER ATTENTION, AND ASK THEM TO SUPPORT LEGISLATION THAT WOULD MAKE FUNDING BY THE STATE FOR ALL COMMUNITY SERVICES FOR THE RETARDED, WHATEVER THEIR SITUATION, 100 PERCENT. WE WOULD JUST BE BEGINNING TO CATCH UP TO CALIFORNIA.**

**PLEASE WRITE IMMEDIATELY.**

Joseph T. Weingold,  
Executive Director

# Appalachian funds for child development

In 1965, Congress passed the Appalachian Regional Development Act which created a variety of economic and human service programs for Appalachian areas. New York is one of 13 contiguous states that have counties located within the Appalachian region. Appalachian Child Development Program (ACDP), located within the Services Research and Demonstration Unit of the New York State Department of Social Services, is a human service program that develops, monitors, and evaluates various children's services programs in the Southern Tier region of the state. The fourteen counties that are eligible for Appalachian funding are: Allegany, Broome, Cattaraugus, Chautauqua, Chemung, Chenango, Cortland, Delaware, Schoharie, Schuyler, Steuben, Tioga, Tompkins, and Otsego.

## OBJECTIVE IS SERVICE

The major objective of the Appalachian Child Development Program is to initiate, in underserved areas of the region, needed services for children under the age of six and their families. The emphasis is on comprehensive child care and prevention of disease and disabilities. The goal of the program is to establish a network of children's services which will address the identified local needs of the 14 counties. The program has funded projects that provide such services as day care (including migrant child care); teenage parent programs; pre-natal and parent education; training of pediatric nurse practitioners; and detection and early intervention of mentally and physically handicapping conditions. The projects have been sponsored by agencies such as **Associations for Retarded Children**, County departments of health and social services, Boards of Cooperative Ed-

ucational Services (BOCES), child care agencies, and non-profit development councils.

ACDP projects can be funded for as many as three years and must show a plan for becoming self-sufficient by the end of the Appalachian funding cycle.

## ASSISTANCE FOR SPONSORS

Prospective sponsors of projects can receive assistance in the process of applying for Appalachian funds. Each spring, workshops to explain the funding process are held by staff from the Appalachian Child Development Program Department of State, and the Local Development Districts (regional planning bodies with offices in Salamanca, Corning, and Binghamton). ACDP staff critique the requests for funds and the Department of State and the Local Development Districts use these critiques in a ranking process. When final determinations have been made by the State, the selected projects are then submitted to the Appalachian Regional Commission in Washington and the Department of Health, Education, and Welfare, Region II, for review and funding approval.

Appalachian projects have been effective in improving the nutrition, health care, child care, and psychological well-being of pre-school children in the Southern Tier. For further information on the Appalachian Child Development Program, please contact:

Sharon L. Bailey, Director  
Appalachian Child  
Development Program  
New York State Department  
of Social Services  
40 North Pearl Street  
Albany, New York 12243  
(800) 342-3715 ext. 43121



# Recodification Advisors hold hearings

Under the terms of the recodification of the Mental Hygiene Law creating an Office of MR-DD in the Department of Mental Hygiene, a new MR-DD Services Act is to be presented to the Legislature of 1979.

To accomplish this purpose, Commissioner Coughlin has appointed an Advisory Committee on this recodification with Joseph T. Weingold, Executive Director of the State Association, as Chairman.

Three public hearings were scheduled by this Committee, the first on Thursday, October 26th in Rochester in connection with the State Convention, the second on November 28th in New York City and the third on December 6th in Syracuse.

The focus of the testimony in the first hearing was on how services are being delivered in the community and the apparatus of funding these services.

There was a consensus that this apparatus was inefficient and had not accomplished the purpose it was set out to do. The inefficiencies of operating through Community Service Boards with the funding going through the Counties and then being siphoned down to the agencies delivering services were condemned almost unanimously.

A great deal of the testimony dwelt on the inequity between the funding of services for the deinstitutionalized against that for persons who had never been institutionalized. Equalization of this funding was demanded by speaker after speaker.

These subjects were presented to the speakers for possible comment:

- 1) Is the present structure for support of community services for the mentally retarded and developmentally disabled adequate to do the job? Should there be changes? If so, what changes are indicated?
- 2) Present State funding mechanisms seem to favor deinstitutionalized mentally retarded and developmentally disabled clients rather than those clients who have never been institutionalized. Are changes warranted in this approach?
- 3) What should be the role of the Community Service Board? Should it be used for planning and supervising? Should it be used to transfer funds from the State to service agencies? What other purposes should it have?
- 4) Is the present organizational structure established by the State Legislature for the Department of Mental Hygiene an effective vehicle for the delivery of services to the mentally retarded and developmentally disabled?
- 5) What should be the goals and objectives of a new Office of Mental Retardation and Developmental Disabilities?
- 6) Should present admissions policies of OMR-DD be altered and revised; and if so, what are the changes needed in these admissions policies?
- 7) What is the role of the State - operated developmental centers? How do they fit into the broad plan for providing service at the community level?
- 8) What other areas of concern relative to the operation of the Office of Mental Retardation and Developmental Disabilities should be considered by the Recodification Committee?

## Advocacy for retarded: Mandated responsibility of President's Committee on Mental Retardation Statement of mission reaffirmed

In a resounding statement of principles, the President's Committee on Mental Retardation reaffirmed its mandated responsibility to the President and the American people to make advocacy, for those who are mentally retarded, the focus of its recommendations for national action.

The full text of the Role and Mission of the President's Committee on Mental Retardation follows:

### PCMR POSITION PAPER THE ROLE AND MISSION OF THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

The President's Committee on Mental Retardation, at its quarterly meeting on August 11-12, 1978, reaffirmed its role and mission under the Executive Order 11280 establishing and sustaining its existence.

**THE COMMITTEE UNANIMOUSLY DECLARED THAT IT HAS A MANDATED RESPONSIBILITY TO THE PRESIDENT AND TO THE AMERICAN PEOPLE TO MAKE ADVOCACY FOR THOSE WHO ARE MENTALLY RETARDED THE FOCUS OF ITS RECOMMENDATION FOR NATIONAL ACTION.**

The Executive Order followed the federal initiatives stemming from the Kennedy Panel's 1962 plan for National Action to Combat Mental Retardation. The order was originally signed on May 11, 1966, and continued under succeeding administrations, states unequivocally that the Committee's mission is to provide advice, information and assistance to the President with regard to the national effort to combat mental retardation. It's role is therefore to serve as a national advocate for mentally retarded persons of all ages and conditions and to promote by all available means the prevention of this type of human disability.

Recently, there have been tendencies in federal, state and local governments to merge programs and organizational efforts dealing with widely varied conditions of disability into comprehensive and generalized channels of authority and advocacy. Conspicuous among these have been 1) operations under the designation of 'Mental Health' presuming to combine under one title all disabilities affecting mental functioning; 2) operations under the designation of 'Developmental Disabilities' dealing with disabling con-

ditions manifest during the early development of children; and 3) operations under the designation of 'the handicapped', including the total range and variety of disabling human conditions under one general term.

There are valid purposes which may be served by the grouping of categorical conditions under broader designations. It may simplify administrative organization and in some cases may be cost-saving; it may provide more inclusive eligibility for services and may enlarge the range of efforts at prevention. In practice, however, such consolidations can and frequently do lead to the loss of identity of specific unique disabilities and tend to constrict the application and development of services to models appropriate to some disabled individuals but not to others. They tend toward vagueness of definition and lead to reduced visibility of many who are disabled in specific ways. They may be biased towards certain types of disability and away from others simply by the commonly understood connotations of terms in the public mind — e.g. "mental health" generally implies reference to psychiatric disorders of personality and behavior more than to mental retardation; while "handicapped" most commonly connotes a physical disability, especially involving dysfunction of the lower limbs (**Note the logo of the wheelchair as the national symbol for the handicapped!**). As a consequence, unless there is careful and persistent identification of and advocacy for those with substantially different types of disability, there is an inevitable inequity and discrimination in the application of public programs and funding.

For generations mental retardation has been subject to strongly negative public attitudes and dehumanizing and inappropriate forms of treatment, with abysmal ignorance of its multiple causes and possibilities of prevention and amelioration. During the past quarter-century real gains have been made in the understanding of this complex, varied and highly prevalent condition, **BY BRINGING IT INTO SPECIFIC AND HIGHLIGHTED FOCUS.** Mentally retarded children have been provided substantially improved opportunities for education and normative development; and, as adults, have gained somewhat improved status and opportunities as citizens of the community. The existence

of the President's Committee on Mental Retardation has provided a major impetus and thrust for this development in collaboration with volunteer and professional organizations. However, there is a real danger that the momentum of this hard won progress will greatly diminish if retardation as a specific condition of disability is lost from view or direct consideration, and that children and adults with such disability will be relegated once again to the shadows. Innumerable examples can be given in illustration of this danger. On the other hand, we recognize that some examples can be given in which mental retardation has been adequately represented in consolidated, integrated and coordinated programs for "mental health," for the "developmentally disabled," or for "all handicapped"; where, indeed, the unique characteristics and needs of those who are mentally retarded have been explicitly identified and appropriately provided for.

On August 12, 1978, therefore, the assembled members of the President's Committee on Mental Retardation noted that it is charged by Executive Order to advise the President of the United States and the Secretary of Health, Education and Welfare on appropriate ways to provide for the greatest possible well-being of mentally retarded citizens, and to seek ways of preventing this specific type of human tragedy. The committee declared that this mission is one of specific advocacy on a national and international basis for persons suffering from mental retardation. PCMR will work closely and cooperatively with the advocates of persons with other forms of disability, especially in view of the frequency of multiple handicaps in the same individual. However, in view of this mandate, it will continue to press for those measures which specifically provide for the unique needs of those disabled by mental retardation and it will encourage measures which assure the identity and visibility of the problems of mental retardation. Finally, PCMR will continue to press for the most advantageous position within the government by which its Presidential charge of advocacy for mentally retarded citizens can be most visible and effectively carried out.

Henry V. Cobb, Vice Chairman  
President's Committee on  
Mental Retardation.

September 28, 1978

## Our Children's Voice<sup>®</sup>

Retarded Children Can Be Helped

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

Published quarterly by the New York State Association for Retarded Children, Inc., a non-profit, tax-exempt organization of parents and friends of the mentally retarded, chartered by the State of New York in February, 1949.

Editor: Joseph T. Weingold, Executive Director

Assistant Editor: John Bertrand

Editorial Assistant: Adele Osinski

President: Eleanor Pattison

Subscription to Our Children's Voice is through membership in a local chapter of the New York State Association for Retarded Children, Inc. The publication is also available to the general public at \$1.50 per year.

Please address all inquiries to:

New York State Association for Retarded Children  
175 Fifth Avenue  
New York, New York 10010  
212-674-1520



## A regressive step

# DD act eliminates categorical definitions

What we had all feared would come to pass (see September 1978 issue of OCV) has happened. Senate (S.2600) bill to extend the Developmental Disabilities Services Act, part of a larger package dealing with the Vocational Rehabilitation program, passed the Senate and was signed by the President.

The final version, H.R. 12467 is a combination of several bills dealing with vocational rehabilitation amendments, developmental disabilities amendments, and the Senate bill which carried changes to both these bills.

The final version written by a House-Senate conference committee was adopted by a 365-2 roll call vote in the House and a voice vote in the Senate.

### HOUSE BILL SPECIFIES DISABILITIES

The Developmental Disabilities Assistance and Bill of Rights Act revises the definition of developmental disabilities to conform with the language in the Senate bill. That measure, using a functional definition, called a developmental disability a "severe, chronic disability which is attributable to a mental or physical impairment or combination of mental and physical impairments . . . manifest before age 22; which is likely to continue indefinitely, which results in substantial functional limitations in certain specific areas and which reflects the need for lifelong, individually planned services." The House definition, which also revised the definition in existing law, specified the disabilities which were to constitute a developmental disability.

The conferees stressed that the new definition was intended to cover anyone currently covered under existing law as well as adding the other disability groups. It was not their intent to exclude anyone who legitimately should have been included under the definition in current law.

The conferees also emphasized that services to persons already covered under the act "should not be diminished as a result of the revised definition . . ."

### FOUR PRIORITY SERVICES PROVIDED

The act also provided four priority services for the developmentally disabled: case management, child development, alternative community living arrangement, nonvocational social

development (including those over 18 years of age). The conference version also specified that 65 percent of a state's DD allotment must, under most circumstances, be spent on two designated services, at least one of which must be a priority service area.

With regard to the make up of the state council, it specified that developmentally disabled persons (or their parents or guardians) are to constitute at least one half of the membership of state planning councils, of which group at least one third shall be persons with developmental disabilities.

Barred from membership on the councils in behalf of the developmentally disabled persons are those who are employees of a state agency or an entity receiving DD funds.

It abolished the National Advisory Council on Services and Facilities for the Developmentally Disabled, responsibilities taken over by the National Council on the Handicapped.

It also stipulated that each state was to receive at least the amount of the previous year's allotment for protection and advocacy systems and barred those entities from lobbying activities.

### FUNDING LEVELS INCREASED

The funding levels authorizations were considerably increased. For example, protection and advocacy services were increased for the fiscal year 1979 to nine million dollars; 1980 twelve million and 1981, fifteen million. State allotments were fifty-five million for 1979, sixty five million in 1980 and seventy-five million in 1981.

The net result, however, is that mental retardation is being submerged into the general category of handicapped and all the gains that were made from 1963 on, may well go down the drain because of this failure to emphasize the purpose of the original act which was the Mental Retardation Services Act.

The reaction to this has been universally bad, almost all agencies dealing with the mentally retarded and other handicaps previously specified protesting this move, but to no avail.

The President's Committee on Mental Retardation, however, issued a resounding statement of principles highlighting their commitment to the mentally retarded as such in their efforts to water this down. See related article on page 3.

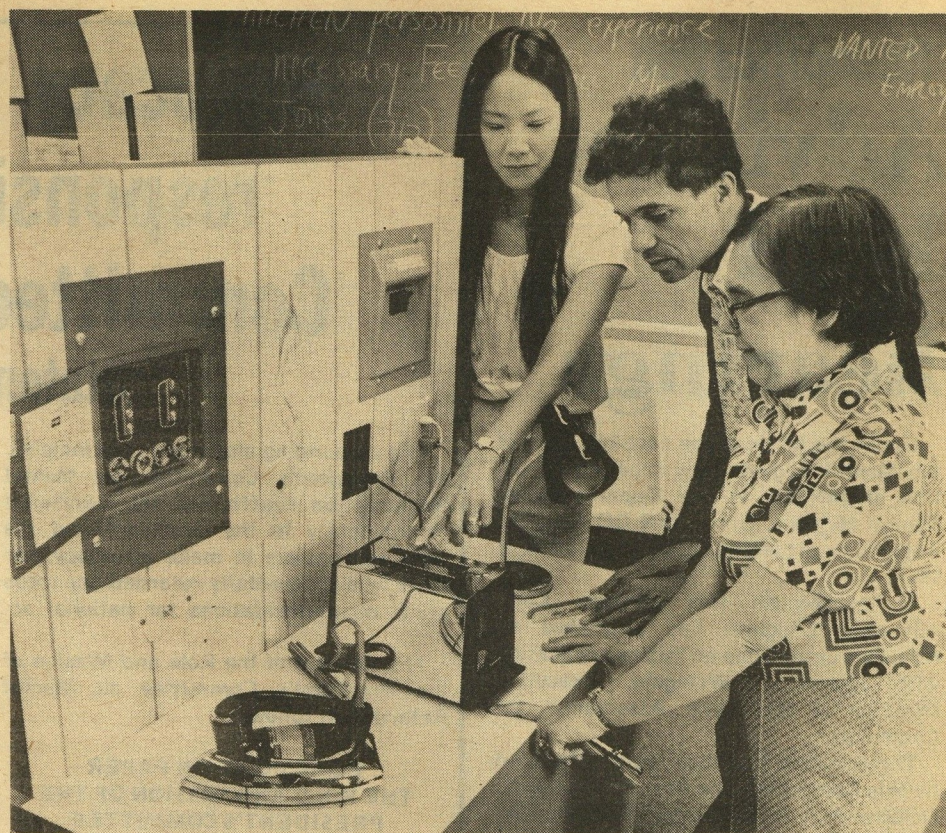
## Client insurance nixed for caretakers

Responding to a report that certain family caretakers have obtained life insurance policies on their charges, the Legal Office of the State of New York Office of Mental Retardation and Developmental Disabilities has made this statement:

Under New York Law, an insurance policy is unenforceable unless the beneficiary has an insurable interest. The term insured interest is defined "to include any lawful and substantial economic interest in the safety or preservation of property from loss, destruction or pecuniary damage." (Insurance Law, Section 148.) In the opinion of counsel, the

relationship between a foster child and foster parent does not convey upon the foster parent sufficient economic interest to constitute an insurable interest.

Usually, the issue of insurable interest arises in the contest of whether one can obtain or enforce an insurance policy. However, the Office of Mental Retardation and Developmental Disabilities may choose, as a matter of policy to prohibit any foster parent from obtaining a life insurance policy. Furthermore, OMRDD may decide to reassess any foster care relationship in which the foster parent attempts to secure life insurance on a foster child.



TEACHING HOME SAFETY AT THE BROOME-TIOGA FACILITY

## Home safety partnership

Teaching retarded people the safe use of electricity in the home is a program that has been developed recently through the joint efforts of the Broome-Tioga Chapter and the local utility, New York State Electric & Gas Corporation. Teachers and others working with the retarded have felt for some time that there is a need for teaching aids in this area. This has become more evident as adults have moved from the institutions into community based living situations.

Pictured here is a demonstration board used to teach many important points. Simple tasks such as the safe way to remove a plug from an outlet, change a light bulb etc., to the causes of an overloaded circuit, circuit breakers and the way to change a fuse can be demonstrated. In addition to the above board

there are eight posters that show in a positive way other safety tips in everyday living.

This training device will benefit not only the adults involved in the various programs sponsored by ARC but the retarded throughout the community. Two demonstration boards have been built so that one can remain in use by the Broome-Tioga Chapter while the other can be loaned out to local school districts and BOCES. The posters can be used independent of the demonstration board to be distributed throughout the special education classes in the area.

If you are interested in starting a similar program in your area and would like more information contact: Joan Fiala, c/o Broome-Tioga ARC, Front Street, Binghamton, New York 13905.

## State has \$600 million surplus

The announcement on October 5th, 1978 by Governor Hugh L. Carey, that the State would end the current fiscal year with a margin of more than \$600 million of income over expenses, makes the attitude of the Administration's existing increased State funding of local services unreasonable, if not bizarre.

In discussing this surplus, the Governor does not speak of increased services, but merely states "This margin will permit us to once again accelerate the payment of State personal income tax refunds on tax returns" and "to broaden the tax reduc-

tion program . . ."

No excuses now can be offered for not spending the money for local services for the mentally retarded at the same percentages many other States are doing.

It is interesting to note that the State of New York is way down the list in how it funds community services — 50 percent.

Michigan, for example, and Pennsylvania, fund community services for the mentally retarded at 90 percent and California at 100 percent. New York State is 26th nationally in how it funds vocational rehabilitation services.

## Wassaic upgrading promised by state

In response to what seems to be a downward trend in services at Wassaic Developmental Center after the action brought by the State Association against the State of New York had been withdrawn, the Office of Mental Retardation and Developmental Disabilities has offered fifteen specific administrative actions to correct some of the deficiencies in quality in care that exist at Wassaic.

Some of these are: fill all unfilled items

immediately; convert high level long vacant items to direct care items; assign new staff to weekend duty; increase visibility of Director at residential unit level; and sensitivity training of Chiefs of Service, Team Leaders, etc.

In addition to these items, and as a result of the supplemental budget for State purposes, an additional 100 items have been added to Wassaic's authorized fill level with a new maximum of 3,069 items.

**Support Your Local Chapter**



## Convention protest

# OVR constricts client service

The financial and regulation pinch on services in the rehabilitation facilities of the Association finally brought a massive protest from the delegates and representatives at the State Convention.

Concerns were voiced about fees for services that have not been increased for at least 15 years, the regulations with regard to SEP, including the fiction that clients must earn \$5.00 a week, the bizarre practice of audits without conferring with the agencies and surcharging them without consultation.

A bill of particulars was drawn and signed by representatives of all Chapters at the Convention to be presented to the Office of Vocational Rehabilitation in Albany on November 9th, 1978 by their Advisory Committee. At this writing, we have had no word as to what has happened in this field.

These are the minimum requirements for the agencies to be able to continue to service OVR clients:

### A. ATTENDANCE

That the agencies be paid in full at the rate certified by OVR for every SEP client enrolled who attends any part of a quarter.

It is well documented that absenteeism among severely handicapped persons far exceeds that of the normal population and even that of the less handicapped. The agencies make financial commitments of space, staff and overhead on the basis of enrollment, not attendance.

### B. EARNINGS

The fiction of earning \$5.00 a week, or any earnings at all, is a contradiction of

the concept in the Federal law and regulations of serving severely handicapped persons.

### C. AUDITS AND CHARGEBACKS

OVR is indulging in a harassing practice of audits, whose purpose obviously is to recoup funds already paid to or due the agencies for SEP services previously rendered. These audits, based on these onerous regulations, are being withheld from the agencies audited. We must insist, therefore, that such audits cease immediately and that all penalties assessed at least for the past year, be rescinded and, if paid, returned to the agencies who acted in good faith in the service of their clients.

Unless the above requirements are met within a reasonable time, the agencies serving the OVR clients will have no choice but to reassess their relationship with the New York State Office of Vocational Rehabilitation.

These minimum requirements were drawn, not only by representatives of the ARC, but representatives of the Coalition of Rehabilitation Agencies representing most of the rehab agencies in New York State.

The new Vocational Rehabilitation Act signed by the President, the increased funding to the State and especially the phase-in of funding in direct relationship to the population of the State without the modifying factor of income should mean a great deal more money to the State of New York since 80 per cent of OVR funding (except for SEP) comes from Federal government.

## Doctors find new disease

Five years of medical detective work by two doctors had led to the discovery of a new disease that afflicts one of every 11 retarded adults.

Already hundreds of inquiries about what will be called the Lekkas - Lentino Disease have been received by the two doctors from other physicians, research institutions, medical schools and the federal Department of Health Education and Welfare.

The results of the findings of Christos N. Lekkas and Walter Lentino, concerning the effects of the interposition of the colon (a part of the large intestine) in the retarded, have been published in a recent issue of the Journal of the American Medical Association.

Interposition occurs when the colon, which normally extends to the rectum, slips between the liver and diaphragm. The disease's symptoms include nausea, vomiting, constipation and severe abdominal pain.

Lekkas, who began the original medical detective work five years ago, pursued his quarry despite his lack of technical research laboratories and equipment.

Lentino, president of the Orange County Medical Society, said the large number of retarded adults in society makes it an important discovery. There are some 10 million retarded persons in the United States, according to mental health officials.

Lekkas, 44, is a Greek native educated in the University Medical School of Athens. Since 1973, he's worked at Letchworth

Village Developmental Center Satellite Unit on the grounds of Middletown State Hospital. His patients are moderately to profoundly retarded adults.

Lekkas said the principal problem he faced was the nature of the patients. Many are so severely retarded, they can't speak.

And for years, it was assumed that this behavior was part of their retardation. His studies led to the conclusion that the symptoms were caused by an interposition of the colon, or large intestine, between the liver and diaphragm.

Lekkas said the interposition occurs in one out of every 4,000 - 5,000 normal persons without producing any symptoms.

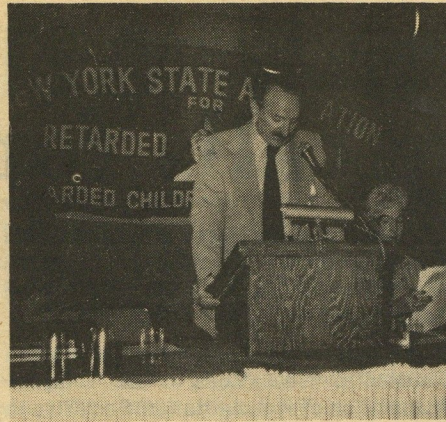
In Letchworth, he discovered that in mentally deficient adults, the interposition occurs once in every eleven persons, or 8.8 per cent.

Lekkas and Lentino said several factors contribute to this phenomenon. At Letchworth, meals are served at fixed intervals. Patients tend to eat rapidly and gulp their food.

Many require spoon feeding, which leads to ingestion of too much air, a condition called aerophagia.

The patient's colons, which are muscles, tend to lose their tone because, since most patients aren't ambulatory, the muscle gets insufficient exercise.

Lekkas began treating the problem. The AMA journal report states: "In all cases, the acute symptoms disappeared once the patient received a regimen of bed rest, forced fluids, enemas and cathartics, e.g., bisocodyl or milk of magnesia."



George Hirsch making his farewell address as President.

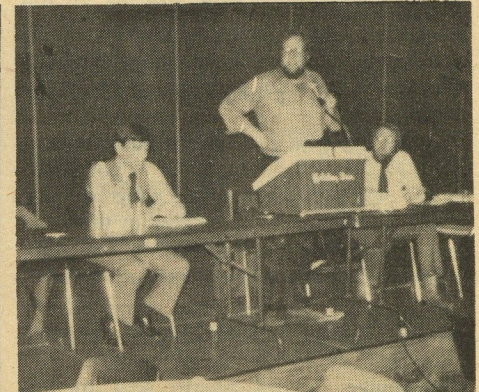
## Seen at the State Convention



Two Education hotshots enjoying the Convention, left to right, Marilyn Wessels and Chairperson, Betty Pendler.



David Wilkie, State Board Member of Rensselaer County Chapter (Ellie's home Chapter) presenting roses to the newly elected President, Eleanor Pattison.



And the Executive Directors also met. Mike Goldfarb of New York City holding forth to audience and Marc Brandt, Chairman of the Executive Directors' Association and unidentified beard on the right.



Kay Nogaj pouring the cup that cheers for Ellie Pattison, newly elected President and Hy Clurfeld, Senior Vice President.



William Lee, President of Sibley's, presenting the first angel in the "be an angel, buy an angel" to Joseph Weingold at Convention.

## 78-79 supplemental budget inadequate

The State supplemental budget for 1978-79, as approved by the Legislature, provides additional State aid in the Local Assistance category for mental retardation in the sum of \$5.8 million.

This \$5.8 million dollar supplemental appropriation is \$1.2 million dollars for matching State aid, \$4.1 million dollars for Chapter 620 and \$.5 million dollars for other matters.

These funds are for the entire State and the New York City share has not yet been determined.

It is noteworthy that the State matching aid for local services is only \$1.2 million and, again, we have the imbalance of \$4.1 million for Chapter 620.

This is a far cry from the promises we have had from the Administration that the supplemental budget provide the funds to avoid the necessity for cutting budgets for local services.

In a letter to our Executive Director, Commissioner Coughlin said that these budgets would not be cut because the supplemental funds plus deficiency appropriations requests would take care of all the increased budgets.

The information coming to the State Office says that this is not the case and that budget after budget, having been approved by the local Community Service Boards, is being cut by the Office of MR-DD.



## State operation of homes criticized

# Testimony calls for parity

In a statement before a public hearing of Senator Padavan's Senate Mental Hygiene and Addiction Control Committee at Queens Developmental Center recently, Joseph T. Weingold Executive Director of the New York State Association made this statement:

The community needs of the mentally retarded are well known to Senator Padavan and to the committee. It is also well known community agencies in this state are willing and able to develop and carry on a complete system of services for this population. What stands in the way, as we all know, is the lack of funds.

If there is one thing we are going to suggest, above all others, it is that the system of delivery of community services for the mentally retarded and developmentally disabled, and the funding, be changed to remove once and for all the discriminating imbalance between the 100 per cent paid to those deinstitutionalized and the 50 per cent paid for those in the community.

There must be parity and equalization. At this point even the call for 75 per cent - 25 per cent is outdated. The Empire State is one of the most regressive in terms of this funding for the person in the community who has not been institutionalized.

In addition, we are presenting here a critique and protest of the Governor's proposal to establish state operated community mental health and mental retardation programs, and to seek the 50-50 division of all future money between state and voluntary community mental health programs. We endorse very strongly the point that programs should not be geared to the employment of CCEA members, but to good programs employing the best qualified persons.

The critique presented was by Pamela Kay Martens, Community Relations Director of the Rehabilitation Institute on Long Island.

This letter was written to Mr. Milton Goldstein, New York State Chapter Association of Rehabilitation Facilities in Menands, New York:

The Rehabilitation Institute is gravely concerned about the Governor's request for \$5 Million this year to establish state-operated community mental health programs and to seek a 50-50 division of all future mental health monies between state and voluntary community mental health programs.

Out of a total Office of Mental Health Budget, only 14 per cent currently goes to the voluntary sector. If the State takes half of this, we will end up with only 7 per cent or \$45 Million to be spread statewide.

The figures are even worse for the Office of Mental Retardation and Developmental Disabilities, which currently only provides roughly 8 percent to local assistance programs.

In conversations with Mr. Terry Williams, the Mental Health specialist on the Senate Finance Committee, we learned that the projected full-year funding for these state-operated community-based facilities is in the range of \$40 Million and that additional construction funds may also be allocated on top of this.

Taking away half of our funding means that, at best, we can expect to reduce our staffs and services by half. . . at worse, close our doors.

But the key issue here is not self-preservation. As we see them, the key issues are as follows:

- (1) The State should not go into competition with the voluntary sector. Historically, the major accomplishments and progress in effective rehabilitation of the mentally ill and retarded have come from the voluntary sector while the State's efforts have resulted in Willowbrooks and loss of accreditation at other major state-run facilities.
- (2) Civil Service employees should not be guaranteed jobs in community-based programs for the mentally ill. They should have to compete with the rest of the work force to ensure that the mentally ill are served by the most qualified candidates.
- (3) Since the State mental hospitals are retaining and upgrading their clinical staffs, the bulk of civil service employees who will be seeking community based jobs will be those who know little more than custodial care. This type of staffing will certainly not be conducive to effective rehabilitation.
- (4) Communities, particularly on Long Island, are openly hostile to the creation of community mental health programs in general and State-operated programs in particular. \$40 Million may be wasted on futile attempts to establish these programs — \$40 Million which could have gone to provide vitally needed services.

We are strongly urging ARF to immediately send letters to all Member agencies asking them to send mailgrams to their Albany representatives.

We believe it would be very helpful to also remind the Governor that CSEA members are not the only voters in the State.

## No sign off power for offices

Although staff of the Developmental Disabilities Service Offices (DDSO's) are beginning to assume an important role in the inspection and certification process to be utilized by the Office, they do not certify programs.

Developmental Centers (DDSO's) will not approve or disapprove programs. They will only make recommendations based on their inspections. The County Service Group Commissioner (OMRDD counterpart to the OMH Regional Director) and his staff actually certify programs. Final appeals can be made to Thomas A. Coughlin III, Commissioner of Mental Retardation.

In answer to a letter from Joseph T. Weingold, Executive Director New York State Association for Retarded Children, Coughlin stated he does not anticipate problems. The major problem relates more to carrying out the total reorganization of the old DMH and establishing all of its previous functions within a new agency, which is in its infant stages.

## Employment ad from Erie

MSW Social Worker to supervise and deliver casework-advocacy services to developmentally disabled children and their families in a County Catchment Area. Supervision of BSW and student. Some program planning responsibilities. 2 years experience in MR-DD required. Salary \$13-14,000. Send resume to Sharon Kern, Coordinator Community Planning-Neighborhood Services, Erie Co., ARC 38 Virginia Place, Buffalo, N.Y. 14202, (716) 883-3350.

## \$2.5 million for injury

A Brooklyn hospital is planning to appeal a \$2.5 million malpractice suit won by a Long Island girl severely brain injured at birth.

The verdict against Bethany Deaconess Hospital, now owned by Wyckoff Heights Hospital of Brooklyn, is believed to be the largest of its kind in the state and, according to some reports, the nation.

A jury in Queens Supreme Court recently ordered the hospital to pay the \$2.5 million to Lisa Villani of Ronkonkoma. The three-man three-woman jury held that hospital negligence during Lisa's birth on July 16, 1966, and for five days thereafter, led to her severe retardation.

Her mother, Lee, said Lisa cannot talk, control her bodily functions or even sit unassisted.

Lisa's lawyer, Charles Kramer of Manhattan, said the child didn't get enough oxygen during a difficult birth.

The jury found the hospital negligently failed to monitor her vital signs or to have the necessary facilities and staff on hand for an emergency caesarian delivery. It also found the hospital failed to properly treat the infant as her condition worsened over the following five days.

Three doctors named in the one-month trial before Justice Arthur W. Lonschein, were exonerated.

Kramer, who has written a book and publishes a newspaper on malpractice, said it was the largest single award in the country for an individual.

## Deaths linked to medication abuse

Samuel Levine, a Nassau County attorney, and Rockland County medical examiner Dr. Frederick Zugibe charged that an undetermined number of mentally ill and retarded patients in state hospitals are dying each year indirectly because of the tranquilizers used to keep them quiet.

Levine, the lawyer for a group of relatives of patients at Pilgrim State Hospital in Suffolk County, said, of the 300 patients who died there last year, 40 were the victims of poor medical practices, including the overuse of tranquilizers.

But, he said, the state Mental Hygiene Review Board, created to investigate such deaths, has done nothing about them.

He said there have been instances of "undetected, and untreated" cancers, heart and circulatory diseases and even pneumonia discovered in autopsies on Pilgrim State patients.

Rockland's Dr. Zugibe said that he sees "several dozen" cases annually where patients from Rockland State mental hospital, in Orangeburg and the Letchworth center for the mentally retarded, in Thiells, have been tranquilized to the point where they're too doped up to complain about pain that would normally be a warning of other diseases.

Dr. Sheldon Sommers, chairman of the state review board, said that of the 200 deaths the board has investigated in the past two years, there have been "no incidents of common or widespread overuse of tranquilizers."

He said the board found no "evidence of neglect, overtreatment or under treatment" in any of the cases referred to by Levine.

But both Sommers and a spokesman for the state Dept. of Mental Hygiene said the state is interested in examining the charges more closely.

## \$11 million for MH..... what for MR?

The State Office of Mental Health was awarded \$11,154,102 to 45 counties and the City of New York to begin developing Community Support System programs for chronic mentally ill patients returning to the community.

The Governor said that the awards, based on plans submitted by the various counties, are part of a \$13.7 million appropriation approved by the Legislature earlier this year to establish a range of community-based services for discharged mental patients.

The money will be used for treatment programs, transportation, housing, vocational training, sheltered workshops, social and recreational programs and to employ case managers to serve as patient-advocates.

The new program, called the Community Support Services System, was developed by the State Office of Mental Health under the guidance of James A. Prevost, State Commissioner of Mental Health.

The Governor said that the first priority in developing CSS programs will be in

areas throughout the State with high concentrations of former mental patients. Included in the list of priority localities are Erie, Oneida, Niagara, Broome, St. Lawrence, Dutchess, Rockland, Westchester, Sullivan, Nassau and Suffolk Counties and nine highly impacted areas of New York City.

The Community Support Services approach has placed New York in the vanguard nationally for its efforts to improve services to the former patient in the community. This is borne out by the recommendations of the President's Commission on Mental Health. The Commission's proposals bear a striking similarity to the initiative which New York has already begun to implement.

The Governor said six major criteria were used by the Office of Mental Health in reviewing plans submitted by the counties or agencies. They were evidence of need, system completeness, readiness to implement, capacity and leadership, commitment to local maintenance of effort and commitment to participate in evaluation and monitoring.

## Letchworth worker charged with beating

A Letchworth Developmental Center attendant has been charged with the beating of a retarded patient at the state institution in Thiells.

Horace Wrenn was charged with assault after authorities said he beat the male patient with his fists while at one of the center's resident cottages.

The patient suffered injuries to his nose and an ear, as well as two black eyes.

The age of the patient was not known. He was hospitalized at the center after the beating.

Wrenn did not have a prior criminal record.



## Youth at the Convention



YOUTH talking it over — where else — on the floor.



Kathy Baker, outgoing President of YOUTH presents award to Susan Crane, YOUTH advisor.

## Transport suit settled

What may prove to be a final settlement was reached in Federal Court in a lawsuit brought by two Buffalo taxi companies which sought to bar the government from purchasing vehicles for the transportation of the handicapped and elderly.

Under terms of the agreement, the case will be adjourned generally while federal, state and local transportation officials conduct a study to determine how the firms can be utilized in transporting the handicapped and elderly in Erie and Niagara counties.

Moreover, the stipulation provides that representatives of the taxi industry will participate in the study.

While the study is going on, community groups already owning government-financed vehicles can continue to use them, and organizations which have applied for vehicles can be granted them, the stipulation said.

The stipulation comes in a lawsuit filed by Yellow Cab Company of Greater Buffalo Inc. in Madison Taxi Co. of Buffalo Inc. against various government officials and 28 community organizations which either have vehicles or applications for vehicles pending with the government.

The companies had sought an injunction against the use of the government-financed vehicles claiming they unlawfully were denied an opportunity to bid for transportation contracts as provided by the Urban Mass Transportation Act of 1964.

The lawsuit charged that the government's action of bypassing businesses engaged in providing transportation in favor of purchasing vehicles outright violated the firms' constitutional right of "due process" and "equal protection under the law."

The stipulation provides that the plaintiffs "retain the right to request relief from the court" in the event the defendants do not complete their obligations as stated in the agreement.

Among defendants in the suit are Brock Adams, secretary of the U.S. Department of Transportation; and Chester Hardt, chairman of the Niagara Frontier Transportation Authority.

## A letter from Kathy Baker

Dear YOUTH Members and Supporters:

I wish I had had the presence of mind to say just a few of the thoughts that came to my mind after Saturday's banquet. During the convention, I'm sure it seemed as though you would never shut me up. You did just fine Saturday night. I was very surprised and overwhelmed. The honor you bestowed on me was one of the happiest moments of my life. I wish only each and every one of you could have gone up and been "distinguished" for your services to, and with YOUTH-ARC.

Saturday, you thanked me but it was I who should have been doing the thanking. If it were not for you the YOUTH, I never would have had all the opportunities a leadership position affords. When I first joined YOUTH-ARC, I was anxious to be the "good Samaritan" and help people who were retarded. Little did I know how much they would help me to learn, not just about mental retardation, but about people and myself. I have enjoyed every aspect of

being a YOUTH member. Looking back, even the frustrations and aggravations were worth it.

This last convention was no exception. During the planning of the convention, I was forced to take a good long look at YOUTH. Needless to say, I did not like what I saw. I was then given the task to make you see our faults. This convention was one of the hardest things I had to do, even though I fully believed what I was saying. It was a challenge to all of us and we rose to the occasion.

I believe that what you were asked to do was very hard because we had to take a look at ourselves, and our local, and admit we are not perfect. We had been so used to patting ourselves on the back, we forgot about our goals, purposes and challenges. We were all so aware of our potential and effectiveness, we never stopped to see where we were, how far we had grown or regressed. We had let ourselves and each other down, and that hurt. We were given different opportunities to stop, but we kept the doors open and by Saturday afternoon,

we were ready to face the second part of our challenge. Now that the convention is over with, it's going to be harder for us to face that challenge, but we have to do it; we can't stop now!

This year's convention marked the end and a new beginning. We have another chance to make it all happen. We know how effective we can be. We deserve to pat ourselves on the back if we can rise to the challenge. If we fully believe in ourselves and our cause, I know we can do it. Start your YOUTH group thinking, taking interest, keep the momentum going, don't disappoint yourself; I don't know how many more chances we are going to be given.

Finally, I would like to thank the following people for their help on the convention: Chris Stevens, Abby Rose, Jon Rose, Chuck Rogers, Jimmy Cunningham, Lisa Riegelman, Sue Gordon, Suzanne Crane, Maythorne Wintirkorn, Isa Ocwieja, Margie Dell, Shelia Dell, and all their committee members, the State YOUTH office, and especially Gerry Sherwood, and finally you, the YOUTH delegates.

You were a delegation that demanded a great deal of respect. You knew how to conduct yourselves; it was great to see that the primary interest was in the convention and not the party. My trust and faith in people was renewed that weekend. Once again, thank you for everything. Together we can! You can color my world, but let me choose the colors!!

Sincerely,  
Kathy Baker  
Immediate Past President  
YOUTH NYS-ARC

## From president, Jim Cunningham

I would like to take this opportunity to introduce myself. I am James Cunningham and I was elected to be president of New York State YOUTH-ARC for 1977-1978 at the annual convention held in Rochester on October 27-29.

In the past seven years in which I have been involved with the ARC, I have been a co-advisor to Suffolk County YOUTH Council, Junior Advisor for Smithtown Junior Auxiliary, and have held various chairmanships. It is this past knowledge which I intend to use as my guide to being president of New York State YOUTH.

For the coming year, YOUTH has its work mapped out fairly well. In 1978-79, the amount of active YOUTH groups will more than double and, with this increase in size, we plan to be much more responsive to the local YOUTH groups across the state. All of these plans involve every YOUTH group now and the new groups which will be formed in the coming year, and together they will all contribute to our continued growth.

For those of you who have not heard, the New York ARC Board of Governors, at their convention this year, set up a new policy which will provide for a YOUTH group in every chapter across the state. With the backing of the ARC, the YOUTH-ARC will be able to increase our strength.

I would like to thank you for your support this year and hope that you will contribute to the growth of YOUTH in the coming months.

I, together with the entire state YOUTH board, am depending on you for input. If you do not tell us you need help, we will not know it. We were elected by you. Take advantage of us.

**Support  
Your Local  
Chapter**

## Rensselaer wins funds

Parents and Advocates for mentally handicapped Pre-School children in Rensselaer County scored a big victory recently with the awarding of transportation contracts by the County for Pre-school bussing services.

Every year, the two Agencies operating Pre-school programs serving mentally retarded and developmentally disabled children, the Rensselaer ARC and Unity Sunshine School submit, through Rensselaer County Family Court, the names of children in need of bussing services. The County then awards a bussing contract to a vendor through a bidding process.

Throughout the 1977-1978 school year a large number of problems were encountered with the contractor who was providing transportation services through Rensselaer County. Staff and parents from both Unity Sunshine School and Pinewoods Center wrote letters, made phone calls and compiled information on the various problems encountered. These included long delays, children not being picked up, inadequate notification when runs would be cancelled or late, frequent breakdowns and problems with Staff hired by the bussing contractor. Initial attempts to straighten out these problems by working with the contractor appeared to fall on deaf ears.

When transportation contracts were awarded for 1978-1979, the Pre-school contracts went to a new firm, Black and White Taxi Company. This firm has previously transported our children from Albany County with no major problems. Since the initiation of the contract with Black and White, there has been a marked improvement in the quality of transportation services received and the cooperation with the new contracting firm.

Throughout the struggle, Ara Baligian, Commissioner of Unified Services, was very helpful in seeing to it that the concerns of parents and Staff were presented to the appropriate County officials.

This victory serves as an excellent example of the kind of positive action that can be achieved through strong advocacy efforts and hard work.

## Lee retires as Tompkins head

D. Boardman Lee has retired as president of the Tompkins County Chapter, to be succeeded by Walter Herr.

In a letter to Jerry Weingold, Lee said he anticipated the new officers will carry on with fresh enthusiasm and vigor. He wrote of his great pleasure to have been associated with the A.R.C. over the years.

In commenting on Lee's long service, Weingold wrote, "I want to take this opportunity to tell you what a pleasure it has been to work with you, and how much I admire your devotion and ability in the cause of the mentally retarded. Your willingness to serve as long as you have has really been inspirational."



# CHAPTER NEWS

What our chapters are doing

This edition of Chapter News, is being written, while sitting at the dining room table, and under great time pressure. Therefore, we didn't alphabetize our chapters but just tossed the material on the floor and are going to report it as we pick it up.

**FULTON COUNTY CHAPTER**, with all their innovative fund raising ideas, had their Annual Fall Auction on October 7th. Maybe those of you who might be interested in a new fund raiser should contact **FULTON** to find out how it's done. They also are opening a counseling group for brothers and sisters ages 8 - 15 where there is a handicapped child in the family, have the Gloversville Police Department coming in to present a Safety Program for handicapped children and plan a train trip from Amsterdam over to Albany.

**CHEMUNG COUNTY CHAPTER** is to be congratulated on their new Newsletter. It began coming out in its present format in May of this year. Like many other chapter newsletters they had a contest to name the newsletter and wound up with the name March. Ask them for a copy of the July issue and find out how they came to this interesting conclusion. You might also want to check with them on their August issue, which talks about the manner in which they can raise funds through labels from vegetable cans.

**ONTARIO COUNTY** is very happy about opening their first community residence located at 233 Washington Street in Geneva, N.Y. We welcome this new project aboard together with Chris Karsten, their newly appointed Director of Residential Services.

I've come down to the **SUFFOLK COUNTY CHAPTER** newspaper, The Lamplighter. It's always impossible to pick one or two highlights out of twelve pages of good stuff. The only way to possibly tell you what it says would be to have you receive a copy yourself. We did note, however, that one of their headline features in their September issue was some of the work that was being done in gardening in their Day Treatment Program which wound up with finished products being prepared in their fully operational domestic kitchen. One of many ARC's who follow the gardening lines.

**OTSEGO COUNTY CHAPTER** very pleased with their plans for a new expanded facility in the town of Hartwick. It appears that after a number of years the County is going to support a move for larger quarters for their existing facility and the size of their program will just about double with the new 620 program they will open in Hartwick. Congratulations to Executive Director Matt Guokas and the Board of **OTSEGO**.

**MONTGOMERY COUNTY CHAPTER** will be building a ranch style home in the village of Canajoharie to house eight persons with developmental disabilities. Although the architect's plan calls for a marvelous building which will cost \$150,000 to construct and should be a real boom to any neighborhood, as usual it was anticipated that some residents of the neighborhood would plan to protest the facility. How sad.

**GREENE COUNTY CHAPTER'S** newsletter indicates they have had their usual Summer Camp Program, ran a Bike-a-thon, and had their Annual County Golf Tournament on Sunday, September 24th. One of these years, I am going to enter that if they have a booby prize. We wish their former Executive Director Carol Anderson, well in her new position as Executive Director in our Columbia County Chapter. Like so many other chapters, **TOMPKINS COUNTY CHAPTER** newsletter contained their feelings about how pleased they are to be looking forward to their first community residence which they hope will be opened in 1979 through the joint ARC-HUD grant. Speaking of community



## Niagara's 11th annual dinner

The Association for Retarded Children, holding its 11th Annual Awards Dinner, honored several groups and individuals who aided the Association during the past year. Among them were Richard Kibler, left, of Thruway, Fasteners, who received a Certificate of Merit, and Anthony Cubello, second from right, who received the Outstanding Service Award. With them are Maryln Zahler, Executive Director of the ARC, and Thomas Glair, Director of Adult Services for ARC.

(Niagara Gazette Photo)

residences, **SULLIVAN COUNTY CHAPTER** came up with a double-first in August when the first issue of the Sullivan County Advocate, the chapter's new newspaper, came off the presses and had as its banner headline the opening of the first community residence in **SULLIVAN COUNTY**. A really neat newspaper, we're looking forward to receiving more issues.

**CHAUTAUQUA COUNTY CHAPTER** pleased to announce a facility improvement grant given to the chapter which will enable them to hire an industrial engineer to service the Director of Manufacturing for the three workshops in the chapter. They also have announced the appointment of Cynthia Filgate to the position of Assistant Executive Director. I continue to be amazed with the number of clients in the **CHAUTAUQUA COUNTY CHAPTER** program, thinking back to the days when we were six clients on the main floor of an old house. Their September 1978 report showed 262 clients on the rolls at Jamestown, 113 at Dunkirk and 39 at Westfield. Keep up the good work.

**ESSEX COUNTY'S** July newsletter was so full of information that they had to publish a supplement. And the supplement was a request for individuals to volunteer to be friends to mentally retarded persons on a one-to-one basis. We will be interested to hear how this project comes out. Thank you, thank you, Paul Greenfield, new President of **STEBEN COUNTY CHAPTER**. In Paul's opening statement in the chapter newsletter this Fall, he says his primary goal is to increase membership. A president after my own heart. Congratulations to **WELFARE LEAGUE** on their highly successful luncheon held November 18th. **CORTLAND COUNTY CHAPTER** announces the resignation of Karin Burgess, long time State Board member, from the State Board, in order that she can now accept the full time position as their Executive Director. ARC in **ULSTER COUNTY CHAPTER**, one of the big show places for the I.B.M. employees in the Annual United Fund

Campaign in their county.

**WILLOWBROOK CHAPTER** also already planning their 1979 luncheon. **MADISON COUNTY** also got in on that business about money for vegetable labels. **MADISON COUNTY** continues to have its Worker of the Month Award, a very interesting approach. Thanks to the members of the Moose Lodge who have been volunteering their time on weekends to paint the exterior of the chapter's Wampsville Learning Center. More volunteers like that, we could use. The chapter also asked for volunteers to help fill in during the vacation period in the workshop. Wonder how that worked? **SCHENECTADY COUNTY CHAPTER** happy to indicate they received a \$13,000 I and E Grant from the Office of Vocational Rehabilitation to help them with their many workshop jobs. **SCHENECTADY**, one of our chapters that continues to operate Boy Scout troops and appears they are continuing to be active. Talk about people helping out, **ERIE COUNTY CHAPTER** had a real highlight where it was indicated that youngsters from their Heritage School took a "Mini Walk" around the block in May and raised \$158.65 for the March of Dimes.

**CHENANGO COUNTY CHAPTER** indicating they have instituted a food preparation experience for their clients and are operating a kitchen in the chapter's workshop. In addition to their daily hot lunches which they are providing for a very reasonable fee, they are hoping to provide special holiday meals during the course of the year for all the hard-working clients at the workshop. **RENSSELAER COUNTY CHAPTER** tried an interesting fund raiser, a cruise on the Hudson. We trust it safely returned to port. They also were very pleased to announce that over \$4,000 was raised in their Walk-A-Thon, thanks to all those Rensselaer walkers. The girls in the **ROCKLAND COUNTY** Auxiliary continue to amaze me with their newsletter. The summer issue was up to five pages including a number of ads. They also are doing Bingo to help the chapter

with its fund raising problems and we think they are doing a terrific job. When it comes to money, I guess everyone really can't hold a candle to **NASSAU COUNTY CHAPTER**. It seems to really know how to do it. We join the chapter in thanking Louis Silver and Gertrude Merinoff for providing leadership in their Annual Rose Ball, an event which makes possible nearly \$250,000 for the chapter's programs and services. Speaking of cruises, **NASSAU** doesn't go for trips on the Hudson but is working right now on a summer cruise to Nassau (the island) and Bermuda. Now that's the way to go. We welcome Mrs. Irene Platt as the President of the **NEW YORK CITY CHAPTER** of the Association. In trying to stay in touch with their far flung projects and programs, **THE CHAPTER** appointed co-chairpersons in each of their borough divisions. An excellent way to keep in touch. Our **MONROE COUNTY CHAPTER** — thank you **MONROE** for all of your hard work in providing such a splendid State Convention. We really appreciate it and everything you did. It was a great meeting. Just to prove they know how to do more than run conventions, the chapter also put together an Annual Dinner which was attended by some 400 persons. John Regan, Chapter Executive Director was honored for his 15 years of service with **MONROE COUNTY CHAPTER** as of this past June 14th. **NIAGARA COUNTY CHAPTER** out with a new newsletter which is so long and loaded that it's more like a magazine than a newsletter. Once again, **NIAGARA** is on the community residence band wagon and is very happy about their first semi-independent residence in Niagara Falls. Some good work done by **NIAGARA COUNTY CHAPTER** in getting the local bus company to arrange a special route which will come directly to the ARC center. Incidentally, **ONEIDA COUNTY** has hopefully managed to arrange the same thing for the Rome workshop.

Keep up the good work everyone.



ing and saying for our children and adults

## Public information committee exchange

Arthur Gasman, Chairman, Public Information Committee, requests all Committees continue to exchange ideas, solve problems in an effort to strengthen all facets of the NYSARC to benefit our MR people and parents. The Public information Committee is aligning chapter areas based on their media coverage. Each chapter will receive various queries to help develop a broad, state-wide program. One of the first questions to which an early reply is requested, is:

**WHAT 'FACILITIES', IDEAS, EVENTS, ETC. HAVE YOU PARTICIPATED IN, ARRANGED OR HOPE TO DO, WHICH FIT INTO THE DESCRIPTION OF "TIE-IN" WITH OUTSIDE ORGANIZATION OR EVENT?**

Ask yourself the following, then make a list of whatever you deem applicable and return the information to the NYC office of NYSARC:

- Does the Chapter have a Speaker's Bureau; how do you promote it and the speakers. Do you send letters to organizations; advertisements; etc.?
- **Literature** — do you prepare brochure and distribute to public locations, libraries, schools, doctors, special educators?

- **Slides** — how do you promote the fact that you can show some?
- **Host** outside organizational meetings; tours, open house, seminars; and how do you promote your available facility?
- What kinds of **buildings** other than your own do you conduct Board of Membership Meetings? Have you requested use of a school room, restaurant, hall or any site operated with tax-payer money?
- What **government agencies** have you asked for direct advice for your programs? For example, the County Extension Service provides menus, recipes, seasonal shopping advice for good nutrition and easy cooking and might like to help with a column in your news letter!
- Have you ever asked **private business** for advice on preparing a news letter; how to locate supplies or materials, etc.?
- Have you responded to announcement of craft sale; flea market; public or community round table; art show, etc.

The TIE-IN is an excellent way of telling the MR and NYSARC story and we hope to compile these activities into a complete public relations package for everyone's use. PLEASE MAKE ADDITIONS.

Please return all information to: N.Y.S. Association for Retarded Children, Inc., 175 Fifth Avenue, New York City, 10010.

## Albany rebounds

Who thought two years ago that the Albany County Chapter, almost bankrupt, and having to discontinue their services for a short time for reorganization, would be cited in an article in the **Albany Times Union** as offering new hope and training programs for the mentally retarded?

The article states "A 30-year old man who never had a day's formal training or education, until he was 'discovered' earlier this year, is one of the retarded adults who will have a better chance to learn in a training program soon to be expanded by the Albany Association for Retarded Children".

"This man can neither speak a word nor perform basic self-care tasks. He has lived most of his life alone with his mother, mostly confined to an apartment in a moderate income residential section."

More comprehensive training, the article goes on, will be made possible by

more staff, more space, more federal state aid and more modern equipment when the ARC in Albany moves to its new quarters at 155 Washington Avenue.

It will teach this man to speak, to perform basic tasks of living, even to earn modest wages by the performance of tasks with his hands.

There will be an enrollment of 110, including 60 trainable mentally retarded and 50 educable mentally retarded at the new facility. In three years, according to Les Rivkin, Executive Director, a total of 180 will be enrolled.

This is a testimonial to the perseverance of the members of the Albany County Chapter, its Board of Directors and especially to the devoted staff of the State Association, who spent so much time and effort in rehabilitating Albany County Chapter to its present status.

## Cortland's Karin on tv



Karin Burgess, Executive Director of Cortland County Chapter, appeared on a Syracuse television show on October 1st, in her capacity as President of the Board of Visitors of Syracuse Developmental Center. The topic was deinstitutionalization. Appearing with her were Chuck Soper, Deputy Director of Treatment Services at the Developmental Center, and Len Slosberg, Chief of Service for Adult Services at the Center.



## Islander's for retarded

Clark Gillies, Captain of the New York Islanders Hockey Team, together with his wife Pam, chaired an Islanders Carnival at Nassau Community College, on Sunday, October 22nd, for the benefit of the Nassau County Chapter.

In the photo Clark Gillies, far left, is shown with team members B. Bourne (center), and Dave Lewis, and one of their special friends from the AHRC Brookville School, Michelle Kuntz.

The carnival began at 12 noon and lasted until 7 p.m., and featured some booths which were manned by members of the Islanders team and their wives in addition to the games, there were special demos, displays, raffles and refreshments.

## 2nd Nassau workshop

A 44,000 square foot vocational center in Plainview, New York, was dedicated by the Nassau Association for the Help of Retarded Children in November.

The facility, which with its renovations cost over one million dollars — most of it raised from the private sector, will provide training and sheltered employment for 250 mentally retarded men and women ranging in age from sixteen years and up, with the average age in the mid-twenties. The center is being named to honor Gertrude and the late Charles Merinoff, long time benefactors of AHRC; Mrs. Merinoff serves as a chairman of the annual AHRC Rose Ball which yearly raises \$250 thousand. The Gertrude and Charles Merinoff Center is expected to be fully operational during the winter of 1979, and will include evaluation, training for semiskilled industrial jobs, an in-plant food service unit and a sheltered workshop which will undertake subcontract work from private industry. An extensive continuing effort is made by the Nassau AHRC to match trainees to jobs in the private sector; last year 60 placements were made.

Program costs, in addition to the subsidy received from New York State and Nassau County, are met mainly through the center's contract work and contributions from the community. The new center, together with AHRC's, 110,000 square foot Freeport facility and its crafts, boutique and horticultural program on the Brookville campus, comprises the largest vocational program for the mentally retarded undertaken by a voluntary organization in the United States.

The Nassau AHRC is a 29 year old organization which, after its Plainview center is operational, will be providing nearly 8,000 program hours daily to the children and adults the organization services. In addition, AHRC maintains several residential and recreational facilities which last year enrolled more than one thousand persons. Those attending the various programs are residents of Nassau County — most of them living at home.

## Book Review

**Mainstreaming — What Every Child Needs to Know About Disabilities.** Published by: exceptional Parent Press, Room 708 Statler Office Building, Boston, Mass. 02116. . . Price \$6.95. Order No. S-103. . . Author: Susan Bookbinder.

"Now I Like Handicapped People and Like to be Their Friend".

This is a quote made by a young student who had a handicapped person in his class for the first time. How he got to understand this child and like him is explained in an excellent book dealing with just how to change attitudes.

This book gives practical and workable suggestions. While it is geared for the elementary school teacher and administrators, I think it is excellent for parents, too, who have young children, and who have to "educate" the public, as they try to explain to relatives, neighbors and young friends what it means to have a child who is retarded.

The book deals with other disabilities as well, but I found the chapter on mental retardation rewarding. We all know that it is hard for young children to comprehend what it means to be mentally retarded, because one cannot SEE the problem, as with persons who are blind, or those who are in wheelchairs.

Some of the activities suggested, for instance, in explaining the tactical difficulties children with mental retardation have, is to have the young friend put a thick sock on each hand, and then ask him to button his shirt. This will give that young child much more patience with his friend who is mentally retarded and who has poor coordination.

Parents will enjoy this book, but more importantly, if you know of any teachers or organizations who have apprehensions on how to deal with the young child who has a handicap in an integrated setting, this book is an answer on what to do and how to do it. It is packed full of simulation activities to be used on young friends to help them understand the child who is handicapped.



# Final roundup-1978 Legislation

## WHAT HAPPENED TO THE 1978 ARC LEGISLATIVE PROGRAM A. STATE INSTITUTIONS AND SERVICES

Parental Liability: The amendment to Chapter 777, Laws of 1977 to make it clear that the abolition of parental liability for fees in the Mental Hygiene and Social Services Law is retroactive. This was introduced by **Senator Padavan S. 7196**, and by **Assemblyman Kremer, A. 9988**. **RESULT:** Passed the Senate; was on the floor of the Assembly, third reading when the Legislature recessed — **no action**.

## B. COMMUNITY MENTAL HEALTH SERVICES

1. Reimbursement to the communities by the state at the rate of 75 per cent for MR services provided locally. **S. 7141 Conklin, A. 9215 DeSalvio** — **no action**.

2. Provision that interest on a mortgage for acquisition, construction or remodeling of a facility to serve the MR be a reimbursable expense, under contracts with mental health boards — **S. 8123 Marino, A. 10531 Kremer**. This bill failed to get out of committee in either House.

## C. EDUCATION

1. Provision that education of the handicapped be mandated from age 3 to age 21. A number of bills were introduced to this effect, including **Assemblyman Gorski**, and **Assemblyman Stavisky**, as well as **Senator Donovan**. Since, however, the Department of Education claimed that this would cost upwards of \$30 million a year, it did not go anywhere. The P.L. 94-142 mandate does not apply to New York State because it does not support pre-school classes, and the law makes this an exception. We disagree with this but we can only test it in the courts.

2. Provision that school districts be permitted to transport persons over 21 years of age to and from rehabilitation facilities, **S. 452 LaValle, A. 6900 Eve**. Although this is a bill that was well received by many of the legislators, because of the money involved, or they thought was involved, it did not come out of committee.

3. Amendment of the Education Law to do the following:

a. The number of parent members of Committees on the Handicapped shall equal that of non parents.

b. The impartial hearing officer shall be chosen jointly by the parent and school administrator.

c. There be provision for funds for the training of parent members of Committees on the Handicapped and,

d. The formula for state aid to school districts for the education of the handicapped shall be changed to conform with the previous formula, the state paying all excess costs.

**S. 9911** — **Senator Nolan**, a bill to provide that the parents of children on Committees on the Handicapped never be less than one-third of the total number and requiring the impartial hearing officer be appointed as we recommended.

**Senator Conklin** introduced a bill in a little different form, **S. 9906**, the counterpart was introduced through the Rules Committee in the Assembly, **A. 12854**. None of these bills went anywhere.

With regard to the provision for funds for the training of parent members of Committees on the Handicapped, this was not even introduced, but the Education Department is embarking on a program of this kind.

Finally, the formula for state aid to school districts was changed to provide, in a complicated formula, for more money for excess costs, but not in the simple manner in which we had proposed.

4. Provision that the Vocational Rehabilitation Act, Section 1004-a of the Education Law be changed to mandate the payment of \$1500 for long-term employment of the handicapped by voluntary agencies, and that clients be eligible for long-term employment immediately upon termination of OVR sponsorship for personal adjustment training, was divided into two bills. The first bill for \$1500 was introduced by **Senator Donovan, S. 7486**, and **Assemblyman M. Murphy, A. 9731**. The bill passed after considerable pressure from the Coalition of Rehabilitation Agencies, which we all know, and it became **Chapter 474, Laws of 1978 on July 11th, 1978**.

The other bill making persons eligible without having to wait two years, was introduced by **Senator Norman Levy, S. 8196**, and **Assemblywoman Amatucci, A. 10530**. The bill was passed and signed into law by the Governor on the same date, July 11th, 1978. It is **Chapter 475, Laws of 1978**.

5. To repeal that part of the Education Law amended in 1977 which removes transportation for children residing in state institutions and attending public school classes (Section 4402, subdivision 4 of the Education Law). Introduced by **Senator LaValle, S. 8171A**, passed the Senate and went to the Assembly Ways and Means Committee where it still languishes.

## D. OTHER MATTERS

1. That life insurance companies may not refuse to insure lives of the mentally retarded up to an aggregate of \$1500 on the sole ground of retardation, introduced by **Assemblyman Silverman, A. 181**, but we did not press for this legislation because at that time we had a company that was writing life insurance on the lives of the retarded.

2. Provision that the Criminal Procedure Law be conformed to recent decisions on constitutional rights with regard to ability to stand trial.

3. Provision that no political subdivision of the state may enact zoning laws restricting the use of any property to group homes for the mentally retarded or enforce any existing laws to such effect.

A bill to this effect, **S. 971A, Conklin; A. 541A Gottfried** was introduced but was then superceded by other legislation, which involved a procedure for notifying local communities and giving them the opportunity to find alternate sites.

This bill was **S. 8213 Padavan** and others, and **A. 30039A**. This bill was signed by the Governor July 6th and became **Chapter 468, Laws of 1978**.

This bill provides for notice by the proponent to the chief executive officer of the municipality of its intentions, including notice of description, nature, size, and the community support requirements of the program. The municipality shall have 40 days to approve, suggest other sites or object because it will result in the concentration of community residential facilities for the mentally disabled, etc.

If the municipality does not respond within 40 days, the sponsoring agency may establish a community residence at any site it shall select.

If the municipality suggests sites or areas that are not satisfactory to the sponsoring agency, the agency shall so notify the municipality which shall have 15 days to suggest alternative sites or areas for the proposed community residential facility or facilities.

In the event that the municipality and sponsoring agency cannot agree on a site, either party may request an immediate hearing from the commissioner to resolve the issue. The commissioner shall personally, or by a hearing officer, conduct such a hearing within 15 days.

The commissioner shall then make a determination within 30 days of the hearing. Thereafter, if the party does not like the decision, it may commence an Article 78 Proceeding of the Civil Practice Law within 30 days of the determination.

Finally, it is stated "a community residence established pursuant to this section and family care homes shall be deemed a family unit, for the purposes of local laws and ordinances."

4. Provision that parents of non institutionalized mentally retarded persons may qualify "as family care providers" as well as parents of "deinstitutionalized" mentally retarded persons. Introduced by **Senator Conklin, S. 4267B, A. 7694 Assemblyman Butler**.

According to the Director of the Budget, however, this would cost much too much and, therefore, an alternative was introduced for a demonstration project by **Assemblywoman Connelly, A. 12309**, requiring the commissioner to establish such a project for in-home care for mentally retarded with a lot of provisos in it. At any rate it is now in the Ways and Means Committee of the Assembly and has not yet been acted on.

5. Provision that the state should allow horse racing tracks an additional day of racing on which the state's share of the parimutuel receipts shall be divided among agencies serving the developmentally disabled.

No legislation to this effect was introduced as the Counsel for the Legislature seemed to feel that this needs a constitutional amendment.

## OTHER MATTERS THAT HAVE BEEN INTRODUCED IN THE LEGISLATURE, NOT PART OF THE ARC PROGRAM.

A. **Senator Padavan** introduced a bill, **S. 7427** to reduce the time from 5 years to 2 years in an institution for eligibility for **Chapter 620 funds**. It passed the Senate. No action in the Assembly.

B. A bill was introduced to provide for payment to matrons on buses, which is now required by law, **S. 5265 Caemmerer, A. 7365 G. Murphy**. This passed the Senate and is languishing in the Assembly.

C. Aid to private schools for the mentally retarded introduced by **Senator Conklin, S. 5988, A. 3924 Burrows**. Also introduced by **Senator Nolan, S. 5964**.

The bill originally intended to raise the fees to private schools from the present approximately \$650 to \$900 and to include payment to out-of-state schools approved by the commissioner, as well as removing the differential between upstate and downstate. It was changed considerably by **S. 10525**, which kept the rate at \$650, removed the differential between upstate and downstate, but did not include out-of-state. In addition, the commissioner of MR and DD is empowered to contract with these providers to furnish services over and above food and lodging up to a total not to exceed \$900 when added to the standard of monthly need, etc., etc. In other words, if the school provided services it may contract for up to \$250 more a year.

The situation in the private schools, as we all know, is becoming quite difficult with the failure of the state to provide any more reimbursement than the \$650 even though the cost of living has gone up over the last ten years. Some private schools are charging the parents additional funds, others are threatening to close down. Nothing is happening in the Legislature to change the situation at this point.

D. With the furor that went on over the operation of the Office of Vocational Rehabilitation, a bill was introduced to transfer **Vocational Rehabilitation** out of the Education Department into the Executive Department, **S. 8864 Donovan**, which was not pursued actively by the legislators that introduced it.

E. The New York State version of the **Wagner O'Day Act** was amended to include services as well as products in powers of the Commissioner of General Services, etc. to purchase from agencies for the blind and other severely handicapped. This is **Chapter 611, Laws of 1978**.

F. Bill to require the Commissioners of the Department of Mental Hygiene to prepare report concerning family care annually for the Governor and the Legislature and for the State Commission on Quality of Care. **S. 10451, Marchi, A. 13125 Kremer**, signed July 24th, 1978, **Chapter 552, Laws of 1978**.

Bill to amend the **Surrogate's Court Procedure Act** in relation to the guardians of mentally retarded persons, **S. 9398 Conklin, A. 13012 DeSalvio, Chapter 490, Laws of 1978**, signed July 20th, 1978. This bill provides the following:

1. The appointment of guardian of person or property in the court's discretion without a hearing upon application of (a) both parents or the survivor or (b) one parent and the consent of the other, or (c) any interested person and the consent of each parent.

2. After a hearing, (a) upon the application of one parent after citation of the other parent, or (b) any interested person after citation of each parent.

Since a number of surrogates have, in their discretion, not required a hearing, I don't see how this bill adds to the present law.

H. Bill to require that the 3 commissioners in consultation prepare for the Governor and Legislature a written evaluation concerning re-training and continuation of employment of persons whose employment in programs of the Department may be terminated because of planning contraction of such programs.

In other words, this is how we are going to guarantee jobs to CSEA employees whether or not they qualify, **Chapter 492, Laws of 1978**, signed July 20th, introduced by **Assemblyman Steingut, A. 12486**.

I. A bill was passed, **Chapter 469, Laws of 1978**, to establish a statewide registry in the Department of Mental Hygiene on community residential facilities for the Department to develop responsibility for planning, administration, licensing, etc., etc. of residential facilities, uniform data, etc., etc. In other words, this is to give a directory of all residential facilities of all Departments to give the community a handle to claim that a hostel for the mentally retarded is too much.

J. Finally, we must not forget **Chapter 23, Laws of 1978** which changed the name of **Willowbrook Developmental Center** to **Staten Island Developmental Center**.



# Community residences continue to grow

In spite of problems and opposition through the state, community residences continue to grow. Five ARC Chapters have reported on their new community residences: Clinton, Warren, Washington, Wayne, Erie and Sullivan.

## CLINTON HOUSES NINE

Clinton County Chapter's new community residence in West Chazy is a large white brick and wood frame house. It was built about 70 years ago by a local businessman for his family. The house is on about 1 and 1/2 acres with a large garage and a small guest cottage on the property. The setting is a quiet, rural community about 10 minutes by vehicle from Plattsburgh.

The house is a two-story building with a large kitchen, a separate dining room, and six bedrooms, one of which is used as a respite bedroom.

Renovations include a new electrical system and a fire and smoke alarm system. An area off the kitchen to the rear of the home has been remodeled into an apartment for live-in staff.

The first clients moved into the hostel on August 28th, the last on September 18th. Seven of the nine people living there came from Sunmount Developmental Center. All the residents are attending day programming at the A.R.C. Rehabilitation Center.

## WING HOUSE AND RIDGE HOUSE

Warren-Washington's Wing House is located in Fort Edward, New York. It is home to 11 mentally retarded adults. The lovely victorian home is located on approximately 2 1/2 acres of beautifully landscaped land. In the back yard there is an inground swimming pool surrounded by weeping willow, apple, and pear trees.

Ridge House, in Glens Falls, New York, houses 13 mentally retarded adults. The house is located within walking distance to shopping, movies, public transportation and the hospital.

This past summer, the Ridge House clients spent a great deal of time camping, fishing, boating and swimming under the supervision of their extremely dedicated houseparents, Steve and Anna Traver.

## WAYNE OPENS SUPPORTIVE APARTMENT PROGRAM

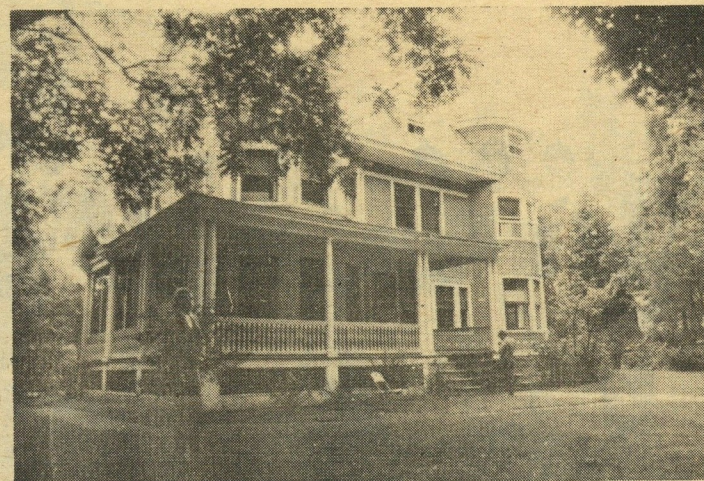
The Wayne County Chapter of the New York State Association for Retarded Children has recently opened their third residential program in Wayne County. The Association has committed itself to developing quality services and the most normalizing residential programming possible. This new residence, a supportive living program, located at Riverside Apartments Lyons, N.Y., is the result of the Association's effort to realize its commitment in the community.

Supportive living facilities in the form of supervised apartments, are an attempt on the part of the chapter to augment its existing services to allow for more flexibility and transition for individuals living in a more restrictive environment. The apartments will make it possible for the residents of the agency's two hostels or the Developmental Center to move on to a less restrictive living situation, while receiving supportive services. It will also allow the agency to provide residential services to the developmentally disabled of the community who may not need twenty-four hour supervision or institutionalization. The apartments will offer different levels of support and supervision, depending on the functioning level of the individual and particular needs.

Presently, the Association has leased a total of three two bedroom apartments to serve six clients. All the residents seem to function very independently and are comfortable in their new apartments.



WARREN-WASHINGTON COUNTIES CHAPTER GROUP HOME



CLINTON COUNTY CHAPTER GROUP HOME

## ERIE OPENS FIRST GROUP HOME

After considerable delay, the Erie County Chapter opened its first Group Home in suburban Orchard Park. It is the only Group Home in the area specifically for children. The four bedroom ranch, located on a spacious lot, is home for eight boys and girls age eight to fourteen. The home features two full baths, a wood burning fireplace, a family room and an in-ground swimming pool. The youngsters, who attend various schools in the area, are supervised by a staff of twelve.

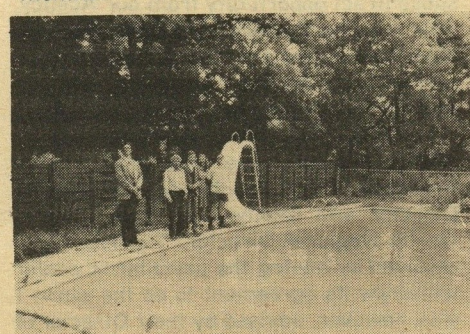
The home is leased by the Erie County Chapter from a private investor so it stays on the local tax rolls. The Erie County Chapter is currently negotiating for a second home for adults in Hamburg, New York. Local residents have voiced opposition to it at Village Board meetings. Plans call for it to be leased from a private investor in a setup similar to the home in Orchard Park.

## SULLIVAN HOME A FIRST

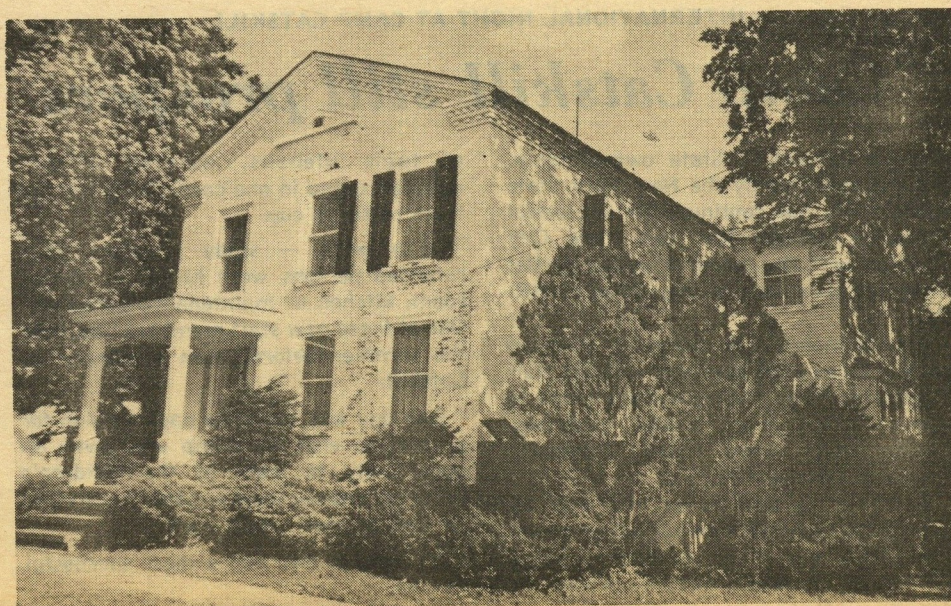
Several years ago, the Board of Directors of the Sullivan County ARC made a commitment to provide home-like residences for mentally retarded individuals both living at home and living in our State Developmental Facilities. The home, opened last summer in Woodbridge, is the first of six group homes planned by the Association to fulfill its goals.

The group home is designed to provide a home-like, family-like atmosphere for 10 residents, all of whom will be women attending A.R.C. programs. All will be over the age of 18. Residents receive training in homemaking, grooming, self care, socialization, money management, traveling and other skills necessary to become producing members of the community.

Within the next two years, the Sullivan County Association for Retarded Children will be opening five additional group homes. The second group home for the retarded will open in Woodbourne and will serve eight male adults. Ground will be broken for a newly constructed home in Monticello. Three other homes are planned to open within the next eighteen months.



THE SWIMMING POOL at the Warren - Washington home.



## Group homes have no effect on property values

The establishment of community homes for the mentally retarded has no effect on the real property values or the turnover rate of neighboring homes, a study released recently by the state Office of Mental Retardation and Developmental Disabilities reveals.

The research was conducted by Dr. Julian Wolpert of Princeton University for the office, which sought to obtain hard facts from an impartial source which it could present to communities apprehensive about the community residence program.

The group home impact study was carried out from May through August in 42 communities within Syracuse, Kingston, Valley Stream, Brooklyn, Albany, Buffalo, Hempstead, the Bronx, Yonkers and Troy. A matching sample of 42 other neighborhoods without group homes was used for comparison purposes.

The Princeton group concluded that properties next door, across the street, or a few doors away from a group home experience basically the same increase (or decrease) in sales value as properties farther away. Also, for the 12 months following establishment of a group home there is no acceleration of sales of neighboring homes. The "turnover" rate remains about the same as in similar neighborhoods without group homes.

The office also noted that the study brought several other facts to light concerning New York's community residence program for mentally retarded and developmentally disabled citizens. Analysis of group home sitings by the

Princeton group showed, "no evidence of neighborhood 'saturation' by group homes — within any given type of community or city."

The study group also reported that group homes don't stand out as "different" because of their type or size of structure or their function. Also, their residents are not generally conspicuous and group home maintenance — outward appearance and landscaping — is generally better than that of surrounding properties.

In all, Dr. Wolpert's staff analyzed data on 754 property transactions in the vicinity of group homes and 826 in the control areas. Of these, 92 group home neighbors and 89 neighbors of control group sites experienced before and after sales relative to the establishment of homes so that property value trends could be analyzed.

Similarly, sales of 153 neighboring properties and 178 control site properties took place within a year following establishment of the homes and could be analyzed for turnover rate.

The attitude of a community toward the placement of a group home for handicapped people in its midst is a "highly" complex matter to unravel. To measure such an issue would require an equally complex research effort.

Instead, he explains in the report, researchers have come to focus upon property values and property turnover rates as indicators of the strength of community attitudes toward establishment of group homes as they may become "translated into household relocation decisions."





INTERNATIONAL NIGHT AT CAMP CATSKILL

## Camp Catskill still prospers

Camp Catskill, a State owned camp, initially operated by the New York State Association, has continued its successful operation through the New York City Chapter, with the cooperation and partial financial assistance of the Office of MR-DD.

Approximately 140 campers attended each of three week sessions, with 127 staff members. Forty staff members came to Camp Catskill from foreign countries, among which were Israel, Denmark, England, Italy and Norway.

A Camp Catskill honor roll was instituted to highlight camper achievement and motivate other campers. Some notable achievements included proper use

of table utensils, walking without assistance and in one case, being weaned from bottle to cup.

In a work — study program, four retarded persons were hired as dining room, kitchen or maintenance personnel. One of these new staff members had, only the summer before, been a camper at Catskill.

One day was set aside each session for parents to visit the camp and given an opportunity to learn of the children's progress and see them engage in activities as well as meet camp staff.

All agreed, this was a most successful session.

## Award for "retarded" label

A Queens man, wrongly branded retarded for 12 years by the Board of Education, is entitled to \$500,000 in damages, according to the Appellate Division in Brooklyn.

By a 3-2 vote, the court ruled that Daniel Hoffman, now 27, was entitled to the first "educational malpractice" award in the state because of the "awesome and devastating effect" the board's actions had on his life.

In the case which will ultimately be decided by the Court of Appeals, the state's highest court, the majority did reduce the original jury award from \$750,000.

The case began three months before his sixth birthday, when Hoffman was in kindergarden in 1957. He was placed in a school for retarded children after he scored 74, one point below the cutoff, on an IQ test administered by a board psychologist.

The negligence occurred when the Board did not re-evaluate Hoffman's intelligence "within a two-year period so that a more accurate estimation of his abilities could be made," as the psychologist had recommended.

Instead, Hoffman was "closeted with mentally retarded children" until 1969 when a second IQ test found Hoffman had "good intelligence" with above average intellectual intelligence." The test correctly revealed that Hoffman was "so incapacitated by a speech defect that communication is very difficult for him

The tragic result, according to psychiatric testimony, which Shapiro incorporated into his opinion, was that Hoffman's family and school personnel "did not provide the stimulation that would otherwise have been given the child" because of "the assumption of the

correctness of the school's diagnosis."

This caused Hoffman to accept "his role as retarded," Shapiro said, "on the basis of his serious speech defect. Knowing that he could not speak as well as other children, his self image was already deflated, making it more likely that he would accept the conclusion that he was retarded.

## Workshop wages are earned income

In a ruling by SSI (SSR78-23), it was held that a disabled individual who is a recipient of SSI, unable to work in an environment other than a sheltered workshop (and where the services he performed in the workshop are not considered part of a rehabilitation program), his services are rendered as an employee within the meaning of the Social Security Act and his remuneration constitutes earned income within the meaning of the Act and is subject to the earned income exclusions.

This ruling is significant in that the disregard to earned income is \$65 per month, where the disregard for unearned income is only \$20 per month.

**Support Your  
Local Chapter**

# Soper is acting director of Broome D.C.

Charles S. Soper of Liverpool, New York has been named acting director of the Broome Developmental Center.

Soper said he wants to limit all 24 bed living units to 20 residents and open 2 new units to help accomplish that, if he can do it using the center's current staff.

Staff and parents' group leaders at the state - operated center and the center's former director, Dr. Erich R. Mamlok, had complained this year about crowding and understaffing on the units. Mamlok resigned recently, saying policies beyond his control led to his decision.

Soper, deputy director of treatment services at the Syracuse Developmental Center, was appointed acting director at Broome by Thomas A. Coughlin III, commissioner of the state Office of Mental Retardation and Developmental Disabilities.

Soper, who advocates an open door policy, appointed a special board to advise him on changes needed at the center. The board includes residents, staff members, parents, and other concerned persons.

More than half the units last year have held more than the 24 residents they are certified for, a source of concern to groups who charged the residents could not be adequately supervised with the staff provided.

Under Soper's plan, the units would be limited to ten two-bed areas. Four-bed areas on the units would be converted to dens or group areas. On each unit, two beds would be reserved to temporarily relieve families who care for their retarded children at home.

Soper said some clients are not in programs they should be in, but he has yet to determine why. Soper has a master's degree in nursing education. His interest in the mentally retarded developed as a boy, when his father was the first male occupational therapist in New York's schools for the retarded.

About a year and a half ago he joined the Syracuse Developmental Center, where he was second in command. Now he finds himself in the unique position of having strong ties to two centers that are searching for directors.

At Syracuse, Dr. George Buchholz plans to retire as director as soon as a successor is found.

A director does not have to be a psychiatrist or physician, but must have at least one year's experience in a position comparable to deputy director.

## Maurer in new post

Robert J. Maurer, formerly administrative assistant to Senator William Conklin, has been named to the post of Deputy Commissioner of Cultural Education by State Education Commissioner Gordon Ambach, with the approval of the Regents.

He will supervise the efforts of the Department's State Library programs, Museum and Science services, Mass Communications, the State Archives, and the Office of State History.

# How DMH helps retarded

The situation that we can only call cannibalizing by one division of the Department of Mental Hygiene on another has been brought to our attention by Tom Sprague, Executive Director of our Herkimer County Chapter.

It concerns activities of the Utica Psychiatric Center underbidding a contract by over 100 per cent from an industry in Herkimer County specifically being served by our Herkimer County Chapter.

I can only print here this letter to Commissioner Coughlin that Tom Sprague wrote hoping to get some kind of an answer from one division concerning the predatory activities of the other:

"Dear Commissioner Coughlin: I am writing to you to advise you of a situation that is of serious concern to our Agency here in Herkimer County.

As of late, the psychiatric and developmental centers in our area have been actively seeking, bidding and taking contracts from our workshop. Most recently, Utica Psychiatric Center underbid a contract by over 100 per cent from an industry in Herkimer County; specifically, Mohawk Data Sciences, for which we were doing the contract. In essence, they "stole" an existing crucial subcontract opportunity from our Agency. This was particularly upsetting since we have been doing the contract to the total satisfaction of the company at our negotiated price.

I immediately telephoned our County Administrator, the Company Vice President, our County Mental Health Director and finally, Mr. Pike, Mental Health Regional Director. The issue was resolved by having the psychiatric center withdraw its agreement to do the work. I was, however, advised by their Director of Vocational Rehabilitation that they will continue to actively seek subcontract work within our county.

Furthermore, the same center is contemplating to establish a 'satellite' workshop within a mile radius of two of our centers. As you undoubtedly know, and as a former ARC Director, we are unable to compete at these odds; i.e., paid State staff, minimal overhead costs, etc. After discussing this with our State ARC officials, I am respectfully requesting you to discuss this with your fellow Commissioners in the Department of Mental Health. In all honesty, we would have to admit defeat and close our workshops if, in fact, the developmental and/or psychiatric centers are going to be moving in the same competitive direction vocationally as we have been set up to do.

Please advise me when you have had an opportunity to discuss this with your colleagues in the Department of Mental Health. This has far reaching affects for all chapter ARC's operating sheltered workshops and would appreciate your keeping our State Administrative Office, specifically, Mrs. Joseph Weingold, advised of the situation.

Very truly yours,  
Thomas A. Sprague,  
Executive Director"

## Correction

In the September issue of "Our Children's Voice", under the article entitled, "Vocational Rehabilitation Bills Signed," credit was given to Senator Padavan for the introduction of the bill to mandate \$1500 for long-range employment program (SEP).

Credit should have been given Senator James H. Donovan, representing Lewis-Oneida Herkimer Counties.

Without Senator Donovan this bill would not have passed, and the credit must be given to him for his statesmanlike concern for this problem.



# Sterilization regs ignore ARC protests

The last issue of OCV printed the full text of the statement of this Association on the proposed regulations of the Department of Health, Education and Welfare on sterilization. The objection made was to the proposed regulation that the mentally retarded could not be sterilized under any circumstances because of the presumption of inability to give informed consent.

The Association for Retarded Children, the coalition of other agencies, The American Association on Mental Deficiency all protested this regulation as being unduly harsh and discriminatory against the mentally retarded.

The contention of the State Association is, that a duly appointed guardian of the person, appointed by the courts of the State of New York, has full authority to give consent to any major surgery, including sterilization.

The Association did not object to all the restrictions put into such sterilization, but merely said the retarded should be included if they were capable of giving consent, either personally or through a guardian.

Although these regulations apply only to Medicaid funding for sterilization, there must definitely be a spill-over into the thinking of others on sterilization of the retarded.

It is interesting to note that the regulation as finally promulgated on November 8, 1978, although giving the positions of many on various aspects, did not address itself to this point at all, nor did it in any way answer the objections of the State Association.

This is indeed a pity and should be remedied in some way by legislation in this state permitting such sterilizations under proper safeguards and with the consent of a duly constituted guardian appointed by the court.

## Correction

MR Hostels Blend Well, on page 5 of the September issue of Our Children's Voice, was written by Harvey McCagg of the Register Star Columbia County. We hereby give credit to Mr. McCagg for his article.

# New regs for education of handicapped protested

New amendments to Regulation 200 etc. of the Regulations of the Commissioner of Education, State Department of Education, have dictated that all private schools educating the severely handicapped must replace their present teachers with so-called certified teachers. These teachers are certified in Special Education, with no necessary connection with competence in teaching the severely handicapped.

A result of this would be that the agencies that have been educating this population for over 20 years, and are doing so now under contract with local school boards, would have to disregard entirely their experience with the education of the specially handicapped, get rid of their excellent staff who may be certified in other areas, such as Early Childhood Education, and employ people who may or may not be competent to handle the education of these children.

The protests have been numerous, calling for at least a grandfather clause to

enable the agencies to meet these standards.

An inquiry to the Advisory Committee on Education of Children with Handicapping Conditions to the Commissioner of Education elicited the information that this Committee was not even acquainted with the regulations before they were passed.

At this writing, nothing yet has been done to alter this situation.

Written protests, should be addressed to the Commissioner of Education, Honorable Gordon Ambach and Mr. Louis Grumet, Assistant Commissioner for the Division of Education of Children with Handicapping Conditions, Albany, New York.

## Convention Demand

(From Page 1)

mitted to transport persons over 21 years of age to and from rehabilitation facilities.

3. Amendment to Article 89 of the Education Law (Chapter 853, Laws of 1973) to provide the following:

A( That the number of members of Committees on the Handicapped shall not be less than 7 nor more than 9, of whom no fewer than 3 shall be parents of children with handicapping conditions. b) That if the parents of a handicapped child and the Committee on the Handicapped cannot agree on the program for the child, the disagreement shall be resolved by an impartial arbitrator who shall be chosen by the parents and the school administrator; if they cannot agree on the choice of the arbitrator, each shall choose one arbitrator and the two so chosen shall choose a third; in this process of choice, the parents shall have access to the qualifications of the proposed arbitrators.

4. Repeal of that part of the 1977 amendment to Article 89 of the Education Law that removes transportation for children residing in state institutions and attending public school classes.

## D. OTHER MATTERS

1. Provision that life insurance companies may not refuse to insure the lives of mentally retarded persons on the sole

# Hepatitis B carriers excluded NYC judge orders school admission

## JUDGE ORDERS ADMISSION

On September 7, 1978, the Board of Education of New York City decided to exclude approximately 50 severely retarded children from public school and to send them to developmental centers for their education. The children were identified as hepatitis B carriers. Commissioner Coughlin of the New York State Office of Mental Retardation and Developmental Disabilities, one of the defendants in the Willowbrook class action (New York State Association for Retarded Children, Inc. v. Carey) sought and obtained an injunction prohibiting the isolation and transfer of these children, 42 of whom were Willowbrook class members. Hearings were held on September 11 and 12.

Hepatitis B is an extremely common illness, especially among children. The acute stage, which is rare, is generally accompanied by jaundice and inflammation of the liver. The acute stage, particularly with children, may also be quite mild and be mistaken for a flu and fever.

## NON-ACUTE REACTIONS

One of the two reactions occur in non-acute cases. In one case, individuals may become infected with hepatitis B, but because their body defense system builds up sufficient antibodies, the hepatitis B virus, or antigen, will be eliminated. The individuals would then become immunized to the disease. In the other case, the body does not create sufficient antibodies to eliminate the hepatitis B antigen. An equilibrium is reached where the person appears to be healthy, but will possess the antigen in their blood. Such people are known as carriers. One carrier can transmit the Hepatitis B antigen to another, who may also become a carrier, without either having passed through the acute stage of the illness.

## HEPATITIS B AFFECTED 98 PERCENT OF RESIDENTS

Testimony at the hearing elicited the fact that some years ago hepatitis B ran rampant at Staten Island Developmental

ground of retardation.

2. Provision that the Criminal Procedure Law be conformed to recent decisions on constitutional rights in regard to ability to stand trial.
3. Provision that parents of non-institutionalized mentally retarded persons, may qualify as "family care providers," (as well as parents of de-institutionalized mentally retarded persons.)
4. Provision that the fees paid by the state to private schools, whether in-state or approved out-of-state, be increased from the present \$650 a month to a limit of \$900 if services other than food or lodging are provided, and that the differential between upstate and downstate be removed.
5. Provision that the Office of Vocational Rehabilitation be transferred from the Department of Education to the Executive Department.

## E. COMMUNITY RESIDENCES

With respect to the recently passed Community Residences legislation, repeal of that portion of the statute which provides for requiring of notice to the municipality of intent to establish a community residence or, in the alternative, an amendment requiring that the municipality designate an alternate residence with greater specificity than that now required and to require that the alternate residence be of comparable quality, currently available and at a comparable price and one comparable terms.

Center (formerly Willowbrook) because of the overcrowding and lack of hygienic safeguards. It was estimated that 98 percent of all residents contracted the hepatitis antigen and are now either carriers or are immune. Medical experts believe that 3 out of over 1000 people in the community are carriers and that 3-4000 non-handicapped children in the New York City public schools are carriers.

Whether a carrier is indeed sick was one issue raised at the hearing. One physician stated that carriers were essentially healthy; another stressed that carriers were ill, and that over a period of 20 years, they may become seriously ill.

Hepatitis B is a disease of limited communicability.

Notwithstanding the guidelines of the Department of Health and the Public Health Service, the Board of Education proposed to return the 50 known mentally retarded carriers to developmental centers indefinitely.

Judge Bartels, the federal court judge monitoring the implementation of the Willowbrook Consent Judgment, held that the Board of Education had overreacted to the Hepatitis B problem, and that:

"... the most serious consequences of the Board's plan would be felt if the pupils were sent to school in developmental centers. The court is convinced that this would have a severely retrogressive effect on the development of these children, and would be an enormous setback to the process of normalization of these children."

The Judge found that the risk of contagion of Hepatitis B among mentally retarded children was not substantial enough to justify their exclusion from school, and that the Board's plan violated Section 504 of the Rehabilitation Act of 1973 since the Board had no plans to exclude non-handicapped carriers from school. Section 504 states:

"No otherwise qualified handicapped individual 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 financial assistance."

Judge Bartels also held that the Board's proposed policy violated the Education for All Handicapped Children Act, P.L. 94-142, the Willowbrook Consent Judgment, and the children's constitutional rights to equal protection and due process, as there were available less drastic remedies:

"We find that upon taking simple prophylactic and classroom management measures which it is in the Board of Education's power to take, there is no substantial risk of communication of Hepatitis B from carrier pupils in the . . . special education programs that justifies their discriminatory exclusion from the benefits of a public school education, particularly in view of the unavoidable and irreparable harm such exclusion would work on the students involved."

The struggle of mentally retarded carriers, however, continues. The Board of Education has formulated another policy recommending segregation of these children in special classes within the public schools. New York State Association for Retarded Children opposes this plan as does the Commissioner of OMRDD and the other plaintiffs in the Willowbrook action. Any segregation unreasonably stigmatizes the children and denies them the right to associate not only with non-handicapped children, but with handicapped children as well. A court hearing was held in November to challenge the proposed plan.

# Rome DC Chapter protests transfers

The transfer of residents (repatriation) to other developmental centers or community based placements has raised anger and frustration among the parents and members of the A.R.C. at Rome Developmental Center, according to Ethel Lombard, president of the Rome Developmental Center Chapter.

The transfers continue in spite of the oral wishes of the residents or the wishes of the parents. According to Mrs. Lombard, there is much concern about the quality of care that residents will receive once they are transferred. Will the doors be shut in the faces of residents in different communities because of the insistence of the department of Mental Hygiene on these transfers? Or will they be placed in a center that is already overcrowded and understaffed?

Mrs. Lombard says, "We know, because of the lack of proper funding, the answer is yes. Again the retarded are caught in the middle."



## Bill forbids DMH from hiring certain felons

A bill of great significance to the safety of the residents and patients in the Department of Mental Hygiene, was introduced in the 1978 session by Senator Padavan and Assemblyman Levy.

This bill amended the Mental Hygiene Law to disqualify certain felons from employment as an officer or employee of any hospital, school, institute or other facility in the department or in the facilities developmental corporation.

Among the designated crimes were assault in the second degree, assault in the first degree, criminally negligent homicide, manslaughter, murder, abortion, in the first and second degrees, rape, sodomy, sexual abuse, etc.

The purpose of the bill was to put an end to the liberal hiring practices of the Department of Mental Hygiene, which has

placed persons convicted of felonies such as this, assault against persons, in the position of authority and even control over patients or residents in the institutions.

Although not great in number, there have been instances of abuse of residents and patients by persons who have been previously convicted of such felonies. It is to prevent the possibility of such instances occurring, and even the exposure of helpless people to the possibility of convicted felons, this bill was introduced.

Although fully cognizant of the necessity of rehabilitating convicted felons, where such felonies are against the person by crimes of violence in one way or another, it is the opinion of this Association that the helpless patients and residents should not be exposed to possible danger in this manner.

## Due process on discharge

The Supreme Court of Albany County, New York, a lower court in New York State, recently ruled that a probationary employee of the New York State Division of Youth's Industry State School was improperly deprived of "liberty" protected by the Fourteenth Amendment of the United States Constitution because he was terminated **without a hearing** for allegedly being involved in an incident of brutality against a resident. The court ordered the State to provide the employee a due process hearing, but denied the employee's request for reinstatement or backpay until a hearing could be concluded. **Hill v. Edelman**, 92 Misc. 2d 485 (Sept. 9, 1977).

### BASIS FOR THE DECISION

Crucial to the court's holding in this case was a finding that the alleged incident of brutality received publicity and notoriety in the press. The court reasoned:

"Where the charges upon which the probationary employee is dismissed have the effect of stigmatizing the employee so that he is not able to find other employment, probationary employees have been granted due process protection prior to being relieved of their employment."

The court relied upon the recent Supreme Court case of **Codd v. Velger**, 97 S. Ct. 882 (1977). In that case, however, the United States Supreme Court **denied** a hearing to a nontenured employee who

claimed to be stigmatized by the mere fact that he had been discharged. There, the Court ruled that an employee's "liberty" interest is not disturbed by the mere fact of termination. Only if the employer creates and disseminates a false and defamatory impression about the employee in connection with his termination is such a hearing required," according to the **Codd** Court.

### SIGNIFICANCE

If this case is "good law", it indicates that public employers in New York State, and perhaps nationwide, ought to implement stringent procedures within the jurisdiction to protect against a publication of the reasons for the discharge of a probationary employee. In order to obviate the necessity of granting each terminated employee an expensive due process hearing or defending against perhaps an even more expensive subsequent lawsuit, public employers would thus be well advised to re-examine their termination procedures pertaining to probationary employees and to make changes where appropriate. Presumably, if a probationary employee is merely terminated without the public jurisdiction providing reasons to the press or the public, then there has been no "publicizing" or "stigmatizing" of the person's name or reputation and, therefore, no need for a due process hearing.

## Carey promises help - later

In response to the questions asked by the Association, as to whether the Governor supports program of 100 percent funding for community mentally retarded, as well as for the deinstitutionalized, Governor Carey's response promised something characterized by a member of the Association as "yes, but in the sweet bye and bye or hereafter".

In a release dated October 31, 1978, the Governor announced he asked his Special Assistant for Health Affairs, Dr. Kevin M. Cahill, to work with the leadership of the Department of Mental Hygiene, etc. to develop legislation to improve the State's funding of local programs for the mentally disabled.

While, the State Association asks for parity, the Governor talks of "equity" saying "the program would promote equity in the funding of services for the mentally disabled. This will be accomplished by authorizing 100 per cent state payment for all increased non-federally aided service".

The operative word is **increased**. Obviously the Governor expects to have the State pay it 50 per cent for all existing services, the services which the voluntary agencies are begging themselves to support and, only over a two-year period, would he phase in this 100 per cent for "future budgetary increases".

This does not fit with his statement that "the State's current program of 50 per cent state aid for service to the mentally disabled has not stimulated sufficient growth in these vital community programs".

Nor does it fit with the statement "the key objective of the legislation will be the elimination of service biases based on method and source of funding".

A spokesman for the Association said, "although the theory, the rationale for making a change is all there, in fact it is the same process of squeezing the dollar and not biting the bullet that has to come".

It is the contention of the Association that this backwardness is due to the fact

## Employer of Year award



EDWARD LICENCE, Chairman of the Awards Committee, presenting Employer of the Year Award to James Papero of the Rochester Institute of Technology.

## Study shows retarded are not dumped

A federally funded study of state developmental centers has shown mentally retarded persons are not being dumped into Western New York communities, the director of the study said.

The study, scheduled for completion in September 1979, is to evaluate the impact of deinstitutionalization on mentally retarded persons, their families and the community. Conducted by the UB Division of Community Psychiatry, it is being funded by the Department of Health, Education and Welfare.

The final year of the study will deal with four developmental centers throughout the state. The first two years of the study, however, dealt with the West Seneca Developmental Center and the J.N. Adam Developmental Center in Perryburg, Cattaraugus County.

Although data from the first two years of the study are yet to be completely analyzed, some preliminary conclusions have been drawn.

Dumping is not a problem in Western New York but there is a need for more

transportation to get the discharged patients to programs.

Also, there appears to be a need for more respite services for parents and family care providers who care for mentally retarded persons discharged from developmental centers.

Respite services give parents and family care providers the opportunity to leave their children or clients with responsible people during vacations or at other times when they are unable to provide care.

The study will recommend changes in some practices and service when it is completed. Until then, it would be difficult to say specifically what recommendations will be made.

The study is different from other studies conducted throughout the nation because it focuses on the parents and family care providers as well as on the individual discharged from Developmental centers.

## Mother's age may not affect Down's syndrome

The Wall Street Journal, in an issue last summer, included this information in a special report on medicine:

Giving birth to a baby with Down's syndrome, the medical retardation once called mongolism, long was thought to be primarily a risk of women over the age of 35. That's why fetal chromosome tests are urged for older pregnant women and why genetic counseling is suggested for older couples.

But new studies show the average age of women giving birth to Down's babies is dropping sharply, reports Dr. Lewis B. Holmes of Massachusetts General Hospital in Boston. Prior to 1970, records show that women over 35 accounted for only 13 percent of all pregnancies, but they bore 50 percent of Down's infants. Today, 65 percent to 80 percent of all Down's babies are borne by women under 35.

There also is new evidence that the father can be a source of the chromosome abnormality leading to Down's syndrome, relieving mothers of some of the guilt feelings, says Dr. Holmes.

that mental retardation and developmental disabilities are tangled up with mental health, alcoholism and substance abuse: in effect the problem's solutions are quite different for these various disabilities.

The Association is going ahead with its plans, rejecting the Governor's statement, to have legislation introduced for 100 per cent funding.

As one of the leaders in this field said, "it will relieve the local governmental agencies of millions of dollars that it is now contributing towards these programs when in fact it is a State responsibility, as it is a State responsibility for the deinstitutionalized".

It must be noted nothing in the State Association's program deprives the deinstitutionalized of any advantages they now have. The word is "parity", not discrimination.



## SSI

# Wages alone cannot decide gainful work

The Administrative Law Judge of the Bureau of Hearings and Appeals of the Social Security Administration in Albany recently held that a person whose wages exceed an average of \$400 per month gross from competitive employment and who still needs attendant home care and vocational counselling and support is not engaged in significant gainful activities to the extent of eliminating him from SSI.

The person involved was denied SSI on the premise that his earnings of over \$400 per month gross exceed the amount he can earn under SSI regulations. Mr. J. had been a resident at Wassaic Developmental Center from 1943 to 1957 and subsequently lived in several family care homes. In April 1977 he began to work at a diner and became a resident of a community residence in September 1977.

In making the decision, the judge did not use wages alone in determining the disability for the claimant. The argument was made that his expenses at the community residence weren't related, to the extent they removed him from the category of being engaged in substantial gainful employment.

The claimant still needed counselling and educational support services at the hostel and was not able to maintain himself solely through his competitive employment. Examples of such support would be: getting to work on time, transportation, particular areas provided by the hostel that would most definitely affect the work productivity.

The judge agreed that these were a continuation of sheltered employment and that removal from SSI rolls was not justified.

## Subchapter C Day treatment

The New York State office of Mental Retardation and Developmental Disability (OMRDD) has received the first group of proposals for day treatment services for the severely mentally retarded to be funded under provisions of Subchapter C of Medicaid. About \$5 million has been budgeted for this fiscal year, the first time the option has been made available through the developmental centers.

The funding mechanism, initiated with the help of legislation approved by the State Legislature last year, makes available fully Medicaid-funded services for mentally retarded people living in the community who might otherwise only find needed services within an institution.

There is no local share of support for this program. The entire cost will be borne by the State and Federal governments.

With Federal concurrence, OMRDD has taken advantage of provisions of the Social Services Law which allow long term care facilities to provide a range of services to people who are not their residents.

Developmental centers qualify under the definition as intermediate care facilities for the mentally retarded. Voluntary agencies may contract to provide the required services.

The Subchapter C program should help correct a growing inequity in funding for day-care services for the mentally retarded which finds former institution residents fully State-Federal supported under chapter 620 or 621 of the Social Services Law while those never institutionalized or briefly institutionalized cannot be so supported even though as much in need of the same type of services.

Such people who are "at risk of institutionalization" can now be treated in a Subchapter C supported program.

Those eligible include severely mentally retarded, cerebral palsied, neurologically impaired, epileptic and autistic people. A Subchapter C contract provides a \$28 per diem.

Information or application for Subchapter C proposals can be obtained from or made to the appropriate County Service Group Office of the State Office of Mental Retardation and Developmental Disabilities. The New York City and Long Island County service group is located at 2 World Trade Center, New York City. All three other groups are located at the OMRDD building, 44 Holland Avenue, Albany, New York 12229.

## SSI eligibility bills pass House, fail Senate

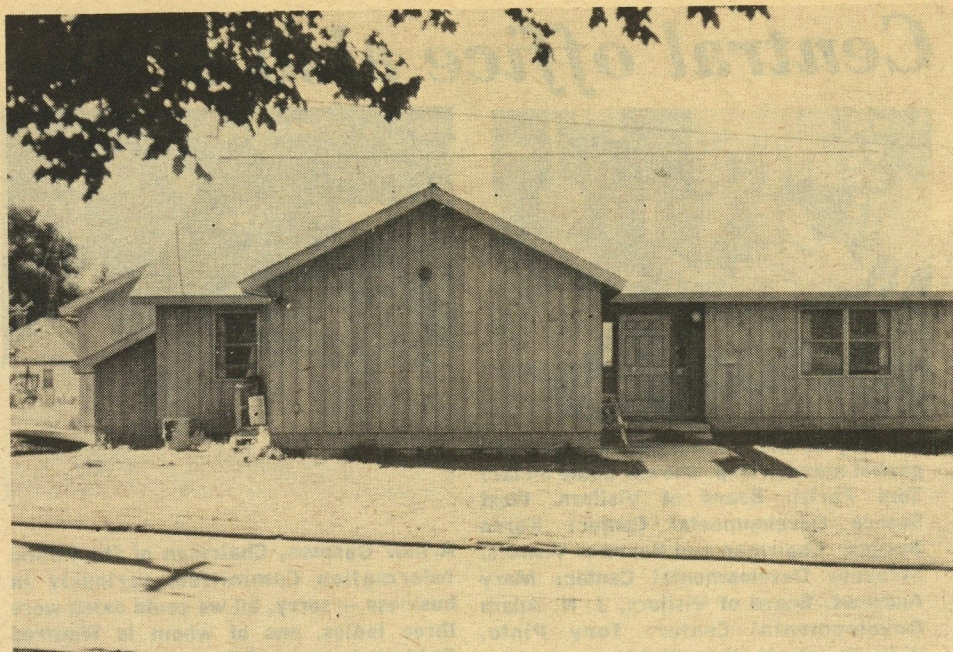
The past session of Congress in the House of Representatives passed two bills of great significance to the mentally retarded. The first was H.R. 10848 (Stark) which provides that an individual who applies for SSI on the basis of disability shall be considered presumptively disabled if he has received Social Security or SSI as a disabled individual within the preceding 5 years. In other words, a person who is on SSI and then gets a job removing him from SSI and then thereafter loses the job, can get back on SSI under these circumstances. This is now reserved for only the aged and the blind.

The second bill is H.R. 12972 (Keyes-California) which raises the SGA (substantial gainful activity) test for the

disabled to the same level as the blind; provides an earnings' disregard for work related expenses for the disabled as is now provided for the blind, and finally provides a disregard for the costs of attendant care for the blind and disabled.

Both of these bills failed in the Senate in the last minute rush to go home, but we are in receipt of a very encouraging letter from Senator Javits who introduced legislation in the Senate along the same lines that these matters will be considered favorably in the next session of the Congress.

In the meantime, retarded are suffering injustices compared to other handicaps, including the blind. All efforts to bring up the other handicaps to the same favored situation at this point have not succeeded.



A VIEW OF THE FRANKLIN GROUP HOME

## A new approach to group homes

In 1976, the Franklin County Chapter embarked upon a new program unlike any attempted by other Chapters. The agency began a Community Residence program to meet the needs of its clients. But it was not planned by the usual method of purchasing property then renovating it to meet code.

The Franklin County Chapter, in cooperation with Adirondack Concepts, Inc., designed and built its first Community Residence for ten mentally retarded ambulatory adults in Tupper Lake, N.Y., and opened its doors in April of 1977. In March of 1978, the Chapter opened

its second newly designed and constructed Community Residence in Malone, N.Y. for ten severely retarded adults. This year, the Chapter is getting ready to construct a newly designed Community Residence in Saranac Lake, N.Y. for 12 mentally retarded senior citizens, and will also operate a unique day program for those 12 clients.

The Chapter finds that designing and building new homes for the Mentally Retarded poses no greater problems than following the more usual way of purchasing existing property.

## Problems of deinstitutionalization

Peter Young, Executive Director of the Orange County Association for the Help of Retarded Children, raised a question regarding community placement in a letter to Commissioner Coughlin. Young's letter addressed the question of the level of functioning of the clients coming out of Willowbrook. Young stated that he met with some serious problems, not only in Orange County, but in other areas of the state dealing with the Willowbrook class.

The judgment requires community placement for every member of the Willowbrook Class, some 5600 people. The plaintiffs in the case, of which New York State ARC is one, has said that all of these people should be, and will be, provided for in ten bed facilities if they are severely or profoundly retarded, 15 beds if they are mildly or moderately retarded. As the population of Willowbrook is run down, currently at some 1600 people, many of that 1600 would appropriately be cared for within an institutional setting if they were not involved with the Willowbrook case. Presently, many of the people who are coming out of Willowbrook right now are the same type of people whom the state plans to have in residence at Letchworth and Wassaic when the five year plan is completed.

Coughlin admitted this is causing a major problem with regard to the mix of functional abilities in the community residence program. Yet, in order to keep the homogeneity of such a residence, that type of arrangement might be necessary just to meet the requirements of the Consent Decree. This gets to be a problem only in certain parts of the state.

Although there are some people at Willowbrook who meet the criteria, an agency is not expected to take in people who need 24 hour medical supervision.

Although the Orange County ARC has rejected some of these people, Coughlin suggests they go back and do a further survey of those people in need of placement who do meet the program criteria.

In the meantime, Coughlin promised to look into the situation further.

## Tennessee removes zoning barriers

Zoning laws, restricting group homes for mentally retarded persons in residential neighborhoods have been superseded by Tennessee House Bill No. 777.

Signed into law by Governor Ray Blanton, the measure allows any home in which eight or fewer unrelated mentally retarded or physically handicapped persons reside to be classified as a single family residence.

Such a home may also include two additional persons acting as houseparents or guardians who need not be related to each other or to any of the mentally retarded or physically handicapped persons residing in the home.

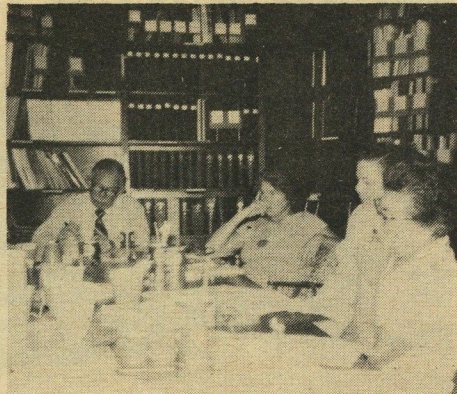
The Act, which went into effect on April 14; (1) takes precedence over any provision in any zoning law or ordinance in Tennessee to the contrary; and (2) does not apply to such family residences which are operated on a commercial basis.



## Central office also active



Meeting of the Institutions Committee's partial membership. Shown, Louie Striar; Toni Parisi, Board of Visitors, West Seneca Developmental Center; Karen Burgess, Chairman and Board of Visitors, Syracuse Developmental Center; Mary Andrews, Board of Visitors, J. N. Adam Developmental Center; Tony Pinto, Willowbrook. (Left to Right).



Arthur Gasman, Chairman of the Public Information Committee, seriously in business — sorry, all we could catch were three ladies, one of whom is Winifred Rabbitt, in the middle.

## How "advance funding" is working for agencies

Under an amendment to the Mental Hygiene Law, the Legislature recognized agencies under contract with their Mental Health Boards are experiencing serious cash flow problems. To answer this, the law was amended to provide for "advance funding," which means that ten days after the contract is signed the first quarter of the contract shall be remitted to the agency.

The fly in this ointment, however, is that money is delivered, not to the agency delivering the services, but to the County with whom the agency has contracted under the law. The Office of Mental Retardation seems to think it is reasonable that another thirty day period should elapse after this before the agency receives the funds.

In the meanwhile, however, the agency may have to go to the bank to borrow money, interest on which is not reimbursable because the Governor vetoed such a bill the year before last.

In a letter to Mr. Weingold, Susan Swift, Assistant Director for Program Operations, on August 15th wrote "The advance payment procedure is new for all of us but is apparently working well at this time."

We have news for everyone. It is not working as well as the Office of Mental Retardation thinks it is.

If the intent is for the agencies delivering the services to get the money, they should go directly to the agency which should not have to wait forty or even thirty days for the funds.

## Death in state group home

Last fall, Robert J. Kalmanash, a 27-year old patient in a state-run home for mentally retarded adults, was found dead. The Medical Examiner's report determined that the death was "natural and accidental." But Paula Kalmanash, Robert's mother, has filed suit against the home's staff and operators, charging that her son was "found dead in circumstances indicating the possibility of wrongful death and not consistent with natural death."

The Larchmont woman maintains that, although Robert had epilepsy, he had never lost consciousness. In addition, Mrs. Kalmanash has asserted, the circumstances in which he was found were inconsistent with his very strong personal habits. Mrs. Kalmanash said that despite repeated requests, she had been unable to obtain a report by Charles C. Donoghue, an

investigator in the Division of Mental Retardation in the Department of Mental Hygiene assigned to the case; instead, she said, she had received a list of the people Mr. Donoghue said he had spoken to about the case.

Mrs. Kalmanash, who said that she had argued with the staff on many occasions before Robert's death about the quality of health care at Lincoln House, added she was still waiting for the answer to that question. "I would like to know what happened," she said. "I am entitled to that."

Mr. Kalmanash, who is 65 years old, and Mrs. Kalmanash, 62, said they had decided to place Robert in an institution because they were afraid he would outlive them. "In less than three months," Mrs. Kalmanash said sadly, "he was dead."

## News and views

# Education report

At the State Convention Workshop in Rochester, the questions came fast and furious. We hope there were lots of answers. One thing was certain — we all have to be kept as informed as possible — we have to be more active in letting the legislators know what we want, and also the Regional Associates. It was emphasized that, if any parents are having a problem that cannot be solved at the local area, they should contact their Regional Associate of the State Education Department.

Many times, the problem is due to lack of communication and not to non compliance, so the representative from the State Education Department urges you do not hesitate to contact him.

It was very heartening to note Mr. Lawlor taking copious notes to bring back to Assemblyman Virgilio. Our parents on the panel gave out valuable information on individual cases that were brought up from the audience, and the representative from the Office of Mental Retardation and Developmental Disabilities indicated to us that she is very well aware of many of the problems involved in transportation, COH etc., and it appears that there is beginning to be more coordination between that agency and the Department of Education.

At the Education Booth, there was much mimeographed material for everyone to pick up — reproduce for their own chapters — use in newsletters etc. Below are a list of a few of the things — and if you didn't get them, you can write to us for a copy of same — Spread the word and the information around.

1. Reprint — Parents — Powerful and Necessary Allies — Roger K. Roth
2. Reprint — Positive Attitudes — A Must for Special Programs in Public School
3. Reprint — Parent Involvement — by Maynard C. Reynolds
4. Reprint — Excerpt from "Closer Look" on Vocational Education — (Summer 1978)
5. Reprint — Recreation Programming for Developmentally Disabled School Children by Richard M. Kamp.
6. How to be an Effective Member of a Committee on the Handicapped
7. How to Evaluate a School Program
8. Policies for the Development of

Written Individualized Education Programs

9. Parent and the Professional Suggestions for Professionals
10. Parent and Professional Suggestions for Parents
11. Writing to School Officials
12. Do you Know your ABC's

Thanks to all those chapters who have been printing items of interest in their newsletter pertaining to Education - Herkimer County and Orleans chapter both quoted from our Edu-Letter in their last issue.

Our Committee would love to receive copies of your newsletters so we can learn from you — won't you put us on your mailing list?

### THE NEW EDU-LETTER IS NOW OUT

If you are not already on our mailing list please sign your correct name, address and telephone number, and chapter affiliation, on the tearoff below and return immediately. Feel free to duplicate this tear-off and sign up any other persons who may wish to receive this valuable newsletter.

I wish to receive the Newsletter of the Education Committee of the N.Y. State Association for Retarded Children.

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

TEL. NO. \_\_\_\_\_

CHAPTER AFFILIATION \_\_\_\_\_

Return to:  
Betty Pendler, Chairperson  
Education Committee  
N.Y. State Association for  
Retarded Children  
175 Fifth Avenue, N.Y., N.Y. 10010

## Support Your Local Chapter

### NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

175 Fifth Avenue

New York, New York 10010

**Our Children's Voice**  
Retarded Children Can Be Helped

Non-Profit Org.  
U. S. POSTAGE  
PAID  
New York, N. Y.  
Permit No. 8245