

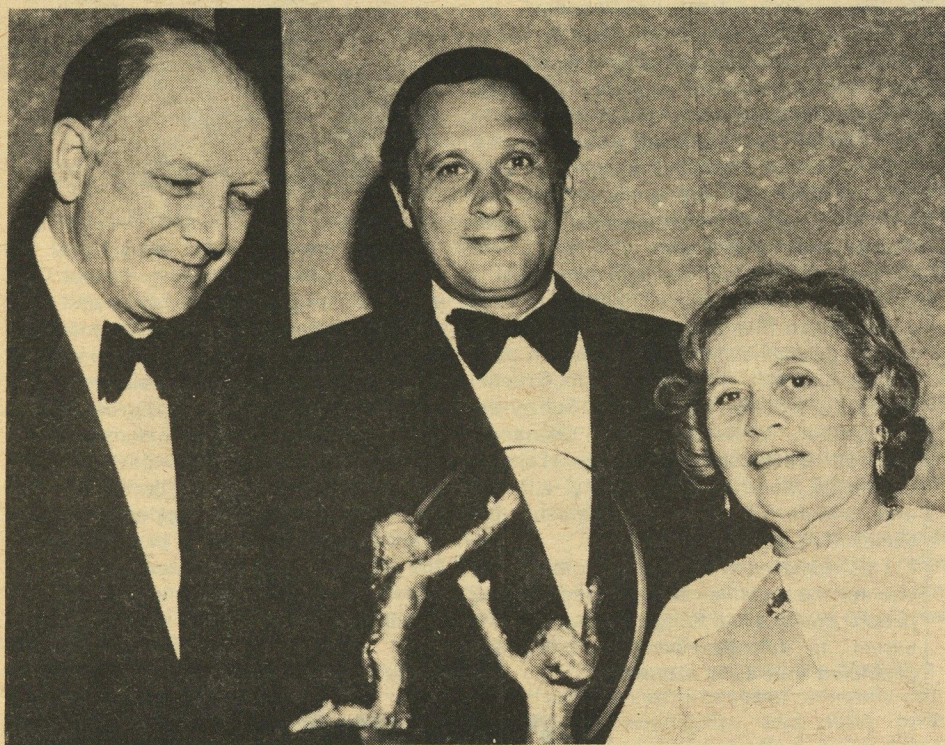
# Our Children's Voice

Retarded Children Can Be Helped

Vol. XXXI No. 3

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

September 1979



New York State Senator Norman J. Levy (center) received the Nassau AHRC's 1979 Humanitarian Award at that organization's annual Rose Ball which was held on June 16th at the New York Hilton Hotel. In the photo with Mr. Levy, who was cited during the presentation for his legislative leadership on behalf of the retarded, are Leonard Olsen, president of the Nassau Chapter and Helen Kaplan, Executive Director. Story Page 16.

## Christmas design winners

We are pleased to announce the winners of our 8th Annual Christmas Card Design Contest sponsored each year by the Association in its efforts to recognize the creative and artistic talents of those who are mentally retarded.

Invitations to participate in the annual event are distributed through our local chapters and developmental chapters, and extended to both adult and children services levels, as well as to public and private schools throughout New York State.



**FIRST PRIZE WINNER**  
Eleanor Walkden

The response this year resulted in 111 entries and covered a wide variety of Christmas and winter themes. Edward B. Licence, Chairman of the Scholarship and Awards Committee, was assisted in the judging, which took place in the NYSARC Conference Room, by Shirley Licence; Diane C. Brandt, creative Director of Williamhouse - Regency, Inc.; Catherine Burke of Nassau Chapter; and Geraldine L. Sherwood, Program Coordinator - state office staff.

The winning designs, which are reproduced as Christmas cards for the 1979 season are:



**SECOND PRIZE WINNER**  
Joseph Spencer

First Prize — \$100 U.S. Savings Bond, Eleanor Walkden, submitted by West Seneca Developmental Center.

Second Prize — \$50 U.S. Savings Bond, Joseph Spencer, Submitted by Wassaic Developmental Center.

Honorable Mention — \$25 U.S. Savings Bond, Elaine Fountaine and Stanley Popielarz, Submitted by Oswego Industries.

### PROFILE OF TWO ARTISTS

West Seneca Developmental Center presents our First Prize winner of our annual Christmas Card Design contest, Eleanor Walkden. Congratulations, Eleanor!

Mary Dafchik, Miss Walkden's Social Worker, advises us that Eleanor is a 31 year-old woman with Down's Syndrome. At present, Eleanor resides at the West Seneca Developmental Center where she attends the Sheltered Workshop on a half-day basis. She also attends Occupational and Recreational Therapy classes daily. Eleanor enjoys coloring and drawing in her leisure. She enjoys all activities and is a very sociable person. Eleanor is a sweet

(Continued on Page 16)

## ARC Legislative Program fails

### No community program relief; Private school aid passes

In a most disappointing legislative session, only one measure of the ARC program passed both houses. This was the increase of aid to private schools for mentally retarded adults from \$693.46, if in New York City, and \$669.46 outside New York City, to \$900.00 a month depending on provision of services over and above board and lodging (S-11A) Padavan.

In addition, the differential between New York City and upstate was virtually eliminated by Chapter 314 - 1979 (A. 8126 - rules).

In probably the most disappointing session in our memory, the following failed passage:

**The Removal of Parental Liability** — (S. 910 — Padavan; A. 1133 Kramer) for fees to the institutions incurred before August 5, 1977. This passed the Senate, but failed in Assemblyman Kremer's committee.

**Transportation to Public Schools for Developmental Center Residents** (S. 1069 Lavallo — A. 1378 Virgillio). This amended the education law to provide for transportation for public schools of school age children residing in state institutions.

**Composition of Committees on the Handicapped** (S. 331 Nolan). Change the composition of committees on the handicapped to include more parents and provide for hearing offices acceptable to the superintendent and the parents.

**Education Beyond Age 20** (S. 364 Flynn; A. 390 Stavisky) amended the education law to provide for continuing education for the handicapped beyond the age of 20.

**Mandated Education from age 3** (A. 1408 Stavisky).

**Removal of Office of Vocational Rehabilitation from state education department to the executive department** (S. 2185 Donovan; A. 1976 Kramer).

And, finally, the bill (S. 2854 Levy; A. 3708 Kremer) to provide 100 percent state aid for local services, as now provided for the de-institutionalized, failed to pass.

In addition, a number of bills, not part of the ARC program but supported by the ARC, also failed. These are:

Forbidding employment in the Department of Mental Hygiene of persons convicted of certain felonies (S. 95 - Padavan; A. 1205 Levy).

Sexual intercourse with a resident in an institution of the Department of Mental Hygiene shall be considered third-degree rape (S. 97 Padavan).

Extending the provisions declaring civil rights to include disability providing that such disability would not substantially impede the duties of employment (S. 201 Flynn).

The record of the legislature is not, however, without some impact on mental retardation in general, although nothing at all passed with regard to aid the funding of

services for the non-institutionalized in the community.

Some of the bills passed and signed by the Governor are:

\$75,000. appropriated for the Special Olympics in New York State (Chapter 449 - A. 6935 Virgilio).

Increasing the SSI supplement for children in group homes from the present \$197.59 to \$442.20, as for adults (Chapter 278, A. 7340A Lewis).

A provision that agencies may bill directly for social services for de-institutionalized and don't have to go through social services departments, (Chapter 277 - Assembly 4516 A - Connely).

Increasing the number to 200 mentally retarded persons for whom Municipal Civil Service Commissions may authorize employment (S. 3004 Goodman), (Chapter 357).

Oh, yes — and the prohibition of the use of the words Mongoloid or Mongoloidism in any state, municipal, or county legislation. Only **Down's Syndrome** may now be used, a very important piece of legislation (S. 4774-A Levy).

And lest we forget, (Chapter 199 — Assembly 4107 Wertz) that notice of guardianship for mentally retarded persons residing in an institution must be given to the Mental Health Information Service.

It is clear, according to a spokesman for the ARC, that the legislature refuses to come to grips with the system of funding community services for other than de-institutionalized, which must, in the end, bankrupt the services and throw the entire burden on the state.

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REGISTER TODAY FOR  
YOUR STATE CONVENTION  
October 18-21  
SEE PAGE 20





## Who nominates the powers?

Members of the Nominating Committee stop to pause during Board of Governors Meeting. Left to right — Frank Sheridan, Northeast Region; Vivian Loughrey, Western Region; Dot Ganin, Chairperson; Frances Reville, Southeast Region and Robert Horn, Central Region.

## Tom Coughlin leaves

After four years in Mental Hygiene, two years of which he was Commissioner of the Office of Mental Retardation and Developmental Disabilities, the departure of Tom Coughlin to the Department of Correction closes a very important chapter in the development of services for the retarded in this state.

This early, it is very difficult to assess what his stewardship has meant, except that it was positive.

It was a time of implementation of the Willowbrook decree; it was a time when de-institutionalization became a catchphrase that threatened the services for the more than 95 percent of the retarded who were never institutionalized; it was a time when services in the community developed at a breakneck pace.

Whatever differences we may have had with Tom on a philosophical basis, he

always was a key figure in these developments. Struggling against a legislature and a division of the budget that refused to fund community services as they should, he developed stratagems to circumvent these barriers. Such devices as purchase of service; Sub-chapter 'C', etc., etc., sometimes meant the difference between life and death for some of our chapters.

On a day-to-day basis, Tom was a good, true and tried friend. Whatever differences we had, we could count on his heart.

We wish him well in his new position where he will have a grand opportunity for "deinstitutionalization".

Good luck, Tom! We shall always remember you as we are sure you will remember us.

# Our Children's Voice

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NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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## President's Message

This first year as president has been one of the most challenging, most stimulating, most frustrating, most fatiguing — and yet, most fulfilling of my life.

There were certain goals and tasks I had set for myself — some I have achieved, or at least begun. Others continue to be tantalizingly out of reach — perhaps because they are not reachable, or perhaps because I must try harder!

One of my main goals was to set a schedule that would permit me to educate myself in a "hands on" way about as many individual chapters as possible. It was also my hope that the time spent would be more than superficial, and that I would be able to visit programs and tour facilities, as well as become acquainted with local Boards and membership.

Although it was disappointing that I could not accept every invitation, to a great extent this goal has been achieved. To the despair of State Office which pays travel vouchers, I have been to Greene, Letchworth, Westchester, Schuyler, Rensselaer, Erie, Niagara, Chenango, Clinton, Jefferson, Wassaic, Nassau, Saratoga, Monroe, Montgomery, Albany, and Oneida, as well as Regional and Committee meetings.

This experience has been an enriching one, for the positive reinforcement of good people doing good things helps, to some extent, to dull the worries of multiple problems that exist statewide.



ELLIE PATTISON

— and worries there are! Local aid cutbacks have just come down, OVR audits are weighing heavy, more and more responsibilities in the community without adequate resources seem to be the order of the day. Many chapters, because of their strong moral commitments, are teetering on a fiscal abyss of over-extension.

There are some difficult days ahead — but then, we're used to that! ARC has fought battles and struggled for many years — and if what I saw in my travels is any example, that dedicated strength and effort will continue for a long time.

You all can be proud!

(Signed)  
Ellie xx

## LETTERS

### On soap operas

We share a letter from K. Hyde on the article in the last issue of OCV about soap operas and mental retardation.

Although I do not watch all these soap operas, I have looked at "Love of Life" and sometimes at "Young and Restless." Then I became interested in "All My Children." But I do not always have the television on during the day. So I have read reports in the daily newspaper and I know that these stories deal with various problems and illnesses that happen to human beings every day. Some people do not like to watch them while some are glued to the set and cannot miss a single show. I honestly believe, that if they had a retarded child on one of these "operas", perhaps on "All My Children", the public would see for themselves that they can be helped. "Social Stigma" is the greatest barrier. Fear and ignorance of a retarded child, as we fear certain diseases; those who have never been faced with having a child who doesn't learn as rapidly or looks and acts a bit different than is expected, these people fear these children and keep away from any knowledge to help them. If it was just shown every day on TV to let them see that these human beings have a right to life and happiness and are accepted in communities, people might really start learning and caring. I have been reading, and I know there are gifted children, who learn very quickly, but emotionally, they too can be disturbed. Retarded children are gifted because, even though they may be more slow, they are filled with so much love, that when you are with them you feel a peace within you. We are too fast in this world and we miss out on a lot of beautiful and lovely things that happen. There are good things every day. (I know there are plenty of bad). They shouldn't be subtracted from any other children and put away in a "cage." They should be free, and loved. When we love, we are loved. I hope someone will do something about it. So, it's a very good idea to have "soap operas" and let the public see a retarded child or adult and watch them progress. Hope it will be very soon.

### Meeting praised

Mrs. Grace Jenack, member of the New York State Board of Governors, writes with enthusiasm about the Educational Rights meeting, sponsored by the Education Committee, in Albany.

Over the years that I have been a member of A.R.C., and have attended many meetings, I feel that the workshop on Educational Rights held in Albany on 4p27-79, was undoubtedly one of the best. It was exciting and stimulating to observe the participation of the many young parents attending.

The Panelists in each of the sessions made excellent presentations, and answered questions readily. I'm sure that each person, whether it be a parent, friend, or educator, left after a full day at the workshops, much more knowledgeable and confident to meet the individual educational need of each child.

As a member of the Board of Governors, I can readily see that this kind of expertise should happen at the Chapter level through its Chapter Education Committee.

### Thanks

Mrs. Dom Foley writes this letter of thank you for receiving Our Children's Voice.

I hope people will realize how much you do for retardation. I, for one, know. I am handicapped now and past 80 years. I had a bad hip fracture and was in a nursing home for months. Now I'm home walking with a walker. That's not important. What is important to me is your Voice and how happy I am now knowing that my dear sister, Helen Goodman, is now in Oasis House in Wingdale. I hear from her often. She was never so happy when she was in Wassaic. I know she likes all the tenants there and has freedom that she never had in all those years.

I want to tell you now that I am thankful to Mr. Goleb, who is the team leader in Wingdale, where my dear sister is and also all the tenants who help my dear devoted sister who is past 62 years. Thank you kindly. Enclosed is a small offering for your very good paper, Our Children's Voice.



# Budget plays havoc with community

## OMR/DD may stop disaster

Efforts with Commissioner Coughlin and Dr. Jeffrey Sachs, Program Assistant to Governor Carey, backed by letters of protest from our chapters has resulted in what may be an alleviation of the disastrous results of the 1979-1980 budget.

All agencies are permitted to spend at the 1979 approved preliminary budget rate. The obvious deficiency resulting will be taken care of through administrative or legislative interchange or a budget deficiency appropriation.

How did this threat to our programs come about? The local assistance budget for the mentally retarded who have not been institutionalized as adopted by the state legislature remains at the 1978 level which is the same as the 1977 level, \$19,300,000.

Letters from chapters all over the state came in to the state office complaining about cuts in their budgets. Some examples of these are Otsego County, cut from \$55,000 to \$38,000. Delaware County from \$71,513. to \$50,000. Other chapters, including Rensselaer, Monroe, have been cut up to 35 percent of the budgets previously approved.

To understand this properly, one must know the budget process.

Local assistance budgets are approved by the community service boards and OMR-DD to begin operations on January 1st of each year. By the time legislature passes its state budget, beginning for the fiscal year April 1st, local agencies are operating on the previously approved budgets for three and four months. When passed on the same level as the previous year, this means obvious cuts in the budgets and therefore, cuts in services.

At this point, unless something was done, hundreds of mentally retarded would have to be dismissed from services and many, many employees would lose their jobs.

A letter to the leadership and to the fiscal committees, as well as the chairman of the mental hygiene committee, state association, protested the situation and asked relief.

At this point, unless something was done, hundreds of mentally retarded would have to be dismissed from services and many, many employees would lose their jobs.

"We, working for the mentally retarded in New York State," stated in a letter to

Honorable Warren Anderson and Honorable Stanley Fink, "are bitterly disappointed by the budgets passed by the legislature for community services for the non-institutionalized mentally retarded. Not only are we disappointed, but scared to death that many of the people we have dedicated ourselves to serve for over 30 years are going to be without services".

"The local assistance budget for the mentally retarded remains at the 1978 level which is the same as the 1977 level. During this time, the cost of living has increased by about 25 percent."

"As a result of this budget, the plans and budgets adopted by the various counties of the state for the community services for the mentally retarded, under which we have been operating for almost 6 months, are being cut up to 35 percent retroactively."

"This simply means that hundreds, if not thousands, of mentally retarded persons will be without services, as well as the dismissal of hundreds of employees by the community agency."

"At present, we find the budget a one-way street, increased annually for de-institutionalization and state operated programs while, in effect, being decreased for community services for more than 95 percent of the mentally retarded. Surely, this must be redressed."

The various bills introduced this year to provide equal funding for the non-institutionalized with funding for de-institutionalized, or even 75 percent instead of 50 percent for the non-institutionalized, have all failed in committee.

At the same time, however, the legislature did vote \$600,000. for about 14 or 15 children at Oswald Heck Developmental Center, autistic persons who were brought back from a school in Rhode Island, whose program the state did not approve.

This cost of almost \$50,000. a year, per person, must be put side-by-side with the \$8,000-\$9,000. a year that the state puts up per person in community residences.

All chapters were urged to bring this situation to the attention of their local legislators and make every effort to get the funds necessary to carry on programs.

As first stated, these efforts, and the championship by Tom Coughlin and Jeff Sachs, have, we hope, averted disaster.

## Montgomery Workshop dedicated



At the dedication of Montgomery County's new facility from left: James Dellasandro, Chairman, Montgomery Board of Supervisors; Ellie Pattison, State President; Frank Capone, Executive Director, Montgomery County Chapter; Thomas A. Coughlin, attending at Commissioner of OMR-DD. (Photo by Tony DeAngelis)

## Retarded child's warning saves family in fire

Charles J. "Chucky" Monteleone, saved the lives of his family early on the morning of April 23 by alerting them to an electrical fire which started in his bedroom. Chucky is only nine years old.



CHUCKY MONTELEONE

"I heard him yelling 'Fire... Wall... Bed...' and pounding on the door", said his mother, Mary Lou Monteleone. "When

I opened the door, the entire wall was engulfed in flames. The room was so hot. His bed was on fire". Mrs. Monteleone grabbed Chucky as the flames spread through their Amherst, N.Y. home.

The entire family, including Chucky's sisters, Kathleen and Donna, and the family dog, Heidi, escaped without injury.

Chucky, who attends a special class at Holmes Elementary School, was awarded a firefighters shield for his bravery. A member of the Ellicott Creek Volunteer department told Mrs. Monteleone it was amazing that Chucky banged on the door. Most children hide in closets when there is a fire.

"You hear so many negative things about the retarded", Mrs. Monteleone said, "but if it weren't for Chucky, we wouldn't have gotten out".

Mr. and Mrs. Monteleone are members of the both PARC-BOCES and the Erie County Chapter.

## Family Care home conditions assailed by N.Y.S. audit

Poor and mentally ill, as well as mentally retarded people, who are forced to live in so-called "family care homes" sometimes face "dirty, cluttered and unsanitary" living conditions, a new state audit says.

The audit, released in June by the Comptroller's office, documents a number of deficiencies in the "family care" homes where about 7,500 former residents of institutions now live.

Besides criticizing the conditions found in some individual homes, the audit was also sharply critical of the supervision and administrative practices of four state centers which oversee family care homes.

It is the latest slap at the state's "deinstitutionalization" program, under which thousands of people have been moved out of large institutions into smaller community facilities.

Although the stated intent of deinstitutionalization was to provide better care and get rid of abuses often discovered in the big institutions, some officials say new abuses are cropping up in the family-care homes.

In a response contained in the audit, officials of the state Office of Mental Health and the Office of Mental Retardation say they have corrected deficiencies uncovered by the audit and are working to implement various recommendations suggested by the Comptroller's office.

For their review of the family-care program, state auditors examined 95 family-care homes and the administrative practices of the four state centers which oversee these homes.

Those centers were Newark Developmental Center located in Wayne County; Suffolk Developmental Center in Melville, Long Island; Pilgrim Psychiatric Center in the West Brentwood section of Long Island and Middletown Psychiatric Center in Orange County.

The auditors found a variety of deficiencies, ranging from "inadequate furnishings" to "safety violations", such as a non-working smoke detector, at virtually every home. But, it said two homes were "poorly operated" and should have "prompt correction of the deficiencies".

It is noteworthy that a recent memorandum from the Office of Mental Retardation and Developmental Disabilities strips the free movement of residents from family-care homes to group homes operated by voluntary agencies. The memorandum, in fact, states that movement cannot occur without the prior consent of the Deputy Commissioner. This was severely criticized by Marc Brandt of our Sullivan County Chapter as an about face in terms of providing "least restrictive environment" for the mentally retarded.

## Carey names Coughlin to head NYS prisons

### Introne acting OMR/DD commissioner

Governor Carey has chosen Thomas A. Coughlin, III as Correctional Services Commissioner to replace Richard D. Hongisto, who resigned after a lengthy political battle.

Tom Coughlin, an officer of the New York State Police from 1962 to 1968, was executive director of our Jefferson County Chapter until 1975 when he became deputy commissioner from M. R. and moved up to Commissioner when MR-DD became a separate unit in The Department of Mental Hygiene.

Although he has had no experience in correctional services, the Governors' aides said he has demonstrated managerial ability with a department with a large institutional population.

As Commissioner, Coughlin will sup-

ervise more than 21,000 prisoners in a 34 prison system plagued with overcrowding, labor problems and tensions.

James E. Introne, recently appointed first deputy to Commissioner Coughlin, is well known to the ARC. He was Program Assistant to Governor Carey during the lengthy negotiations on the restructuring of the Department of Mental Hygiene and brings a good knowledge of our problems to the job.

At thirty-four, he will be the youngest Commissioner, if appointed to that position.

As the paper goes to press, Coughlin is serving as Acting Correction Services Commissioner, awaiting Senate confirmation.



## Parents upheld on committing

The Supreme Court, in a 6-to-3 ruling, upheld the constitutionality of state laws that allow parents to commit their minor children to state mental institutions.

Thirty-six states, including New York, New Jersey and Connecticut, have such laws. Federal judges in Georgia and Pennsylvania had struck down such laws on the ground they lacked the constitutional safeguards necessary to assure that the parents were acting in their children's best interest.

While the Justices ruled that a state hospital's medical staff must independently conclude that treatment is needed before admitting the child, they unanimously rejected the two lower courts' rulings that the parents' decision must be explored at a formal, adversary-type hearing before the child is admitted.

Chief Justice Warren E. Burger wrote, in a majority opinion joined by four other Justices: "Our jurisprudence historically has reflected Western civilization concepts of the family as a unit with broad parental authority over minor children."

"The law's concept of the family rests on a presumption that parents possess what a child lacks in maturity, experience and capacity for judgment required for making life's difficult decisions," Chief Justice Burger said. "More importantly, historically, it has recognized that natural bonds of affection lead parents to act in the best interests of their children."

The opinion continued: "That some parents may at times be acting against the interests of their child creates a basis for caution, but is hardly a reason to discard wholesale those pages of human experience that teach that parents generally do act in the child's best interests. The statist notion that governmental power should supersede parental authority in all cases because some parents abuse and neglect children is repugnant to American tradition."

Children's rights advocates were disappointed by the decision. "It doesn't comport with reality," said Norman Rosenberg, a lawyer for the American Civil Liberties Union's Mental Health Law Project. He said that parents who decided to institutionalize their children were frequently under extreme stress and a decision made in such circumstances should be subject to "rigorous, impartial review."

The dissenters said that the Court should have held that at least one prompt, formal post-admission hearing was constitutionally required.

Both the majority and the dissenters agreed that a formal hearing before commitment posed a number of practical problems, including the possibility of delaying necessary treatment, deterring parents from seeking treatment for their children, and further injuring an already damaged relationship between parent and child.

## Job funding for retarded

Westover (Mass.) Air Force Base Hospital placed this ad in local newspapers: "Help wanted: nursing assistants." Nobody applied. Then someone in the personnel office had an idea:

"Let's hire retarded people instead of nursing assistants. They can do a lot of the less-skilled work we now ask nurses and nursing assistants to do. We can rewrite job requirements; everybody will be happy."

The hospital started with 2 retarded people, then 25 more. Sure enough, everybody's happy: nurses, nursing assistants, new retarded workers.



Michael Destro of Chautauqua Chapter demonstrate how new voting machine (which can be dropped) may be used by the physically handicapped.

## Voting machine for disabled

Automatic Voting Machine Corporation of Jamestown, New York, recently visited the Jamestown Achievement Center to take photographs to be included in the advertisement of their new voting machine Model 120, style D.V., this is a new voting machine for the disabled. Adjustments can be easily made by the

election officials to meet the needs of the physically handicapped as shown in the picture of Michael Destro.

The Chautauqua County ARC would like to congratulate A.V.M. for making available this machine and for their efforts in helping meet the needs of the handicapped.

## Congress proposes Fair Housing protection for handicapped

Legislation has been introduced in both the House and Senate that would add handicapped persons to the classes of persons protected by the Fair Housing Act of 1968 (Title IVV of the Civil Rights Act). Without a specific statutory mandate to protect handicapped persons from housing discrimination, the Civil Rights Commission has been able to do little on their behalf.

In the House, the Bill (H.R. 2540) is being co-sponsored by Don Edwards (D-Calif.), Chairman of the House Judiciary Subcommittee on Civil and Constitutional Rights, and Edward Drinan (D-Mass.). In the Senate, an identical bill (S. 506), has been introduced by Birch Bayh (D-Ind.), Chairman of the Senate Judiciary Subcommittee on the Constitution, and Charles Mathias (R-Md.). Both House and Senate Subcommittees are in the process of holding hearings on the implication of the legislation, which also would expand the Department of Housing and Urban Development's enforcement powers under the Fair Housing Act. Similar legislation was considered in the previous Congress, but never was reported out of committee.

In a recent report entitled, Housing for Developmentally Disabled Citizens, NASMRPD identified discrimination as a major barrier to establishing community housing alternatives for handicapped persons and recommended that legislation similar to H.R. 2540 and S. 506 be enacted. The report also recommended that Congress pass a law to discourage local authorities from enacting zoning ordinances designed to exclude handicapped

persons from single family neighborhoods. While provisions prohibiting exclusionary zoning practices involving racial or ethnic minorities were included in last year's House bill, the current measures do not contain such language.

Some issues raised by the inclusion of handicapped persons as a protected class include: (1) whether the legislation would require remodeling of existing housing to allow access by physically disabled persons; (2) whether all new housing would have to be built according to accessibility standards; (3) whether the regulations HUD is developing to implement the non-discrimination provisions of Section 504 of the Rehabilitation Act of 1973 will be applicable to fair housing enforcement; and (4) whether exclusionary zoning prohibitions developed through housing case law would be applicable to handicapped persons. Both House and Senate Subcommittees have indicated an interest in hearing testimony on these issues from organizations representing disabled persons.

## Daily rates in Developmental Centers upped again

Did you know that the daily rate for services (so-called) in an institution of The Office of Mental Retardation and Developmental Disabilities is now \$72.55 a day?

Here is how this rate has gone up since 1975:

April 1, 1974 to March 31, 1975 \$47.28;  
April, 1975 to March, 1976, \$54.65; April,

## Group home battles still rage in state

From all over the state, we are receiving notices and articles on the continuing battle to provide group homes for the mentally retarded in this state.

Some are good, some are bad, but all of them indicate a real struggle with the community to provide homes for this most neglected group.

Some examples are:

Community Board 15, Brooklyn, New York rejects a home site for the mentally retarded by a vote of 26 to 1.

Significantly, a Rabbi, Rabbi Abraham Peck warned that property values were stabilized in that community "by the grace of God." Furthermore, that establishment of a community residence for the mentally retarded, he forecast, would tip the balance for the worse.

In Buffalo, a proposed residence of our Erie County Chapter in Hamburg is still on a Merry-Go-Round. With the ARC rejecting alternate sites in the town of Lancaster.

In Troy, New York, the chapter was barred from using 147 Pawling Avenue but have been offered two other sites. The chapter is still exploring options with the Pawling Avenue building and is reluctant to go before the Zoning Board of Appeal for approval of the site. "The planning commission would walk all over our rights. If they treated us like they did the last time, the case could end up in the state supreme court," per Jim Flanagan the executive director. The Pawling area site is still in the courts.

In Cortlandt, the Town Board is protesting state plans to establish three more group homes for the mentally retarded in the town. So the fight still goes on.

On the positive side, Schoharie villagers learned about services through our county chapter when they met to discuss a possible residence for retarded adults. The same efforts brought about a positive approach to a building by our Fulton County Chapter which plans to build its fourth group home although these plans are still stalled in the Office of Mental Retardation and Developmental Disabilities.

In Yates County, our chapter is trying to educate the community and hopes it will succeed.

Onondaga County — we understand that Manlius has finally okayed a group home on Elmbrook Drive; and, in Oneida, five Oneida aldermen say they won't oppose a group home for the retarded that our Madison County chapter wishes to set up on North Willow Street in Oneida.

Also on the positive side, the State, in a hearing, has ruled in favor of the establishment of the community residence in Plattsburgh — and, to put icing on the cake, our Albany County Chapter wants New York State to give it the former New York State University Chancellor's house at 40 Marion Avenue to use as a community residence. We don't know what happened to the auction that was to be held of his house but we thought the approach was certainly worthy of note.

1976, to March, 1977, \$60.72; April, 1977 to September 30, 1977, \$72.55.

In the last three years, however, the Governor has kept this budget for Local Assistance, that is for Community Services for the non-institutionalized, at exactly the same figure for three years.

Schizophrenia? No. Obvious double standard.



# Gouverneur residents stay at Flower 5th

The Willowbrook Review panel has agreed to allow a Manhattan retardation center to continue caring for 125 former Staten Island Developmental Center residents.

The panel, a court-appointed monitor of services provided former and current residents at the Willowbrook institution, had urged the Brooklyn Federal Court to order the one-year-old center closed by September 30. Panel members said the program, operated by New York Medical College at Flower and Fifth Ave. Hospital, provided substandard care, even though it has operated with a record - annual Medicaid rate of \$89,435 a patient.

But in a court session before Judge John R. Bartels, panel representatives reported that hospital officials had made some progress in meeting minimum - care standards required by a 1975 court decree. Much of the improvement occurred, they said, after release of the panel's unfavorable audit, which was released several months ago.

Panel members, however, asked Bartels to ban future admissions to the East Harlem center until it could reach an agreement with center officials for further improvements.

Bartels denied the request after state Mental Retardation Commissioner Thomas R. Coughlin said the hospital was losing \$4,000 a month because it was 26 patients below the enrollment hospital officials say is needed to break even financially.

Coughlin said the hospital will now admit 26 new patients, many of whom are residents in acute-care city hospitals not equipped to deal with the mentally retarded.

Many of the improvements at the hospital have been credited to Alfonse Sorhaindo, a former official at Manhattan Developmental Center, named program director in the early spring.

For nearly six months, the center had operated without a program director. Dr. Margaret Giannini, the program's initial director, resigned suddenly last October. State officials said it was her reputation in the mental retardation field that persuaded them to fund the program at record levels - three times the Medicaid rate awarded state facilities for the retarded.

The failure of hospital officials to promptly replace Dr. Giannini was described as an "unbelievable lapse" by panel members, especially since, they

said, it was suffering from serious staffing and organizational problems.

Coughlin, who said the state was also disturbed by Dr. Giannini's resignation, contends that Sorhaindo's hiring has resolved most of the administrative problems.

"There is no longer any critical problem or threats to the life and safety of the residents," Coughlin said. "Everyone seems to agree that Flower and Fifth Ave. Hospital is conducting its business properly."

Shortly after the program opened last May, six patients died. Although state officials denied any negligence by the hospital, Manhattan Borough President Andrew Stein charged it was evidence of inadequate care.

Sorhaindo said the hospital, a subsidiary of the Archdiocese of New York, is now committed to making "the program the best program" in the country. It now serves 125 severely retarded and multiple handicapped residents, who the state concedes were neglected for years in the Gouverneur unit of Manhattan Developmental Center before their transfer last May.

"We want to prepare every resident to live in the community," Sorhaindo said.

## Dealing with State: it isn't easy!

In a reply to an inquiry from Jim Flanagan, concerning overdue payments for Community Resident Programs, we received the following letter from an acting business officer of the Office of Mental Retardation and Development Disabilities.

In our opinion, this letter is an outstanding example of governmentalese. The letter follows:

"Dear Mr. Flanagan:

This is to confirm our conversation concerning the status of payments due your organization under the provisions of contract C-152267 and C-152269.

As discussed, these two contracts overlap the state fiscal year which runs from April 1 to March 31 each year. As a result, second quarter payments due you each year cannot be made until the Legislature passes the state purposes budget. Once the Legislature passes the budget, we must then await the issuance of a budget certificate by the Division of the Budget. This occurred on April 27 this year. This has the effect of depositing funds into the Community Residence Program account once the certificate is posted by Audit and Control. This occurred on May 3, 1979.

With funds now in the proper account, we are required by Audit and Control to submit for approval our encumbrance document to set aside funds due you between April 1979 and March 1980. This process takes approximately three weeks. Once the encumbrance document is approved, we are then permitted to submit your second quarter vouchers to Audit and Control for payment and issuance of a check. This takes approximately 3 weeks. It will, therefore, be about six weeks before you receive your second quarter payment.

I regret the inconvenience this causes you. If I can be of any assistance please call me at (518) 473-1341."

We welcome any simple interpretations other than "You just starve to death until we get around to pay you".



AT THE AWARDS CEREMONY

Mr. and Mrs. Ed Licence, Ellie Pattison, and John Bertrand, (left to right).

## Outstanding employees honored

Twenty-two Outstanding Employees in the field of mental retardation representing all of the State Developmental Centers, the Institute for Basic Research and the Central Office of OMR-DD were honored in joint ceremonies, co-sponsored by the State Association for Retarded Children and the Office of Mental Retardation and Developmental Disabilities. This year's Employee Recognition Day was held on Thursday, June 21st at the Best Western Thruway House in Albany. A new wrinkle was added to the 1979 awards, as the State Association sponsored a Hospitality Hour the evening before the awards presentation in order to let everyone have an opportunity to get to know one another, before the ceremonies the following day. On the morning of the 21st, a tour of the Empire State Plaza and State Capitol was arranged for all the award winners and they returned to the Thruway House for the Awards Luncheon.

The awards were presented by Edward B. Licence, Chairman of our Scholarships and Awards Committee. The Association was also represented by our State President, Eleanor Pattison, Assistant Executive Director, John Bertrand and Mrs. Shirley Licence, member of the Scholarship and Awards Committee.

There was one very sad note to the 1979 Ceremonies. Mrs. Andre Fucci who had been named Outstanding Employee at Wilton Developmental Center died in late May, shortly after having been named Outstanding Employee, and before the award presentation was made. Her award was accepted by her daughter, Mrs. Evelyn Butto, and the other employees and their guests responded most warmly in memory of Mrs. Fucci.

The employees honored and the facilities from which they come are:

Norma Guinan, Broome Developmental Center; Delores Taylor, Rome Developmental Center; Floyd H. Carmichael, Sunmount Developmental Center; Tom Angiolillo, Syracuse Developmental Center; James Evans, Craig Developmental Center; Janet Peters, R. N., J. N. Adam Developmental Center; Pamela Meyer, Monroe Developmental Center; Shirley Boeye, Newark Developmental Center; Margaret Nevilles, West Seneca Developmental Center; Bob Rafferty, Letchworth Village Developmental Center; Beth Crounse, O.D. Heck Developmental Center; Francis Leewee,

Wassaic Developmental Center; Michael Schulman, Westchester Developmental Center; Andre Fucci, Wilton Developmental Center; Dwayne King, Bernard Fineson Developmental Center; Leonard Goody, Bronx Developmental Center; Evelyn Crittenden, Brooklyn Developmental Center; Deloris Hightower, Manhattan Developmental Center; Lulu Ramirex, Plurad, M.D., Suffolk Developmental Center; Helen McNally, Staten Island Developmental Center; James LaMantia, Institute for Basic Research; Julia Austin Central Office.

## Retarded daughter can be sterilized

A Morris County Superior Court Judge ruled recently that the parents of an 18-year old retarded woman should be allowed to have their daughter sterilized.

In a 37-page opinion, Superior Court Judge Bertram Polow approved the request of Edward and Luanne Grady of Sparta to have the court allow Morristown Memorial Hospital to perform a tubal ligation on their daughter, Lee Ann. She is a victim of Down's syndrome, also known as mongolism.

The Gradys claimed their daughter would not be able to care for a child if she were to become pregnant and would have more freedom if she were sterilized.

The case was assigned to Polow several months ago after Morristown Memorial Hospital refused to perform the operation without a court order.

"Her parents should be permitted to exercise their judgment," Polow said. "It is not for this court to substitute its judgment for the informed consent of Lee Ann Grady. . . nor to weigh the relative advantages and risks of other methods of contraception."

Polow said his decision "is not to be interpreted as authorizing parents to consent to the sterilization of incompetent person, absent authorization by a court of competent jurisdiction. Each application must be decided on its own merits."

The Grady parents had argued that the precedent - setting Karen Ann Quinlan decision, handed down by the state Supreme Court three years ago, can be applied to the sterilization question.

## Protection & Advocacy Announcement

Attention: Patents of Willowbrook class members living in the community.

The Protection and Advocacy System for Developmental Disabilities, Inc. received a grant to provide advocacy services to Willowbrook Class members living in the community. Any community class member or other interested person may call our office to request free information or assistance in solving a problem or particular need.

If your son or daughter is a Willowbrook Class member residing in the community, it is important that you are aware of the services this agency can provide for your child. To receive this information or assistance call or write the Protection and Advocacy System for Developmental Disabilities, Inc. at:

Protection and Advocacy System for Developmental Disabilities, Inc., 175 Fifth Avenue, Suite 500, New York, New York 10010. (212) 982-1140.



## Prevention

# Hypothyroidism breakthrough

Severe mental retardation in hundreds of children born every year — victims of congenital hypothyroidism — may now be prevented by the use of early detection techniques followed by conventional treatment, according to the National Foundation — March of Dimes, which supports research in this area.

Untreated children born with little or no thyroid function appear normal at birth but later become "cretins," short, stocky, expressionless individuals often relegated to mental institutions. Until recently, a thyroid deficient child might recoup some of its physical growth with treatment. But brain development, stunted during the first year of life, has been permanently retarded.

This condition strikes about 1 in 5000 children each year, or an estimated 600 annually in the United States.

### SYMPTOMS NOT IMMEDIATELY APPARENT

So little is known about its cause that parents and pediatricians are usually unprepared for its symptoms. By the time sluggish development and other signs become apparent, the child is past the age of a few weeks when treatment must be started to prevent brain damage.

Today, New England toddlers, diagnosed at birth during a pilot screening project begun in 1976 and immediately placed on thyroid medication, are as bright and active as their unaffected playmates.

Follow-up studies must continue over a period of years to confirm that long-term prevention of brain damage has indeed been achieved. But results of initial screening studies offer real hope that such a "break-through" has occurred.

The program, aided by March of Dimes grants, was started at Tufts University School of Medicine and the State Laboratory Institute of the Massachusetts Department of Public Health under the direction of Drs. Robert Klein and Marvin L. Mitchell. It was later regionalized to become the New England Congenital Hypothyroid Collaborative Study, involving all the New England states except Vermont.

Another March of Dimes grantee, Dr. P. Reed Larsen at Peter Bent Brigham Hospital, developed one component of the detection method which involves a drop of blood taken from the newborn's heel—the same drop taken for PKU screening, mandatory in most of the United States. The blood is analyzed for a hormone normally secreted by the thyroid gland. If the hormone level is too low, further blood tests are done to confirm the diagnosis, and treatment can be started.

### HOME VISITS START EARLY

Dr. Francesca LaVecchio, staff developmentalist, and her assistant make regular home visits to each child whose hypothyroid condition is picked up through screening and whose treatment is begun within two and a half to three weeks after birth. At present, they are following more than 100 such babies in five states. All of them appear to be developing normally.

After receiving grants from the March of Dimes, Drs. Klein and Mitchell have now received federal funding to continue the follow-up and evaluation studies. The March of Dimes continues to support the diagnostic laboratory services provided at Peter Bent Brigham Hospital under Dr. Larsen's direction.



Dr. Leon Sternfeld (United Cerebral Palsy), Dr. Ian Porter (Department of Health), and Dr. Irv Bialer (Long Island Research Institute), discussing agenda for statewide Symposium on the Prevention of Mental Retardation to be held November 18-21, 1979, with Joseph T. Weingold, standing.

## Prevention symposium planned

Under a proposed contract with H.E.W., Region II, the New York State Association for Retarded Children is planning a Symposium on Prevention of Mental Retardation and Developmental Disabilities to be held in November.

In addition to the presentors at the Symposium, which will cover the total gamut of disabilities and possible prevention, it is proposed that each of the agencies serving Developmentally Disabled, Mental Retardation, Cerebral Palsy, Epilepsy and Autism will be invited to send one representative for each chapter to attend in order to bring back to the community the ideas that are developed.

In addition, the Legislature is being asked to participate and Senator Padavan has graciously accepted. Others are yet to be invited.

This is to be a three-day meeting and hopefully we will come up with Action Plans the State and Federal Government can implement to further the prevention of Mental Retardation and other Developmental Disabilities.

The funds allotted by H.E.W. will be matched by the New York State Health Department. The Office of Mental Retardation and Developmental Disabilities has also been asked to match these funds but has not yet responded.

A similar Symposium was held in the State of New Jersey and successfully presented the state of the art as it now exists.

Dr. Margaret Giannini, former President of the AAMD and Director of the Mental Retardation Institute at Valhalla, is coordinating the professional program.

## Risk raised for unborn

Blood of newborn infants whose mothers took aspirin in the weeks prior to delivery failed to clot at birth, reports Dr. Sumner J. Yaffe of the University of Pennsylvania School of Medicine and Children's Hospital, Philadelphia.

Common medications, as well as alcohol and tobacco, can be damaging to the unborn fetus, he writes in the current issue of "Guidelines to Professional Pharmacy." The Upjohn Company's scientific publication.

The pediatrician's warning, in what he calls an era of indiscriminate self-medication, is underscored by the recent HEW announcement that alcoholic beverage consumption is the third leading cause of birth defects involving mental retardation.

It is also supported by a joint U.S.-Canadian study which linked smoking during pregnancy to a higher risk of early fetal and premature newborn deaths. Other studies have found that smokers' babies weigh less than non-smokers' babies and that the weight difference is proportional to the number of cigarettes smoked by the mother. Scientists now know that the nicotine in cigarettes suppresses fetal breathing movements and that the amount of carbon monoxide in the blood of both mother and fetus is increased in mothers who smoke during pregnancy.

Although the immediate effects of aspirin on the newborn are apparently temporary, according to Dr. Yaffee, no one knows what the longterm results of drugs administered at or before birth may be and therein lies the danger. "We cannot say something is safe simply because we

don't know what the hazards are," he says.

Other common drugs taken late in pregnancy can also affect the newborn infant. For example, Dr. Yaffe cites studies that show that reserpine, a sedative and antihypertensive causes lethargy and a slow heartbeat. Diazepam, a popular tranquilizer lowers the body temperature and causes a loss in muscle tone in the infant. Infants delivered by mothers addicted to heroin develop withdrawal symptoms shortly after birth.

## How to get things done

Wassaic Developmental Center is in line for an increase in staffing. Understaffing has plagued the facility for more than a year.

The state Office of Mental Retardation and Developmental Disabilities says the additional money should be available within several weeks, making possible the hiring of more patient care workers.

How did this come about? It came about as a result of a meeting of the officials with representatives of the Civil Service Employees Association, representing 1,500 Wassaic employees.

Harold Ryan, president of the Wassaic CSEA unit, said he would give the state two weeks to make good on the promises. If the increased staffing is not provided, he said, the union membership will consider a job action in protest.

All we can say to our chapters is "go thou and do likewise".

## A blow to PKU

A team of five research scientists at the Institute for Basic Research in Mental Retardation on Staten Island say that they have identified the basic molecular flaw in a genetic disease that can cause severe mental retardation if left untreated.

Dr. Henry Wisniewski, director of the institute, said that the discovery may lead to more effective prevention of mental retardation caused by the disease, phenylketonuria, or PKU.

For years, physicians have known that PKU does its damage because patients lack an enzyme that handles an amino acid, phenylalanine, that is found in many foods. Mental retardation can be prevented by feeding children with PKU a diet that contains no phenylalanine.

The Staten Island researchers say they have gone one step further in identifying the cause of mental retardation in PKU. They say the damage is done, not by phenylalanine itself, but by a chemical that is produced as the body metabolizes phenylalanine.

The research was done by Dr. Wisniewski and Drs. Yen Loo, Guang-Yeong Wen, Judy Shek and Edmund Jenkins, who used experimental animals to search for the abnormal chemical.

The institute's finding that only the phenylacetic acid compound causes brain damage in PKU offers the possibility that a less restrictive diet may be developed to provide long term and more effective prevention of the effects of the disease.

The director noted that "presently newborn infants with PKU are maintained on a rigid phenylalanine controlled diet for the first five years of life."

"It is not very palatable," he said — "It consists primarily of carbohydrates, leafy vegetables and fruits along with a special food product, Lofenalac, which provides amino acids, minerals and vitamins with only minimal amounts of phenylalanine."

Coincidentally, it was the institute's first director, Dr. George Jervis, who first defined the biochemical disorder that results in PKU as the body's inability to break down and convert phenylalanine, an essential amino acid that appears abundantly in the foods we eat.

These findings and others led to the development of diagnostic tests and dietary treatment to effectively prevent or limit severe mental retardation in PKU infants diagnosed within the first month of life.

Mass screening tests for PKU are now required in 44 states.

Recently, PKU clinics throughout the country have reported IQ drops and difficulty in school grades among preteen children who have discontinued the diet for an average of five years.

Physicians and parents of PKU children are becoming more concerned about terminating dietary treatment after five years.

"More than 90 percent of the offspring of PKU women untreated during pregnancy are severely retarded, not because the infant himself suffers from the deficiency, but because of the abnormal chemical environment in the uterus and its damage to the brain of the developing fetus."

If the new PKU findings at the institute can lead to the successful development of measures to prevent the accumulation of phenylacetic acid, a more varied and less rigid diet may become available in effective long-term treatment of the genetic disease, said the director.

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# \$52 million suit for brain damage

A Binghamton man is suing two local physicians and a drug firm for \$52 million, claiming inoculations between 1962 and 1965 left his two youngest children brain-damaged.

The lawsuit has been filed in state Supreme Court in Broome County by Daniel E. Resciniti of 3 Goethe St., whose sons Anthony, 16 and Leo, 14, suffer from brain damage.

Named as defendants in the largest medical malpractice claim ever filed in Broome County are Dr. Martin Weiss, Dr. David Bloom and Merrell-National Laboratories of Cincinnati.

The case has national implications. It involves a claim that Anthony and Leo were tragically injured as infants by repeated injections of "DPT" or triple vaccinations.

The shot combines three vaccines to provide lifelong protection against diphtheria, tetanus and pertussis (whooping cough). It ordinarily is administered in a series of three doses in a child's first year, a fourth at 18 months, and a booster shot at about age 4.

The lawsuit contends the Rescinitis were never warned of the possible side effects of the vaccine. It is now the practice of many health officials, including those in Broome, to require parents to sign statements containing such warnings.

A spokesman for the Broome County Health Department today said, that for the last few months, parents have been required to sign an application for inoculation that warns of possible side effects. Before that, oral warnings were given, she said.

The application says that one of every 7,000 children who get the DPT shots will have a more serious side effect than the usual tenderness and swelling, including high fever, convulsions or shocks. It warns that, about once in 100,000 shots, "inflammation of the brain (encephalitis) or brain damage may occur. Death may occur even more rarely."

The lawsuit asks \$25 million for each boy and \$2 million for expenses the father has incurred and anticipates. This includes \$10 million sought from Weiss and Bloom and \$30 million from the drug company for breach of warranty and alleged failure to use "reasonable diligence" in production and distribution of the vaccine.

Jerome A. Nealon, a lawyer representing the family, said Anthony and Leo suffered repeated illnesses as babies, but the extent of injuries and purported connection with the vaccine were not immediately evident to their parents. Meanwhile, the two-year limit expired for filing claims against federal authorities responsible for the sale, manufacture and use of the vaccine.

However, Rep. Matthew F. McHugh, D-Ithaca, has introduced a bill that would lift the legal barrier — in the Resciniti case alone. An aide said it was one of the few times McHugh had sponsored what is known as a "personal" bill, and that he did so because he was deeply touched by the plight of the Rescinitis.

U.S. Sen. Daniel P. Moynihan, D-N.Y., has introduced a similar measure in the Senate. Both bills are before congressional judiciary committees.

If the special legislation for the Rescinitis is enacted, it would have no direct effect on the lawsuit against the two physicians and the drug firm.

According to the Resciniti complaint, Weiss administered a series of shots to each of the two boys while they were infants.

The legal complaint states the boys injuries were caused by a failure by Weiss "to exercise reasonable care and diligence."

Weiss declined to comment on the lawsuit.

Rules of the state Supreme Court protect children from the ordinary statute of limitations, making possible the current lawsuit.

## David Jenkins appointed



DAVID JENKINS

For a number of years, New York State has operated a Developmental Disabilities Council to oversee compliance with federal regulations related to the Developmental Disabilities Act. In addition to monitoring activities of state agencies, such as the Office of Mental Retardation and Developmental Disabilities, this council administers the Developmental Disabilities Act grant program for the senate.

In 1978, the Developmental Disabilities Act was revised. Among the changes was a requirement that each state's Developmental Disabilities Advisory Council consist of at least 50 percent consumer membership. The act further mandated that at least one third of this membership be consumers themselves and not parents or guardians of consumers. To bring the composition of the state's Developmental Disabilities Council into compliance with the new federal guidelines, the state in February, 1979 invited agencies to submit nominees for the consumer positions on the Council.

The Rensselaer County Chapter of the Association for Retarded Children submitted the name of David Jenkins to the

Governor's office as a nominee for a consumer position. In early May, word was received that David was selected and would soon be formally appointed by Governor Carey.

A native of Troy, David Jenkins lived at Rome Developmental Center for 19 of his first 21 years. Despite a serious heart condition, that required open heart surgery at one point, David was very popular with his fellow residents and was selected President of the student body at Rome.

In 1975, he was resettled from Rome to the ARC community residence at 54 Maple Ave. in Troy. In addition to training through the Adult Educational and Vocational Services program of Eleanor Roosevelt Developmental Services, David became a student of the Educational Opportunity Center operated by Hudson Valley Community College. He made rapid progress in his vocational training and moved through the placement program of the Menands Workshop and into a position in competitive employment in the messenger service with the State Assembly, where he is presently employed.

After mastering many of the skills of daily living, David was also recently able to move from the Maple Ave. residence to the new supervised apartment program operated by the Rensselaer ARC at 2 Prout Ave. in Troy. He is working toward a goal of even more independent living in his own supportive apartment.

David indicated he was very excited about the opportunity to take an active role in expanding the opportunities available to the developmentally disabled citizens of the state. In early May, he attended his first meeting of the Council, where he made a number of new friends among Council members and took an active role in Council discussions.

Members of the ARC Board and staff expressed a great deal of pride in David's selection and the recognition, by the state, of the important role he can play in shaping the future of state policy toward the developmentally disabled.

## Court gives impetus to genetic counseling

New impetus is being given to genetic counseling by recent court decisions holding doctors liable for failing to warn parents of the potential of giving birth to an abnormal child.

In decisions by the New York State Court of Appeals last Dec. 28, the court ruled in favor of two women who claimed their doctors did not warn them of their potential for giving birth to mentally retarded, deformed or afflicted children.

One woman gave birth to a girl suffering from Down's Syndrome or Mongolism. At 37 and in her first pregnancy, the woman was in the high-risk age category for Down's Syndrome.

The second woman gave birth to a second child with polycystic kidney disease. Several years earlier, the same woman had a child with the same disease, who died five hours after birth, but doctors told her the chances of having a second child with the same ailment were "practically nil." The second child died at age 2½.

### DOCTORS COULD BE LIABLE

The New York Court said doctors who fail to warn of such high-risk pregnancies could be held liable for payment of the special care and treatment over the lifetime of the persons born with genetic defects and diseases.

"The court acted upon two cases that might never have happened had the physicians and patients availed themselves of the services provided by the National Genetics Foundation," according

to Dr. George W. Melcher Jr., president of the foundation.

The New York malpractice cases and similar ones in other states have brought genetic medicine out of the family closet and focused welcome attention on means of identifying, detecting, treating and preventing genetic diseases.

### AMNIOCENTESIS IS RELATIVELY SIMPLE

Many doctors are more routinely administering a relatively simple procedure called amniocentesis to determine whether Down's syndrome or other genetic diseases are present in a fetus. But this is a surgical probe and there is some risk — in less than 1 percent of the cases, the patient or the fetus suffers some damage. Many doctors are exploring a safer, though more time-consuming, alternative — genetic counseling.

Founded in 1970 as a nonprofit agency, the National Genetics Foundation has been fighting an uphill battle to get physicians and parents to use its service. "The sad part is that we were not getting sufficient inquiries from doctors," said Arthur G. Steinberg, chairman of the foundation and professor of human genetics at Case Western Reserve in Cleveland.

But with the threat of medical malpractice suits, doctors today are turning to the foundation out of self-protection if not medical enlightenment. "Physicians are going to have to use centers like ours more and more each day," Steinberg said. "They're going to have to turn to us for help."

The foundation provides the most complete storehouse of information on the 2,000 identifiable genetic disorders through a network of 54 centers located in medical teaching institutions and linked to a central clearing house in New York City.

### CENTERS PROVIDE TESTING

Prospective parents can inquire directly to the centers or through their physicians. The centers provide testing to determine the risks of a genetic disorder in a newborn and give guidance on treatment and prevention. The goal is to make genetic counseling as common as a dental examination.

The most critical element in determining the risks of giving birth to a genetically disabled child is a thorough medical history of the family. Because a social stigma is irrationally attached to genetic disorders, and most people are reluctant to reveal family health secrets, the medical interview must be handled with sensitivity and caring, Steinberg says. "You learn very quickly that genetic histories take a long time to get. People block it, hide it and don't want to talk about it."

He told of one family he visited in their home after four children had died of leukemia. "They kept denying it. After three hours of getting nowhere, I was on my way out the door. As I was walking out, the old grandmother yelled, 'we told them not to get married. They're second cousins and no good would come of it.'"

Too often, he adds, physicians are in-

capable of doing such interviews or do not want to spend the time to conduct them. In either case, all the doctor need do is refer the patient and family to one of the foundation's centers. "Any physician anywhere in the United States can appeal to us for help," says Steinberg.

### GENETIC SERVICES MADE MORE AVAILABLE

In some instances the foundation has taken its genetic services to sparsely populated areas to help families where no center is geographically convenient. The foundation has gathered in one place extended families, comprising 200 or 300 people for a kind of genetic family reunion. Despite the fact that medical malpractice cases are focusing more attention on genetic diseases, Steinberg said the "average physician thinks genetic diseases are rare. They say, 'I don't need information on that. I don't have time to spend on something very rare, very esoteric.'"

Steinberg says doctors also don't like to deal with genetic disorders because many view them as "not treatable, and physicians do not want to have anything to do with something that is not treatable."

According to the Genetics Foundation, between 12 million and 15 million Americans have a genetic disorder and one out of three hospitalized children is being treated for genetic problems. One fourth of all people in institutions for the handicapped have a genetic disorder of some kind.





Susan Friedman, Volunteer, looks on as Larissa Bilious builds her flying machine.

## The magic of friendship

On her recent visit to Chappaqua, a small community on the outskirts of Westchester, Lifestyles' staff writer, Jane McMahon, was introduced to a new kind of magic. It was the kind of magic that comes from teenagers helping teenagers in a brand-new program.

The interaction is the result of persons from two groups: one includes seven special education students from BOCES (Board of Cooperative Educational Services) schools; the other, 11 volunteers from the northern Westchester chapter of YOUTH-ARC, the acronym for Youth Organized and United to Help the Association for Retarded Citizens.

The purpose of the independent youth group was explained by its president, Nancy Robbins, 17, a junior at Horace Greeley High School in Chappaqua. "These kids are all adolescents and they need friends, and we try to give them friends. When one girl first came to us, all she would do was scream because she wanted attention. Now she has calmed down quite a bit because she knows she will get the attention she wants. Another boy just stared at the ceiling, but now he joins in with all the activities."

The simple format is planned each week by one of two group leaders with the help of group advisor Judi Masseth of Mount Kisco. There may be a story or short movie combined with arts and crafts dramatizations. The library staff assists in selecting materials.

Nancy outlined the activities. "Today we're going to watch 'The Sneetches' film by Dr. Seuss and we're going to take off from there and make inventions like the crazy Seuss contraptions," she said. "They really enjoy acting out so we are going to act out the inventions."

When the film ended, newspapers were spread on the tables in the community room and it was invention time. Volunteer Susan Friedman helped Larissa Bilious make a flying machine. Cindy Talman worked with Arden Leonetti on a house with walls that insisted on collapsing. Chris Travis and his volunteer friend, Jodi Mindell, made bionic glasses. Laurie Ross and Jean Milligan collaborated on moon sneakers to wear on space walks.

Mary Daly made a wand for a fairy godmother to help a girl who did not have a date for the prom. In the skit that followed, Mary touched a girl with her wand and a date popped up, played by Jim Homet. Rick Damman, whose brother, Mark, is a volunteer, wanted to do his skit with a

cardboard gun last and he added on a surprise finish all his own.

After each session, Ms. Masseth meets with the volunteers and they critique their approach. On this particular Thursday, she suggested that the volunteers make sure that their guests have more of a part in the proceedings because she felt there was a tendency to help them too much.

Parents arriving to pick up their youngsters were enthusiastic about the success of the Thursday afternoon. They said they were pleased because it exposed their children to peers who were not handicapped and provided them with experiences not available in their schools.

A career in the field of mental retardation may result for some of the Greeley high school students involved in YOUTH-ARC, a branch of a statewide organization that offers its local groups many benefits, including scholarships. Nancy Robbins has been working with retarded adults at group homes in Bedford since she was a ninth grader and says she'd like to become a psychiatric social workers.

"We are hoping to try all different things with the group," she said. "There is room for more retarded teenagers in the program and we would welcome more volunteers."

YOUTH-ARC volunteers also work in a gymnastic program for the handicapped sponsored by the recreation department every Wednesday at the Bell School in Chappaqua. They have completed a training program to act as sitters as a service for parents of the retarded and are planning a buddy program which will have no age restriction and match volunteer and client with the same interests.

While the Westchester Chapter sponsors additional programs in Yonkers and Greenburgh, and other chapters throughout the state sponsor a variety of direct and indirect service projects for those who are mentally retarded, Ms. Masseth, the Westchester YOUTH-ARC adviser, feels her Chapter can be justly proud of the Chappaqua library program for its "the only one like it in the state."

NYSARC, however, is very proud of Judi Masseth, and regards her as a rare, precious resource in our chapter. Without her tireless efforts, enthusiasm and rapport with the young people of this community, the mentally retarded may not have had this opportunity to share in the "magic of friendship." Thanks so much, Judy, keep up the good work!

# Membership tops 34,000

## 20 chapters increase; 13 top goals

Almost half of the Association's 62 chapters showed an increase in membership for the 1979-80 membership year. With four chapters still not having reported their memberships by the June 30th deadline, our chapters have submitted a total of 34,413 memberships, an increase over the 33,011 received in the entire 1978-79 year.

Proving once again the validity of the position that membership chairmen are important, it should be noted that 11 of the 13 chapters that went over their goal had a chairman appointed this year, and another, New York City, makes a specific staff assignment for this purpose.

Absolute special mention must go to both Erie County Chapter and its Chairman, David Essrow, and the Steuben County Chapter and Chairperson Gloria Gibson, both of whom more than doubled their chapter's 1978-79 membership. Erie County, under Mr. Essrow's leadership went from a membership of 303 to 615, which is easily more than double the greatest membership Erie County Chapter has ever had. In Steuben County, Mrs. Gibson's work increased the membership from a 1978-79 total of 115 to 232 members.

Special mention must also go to Rensselaer County which showed by far the largest gain in memberships in the Association, but who used an unusual

technique for the increase. Rensselaer was involved in a capitol funds drive this year, and anyone who made an contribution to that campaign was given an honorary membership in the chapter for this year. Chairman Russell McGrath should be complimented on increasing the membership through this means from 335 to 1,755. It will be interesting to watch the membership retention figure next year.

Additional memberships will be accepted from chapters at any time during the year and it will be our hope that perhaps this will be the year that we break the 35,000 barrier in numbers of members.

This is a listing of those chapters who exceeded their goals with the names of their Chairpersons:

Also increasing membership over last year were: Cattaraugus, Cortland, Dutchess, Madison, Nassau, Oneida, Ontario, Orleans, Oswego, Otsego, Rockland, Schenectady, Seneca, Warren, Washington, Welfare League and Wilton Developmental Center. J.N. Adam Developmental Center Chapter, a new chapter has come in with 69 memberships, so far, surpassing 8 previously established chapters.

Chapter and Chairperson	79-80 Membership	78-79 Membership	79-80 Goal
Allegany, Susie Robinson	233	175	225
Erie, David Essrow	615	303	400
Essex, Jennifer Deming	226	205	225
Herkimer, Judy Sprague	304	261	300
Jefferson, Roland Burand	503	379	435
N.Y.C., Anne Kraus	7613	7363	7500
Rensselaer, Russell McGrath	1755	335	375
St. Lawrence, Caroline Smith	218	129	150
Schuyler, Irene Brown	171	106	125
Steuben, Gloria Gibson	232	115	200
Suffolk, Margaret Howard	1331	1202	1325
Sullivan, Marguerite Cahalan	1112	1037	1100
West Seneca D.C.	608	565	600

## Zoning laws in Tennessee

The 1978 session of the Tennessee General Assembly recently passed landmark legislation when it enacted a new zoning law which allows group homes to be established in any residential neighborhood.

The zoning act, which faced serious opposition from many special interest groups, was passed by both the House and the Senate as the 90th General Assembly neared the close of its 1978 session.

The new law supersedes all local zoning ordinances and defines group homes serving up to 8 mentally or physically handicapped people as single family dwellings for zoning purposes. This new law will eliminate a number of problems which group homes have faced in recent years.

Many cities' zoning laws prohibit group homes in most of the desirable neighborhoods by classifying them as boarding houses. Other cities' zoning laws are vague concerning the location of group homes. The result has been that group homes across the state have faced stiff opposition and court battles over zoning problems.

Several group homes have been forced out of existence or tied up in court by neighbors who oppose them. The new law will eliminate these problems.

The longest ongoing court battle over a group home in Tennessee involves a house purchased by the Coffee County ARC in Tullahoma in 1972. The Coffee County group was sued by the neighbors seeking to block the establishment of the group home. Both the ARC and the neighbors

have continued the battle for 6 years, and, before the new law was passed, the neighbors seemed to be on the verge of winning as the courts were ruling in their favor.

Now, with the new zoning law, the ARC is free to open the group home.

## NEW increases

### monthly SGA test

The Social Security Administration recently announced an increase in the Substantial Gainful Activity test, a benchmark used to determine the eligibility of certain disabled persons under the Supplemental Security Income program (Title XVI) and the Social Security Disability Insurance program (Title II). The SGA level is raised to \$280 a month, retroactive to January 1, 1979, and \$260 a month, retroactive to January 1, 1978, according to a notice published in the Federal Register on March 23, 1979. SSA had just upped the SGA test to \$240 last July.

Prior to January, 1978, the upper limit on earnings had been \$200 per month since January, 1974.

If the individual works in a sheltered workshop or a comparable facility, earnings of up to \$280 per month (\$260 a month in calendar year 1978) normally will not be considered evidence of the individual's capacity to engage in gainful activity.



# Special people make Special Olympics

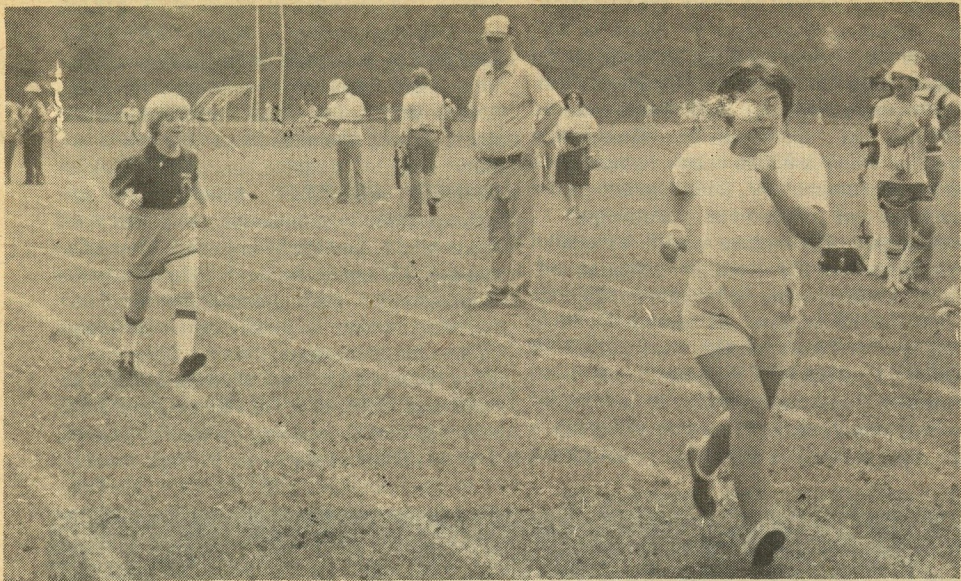
(All pictures by Olean Times Herald)



Eighteen-Year-Old Special Olympian France Green of Brooklyn, left, proudly displays two gold medals he was awarded during New York State's Special Olympics, while volunteer "hugger" Gary Van Skiver of Allegany, looks on. The more than 400 volunteers who devoted their time and energy were an integral part in making the weekend games the astounding success they were.



ON YOUR MARK



IT'S JUST FUN



RESTING BETWEEN EVENTS

The entire campus of St. Bonaventure University near Buffalo was awash with a variety of colors throughout the first Saturday in June — the blues, browns, reds and greens of the uniforms of the nearly 1,200 Special Olympians taking part in the day's events — and the distinctive white hats of the more than 400 special people who had devoted a day in helping to make the New York State Special Olympics the astounding success it was.

To the participants of the games went the medals, the pride in having competed and succeeded and the feeling there are people — a great number of people — who care a great deal.

Eighteen-year-old Special Olympian France Green is back in Brooklyn, having left St. Bonaventure with memories of opening ceremony parades, athletic competition and victory celebrations. But, as he said, he will also remember a 19-year-old volunteer who was an important part of his three days at the 1979 New York State Special Olympics.

Allegany resident Gary Van Skiver first became involved in the Special Olympics program after having been asked to participate by the Allegany American Legion post, an organization which, along with several others throughout the area, was an integral part of the successful games.

He was designated a "hugger" by Special Olympics organizers — an individual volunteer who is assigned to accompany one Special Olympian for the entire day, providing assistance, moral support and most importantly, friendship.

Gary Van Skiver of Allegany and France Green of Brooklyn had met for the first time Saturday at 7 a.m., and by early afternoon, following a morning of competition, the two had become friends.

"Gary is my friend," the athlete said as he displayed the medals he was awarded for taking first place in both the 100-yard dash and softball throw events, "he's a very good fellow — he showed me around this morning and he was so proud of me when I won my medals."

But while the 1,200 Special Olympians benefited from the time devoted by the volunteers, so too did the volunteers themselves — from being a part of the games and helping to make them a success.

"I like the idea of helping kids," Gary said, "this event is something special, and it makes me feel special to be a part of it."

The Special Olympic Games could not have been a reality had it not been for the more than 400 people like Gary Van Skiver who had volunteered their time and energy for the event. Under the direction of Jean Trevarton, volunteer chairman, those individuals served not only as "huggers", but also as escorts, time keepers, score keepers, cartoon characters, entertainers — in other words doing any job the organizers of the games deemed necessary.

Several organizations and corporations also contributed in making the games successful — members of the Y's Mens Club from the Olean YMCA were on hand throughout the day supervising swimming events and cheering athletes on to victory in the Reilly Center pool; eight members of the ORAK Grotto in Bradford donned clown outfits to entertain athletes; Ronald McDonald entertained on stage for two shows and the Eastman Kodak Co. of Rochester supplied representatives to take color snapshots of participants as they were awarded medals.

The end result of the months of planning and organizing by university and Special Olympics officials was a weekend that nearly 1,200 special athletes and countless thousands more volunteers and spectators

will most likely never forget.

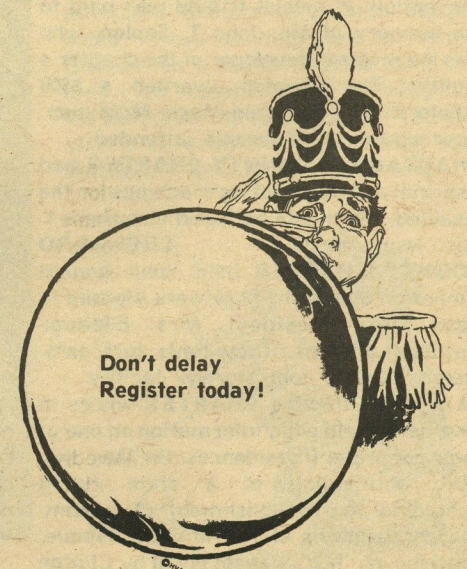
A sense of pride in achievement and the type of sportmanship rarely seen today prevailed in every aspect of the Special Olympic Games.

Athlete France Green, who typified every participant in the games, perhaps summarized that feeling best when he said, "I have worked very hard all my life and I was very proud when I won my medals. . . but that isn't the most important thing because I have good sportmanship — that makes me a good athlete."

And also overheard was a young Special Olympian who walked off the field after an event, he his head slightly down, and said to the "hugger" walking beside him, "It's not so bad. . . there's always next year."



Ronald McDonald was among those awarding medals to participating athletes. Rochester's Eastman Kodak Company issued free instamatic pictures to each of the almost 1,200 Special Olympians who participated in the games.

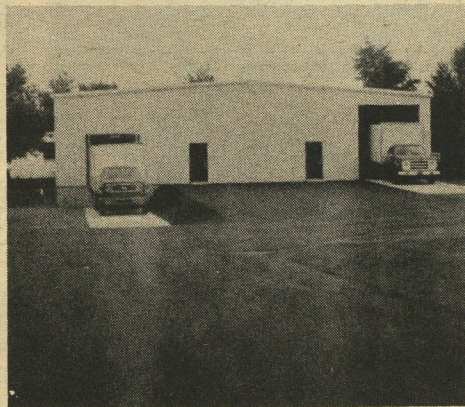




# CHAPTER NEWS *What our chapters*

Seems it was easiest to tackle the material for Chapter News in reasonably alphabetical order, so we'll come rather close to that in this issue. Let's start off with **ALLEGANY CHAPTER**, where we join the chapter in the community in thanking former State Board Member, J. Charles Shine for, once again, sponsoring the Annual Sports Night Banquet which is held as the major fund-raiser for Allegany County Chapter. This is about the 16th consecutive year that Charley has sponsored this most worthwhile activity. Always glad to see pictures of our chapters receiving money and we were delighted that Alleghany County Chapter received \$600 from a surplus from the Wellsville United Fund Drive. . . **CATTARAUGUS**

surrounded this residence throughout the forty day site selection procedure and culminated in an appeal to Commissioner Coughlin by the Clinton County ARC late in March. A public hearing was held April 4th in Plattsburgh with Associate Commissioner, Zygmund Slezak presiding. ARC President Edward McShane presented a statement on the philosophy and goals of the residential program and addressed the issues at hand, those of need and saturation. The statement clearly established the need for the residence and showed that there is not a saturation of residences in the neighborhood or in Plattsburgh. Representatives of the immediate neighborhood challenged the constitutionality of the Site Selection Law



Chenango County Chapter's new storage facility.

**COUNTY CHAPTER** had over 100 bikers taking part in their 1979 Bike-A-Thon. . . **JEFFERSON COUNTY CHAPTER** celebrated its 25th Anniversary with a Dinner-Dance at the Carriage House Restaurant in Watertown and numerous other activities. One of the highlights was the return for the programming of former State President and Chapter Founder, Peter Keischgens. Sorry we couldn't be there to see you, Pete, but we heard it was an absolutely wonderful time. . . While **MONROE COUNTY CHAPTER** carries on with its usual outstanding programs, they took a little time aside on July 8th to honor retiring Executive Director, John Regan. It was a wonderful affair, paying tribute to John for his 16 years of services to the chapter. We offer every good wish to Mr. James Mroczek who has remained as John's successor. . . Not to be outdone by sister chapters, **MONTGOMERY COUNTY CHAPTER** has started up a new newsletter, The Liberty Enterprise Advocate. . . We are always glad to be able to find **NASSAU COUNTY CHAPTER** because they are always so busy and sometimes we think we will find them buried under work. For instance, they again recently held their Annual Book Fair with over 100,000 books to be marked and categorized for the fair. That's the way Nassau does things. Also delighted to note the opening of their fourth community residence this Spring, and of course, we cannot overlook the Annual Rose Ball, noted elsewhere in this issue and its usually outstanding success. Incidentally, for the rest of you, you might be interested to know that at Hofstra University, the 22 hour Dance-A-Thon was undertaken this Spring, which earned more than \$15,000 more for the chapter. . . **NEW YORK CITY CHAPTER** was able to have the City of New York declare the Month of May, AHRC Month, for which we thank Mayor Koch. That's the way to get the word out about us to people. . . **ONONDAGA COUNTY CHAPTER** delighted to announce their new brochure entitled, ARC from A to Z. Sounds interesting. Thanks as always to Unity Mutual Life Insurance Company for their Annual Tennis Tournament, which is really a major fund-raiser for Onondaga County Chapter. . . Very difficult to keep up with all the activities of **ORANGE COUNTY CHAPTER**, which is certainly doing its best to provide a wide-range of services to their county.

## Unity Life does it again



### VICTORY SMILES

Annual Pose after Unity Life's fourth annual benefit, THE Tournament. From left, front: Dave and Barb O'Donnell (Finalist-Pro); Dr. Robert Diamond and Norma Tippet (Finalist-A); John Brusa and Anita DeSantis (Finalist-A) and Stephan Wallenfels and Amy Lockwood (Winner-Pro). From left, top: Linda and Frank Pizzaca (Winner-B); John F. X. Mannion, President and Chief Executive Officer of Unity Mutual Life Insurance Company in Syracuse, New York; Dean Vlassis owner of Limestone Tennis Club and donor of all court time; Linda Schoenwald, volunteer tournament director; Ira Ames and Mary Ann Rhinehart (Finalist-A). Onondaga received \$7,600 from the three day tournament plus a tremendous amount of publicity and good will. Unity Life also supports Onondaga County Chapter by contracting with the workshop, Monarch Industries, to stuff and mail its monthly newsletter, Unit Life and Times.

**COUNTY CHAPTER** held their, Annual Dinner at the Castle Motel in Olean which many will recall as the site of our 1972 convention. A special tribute was paid to the memory of Mr. John T. Soplop, who was the original developer of the chapter's facility. The Chapter awarded a \$500 scholarship to Kathleen Marie McMullen. Approximately 70 people attended. . . **CHAUTAUQUA COUNTY CHAPTER** had a special article on voting machines for the disabled, which can be found elsewhere in this issue of OCV. . . **CHENANGO COUNTY CHAPTER** held their Annual Dinner on May 11th. They were pleased to have State President, Mrs. Eleanor Pattison, present. They have just completed an 8500 foot storage facility. . . **CLINTON COUNTY CHAPTER** writes to give us the following information on one of their community residences. On May 2nd, 1979, notification of a state ruling upholding the establishment of a community residence at 31 Tremblay Avenue, Plattsburgh, N.Y. was received by Clinton County. A heated controversy had

and voiced many concerns about the negative effect on property values and the local tax base. The Commissioner's ruling cleared the way for the ARC to establish the program. . . **COMMUNITY LEAGUE, WASSAIC CHAPTER** reports, through former President Dorothy Vine, that the enclosed picture is their new popcorn machine just purchased to replace a 30-year old item. The popcorn made by the machine is highly enjoyed by the residents of Wassaic and they had been without this extra treat for a while before the purchase. . . **CORTLAND COUNTY CHAPTER** finally was able to have the formal dedication and open house of the Laura Burch House, its first community residence. The residence was made possible by a generous contribution from the Estate of Laura M. Burch through the kindness of executors Theodore Fenstermacher and Howard Leagle. A portrait of Mrs. Burch has been placed in the home for future remembrance. Can't leave Cortland County without mentioning the fact that Chapter Executive Director,

Karin Burgess, was one of five women in Cortland named by the local Zonta Club as "Woman of Achievement".

Congratulations Karin! . . . **DELAWARE COUNTY CHAPTER** had themselves a Bike-A-Thon this Spring. Hope it made a million. . . In addition to the several other interesting tales about **ERIE COUNTY CHAPTER**, covered elsewhere in this issue, including their outstanding membership effort, we should mention the Jonathan David Lodge of the Knights of Pythias presented two Employee-of-the-Year Awards at the Annual Dinner - Dance May 12th. Mr. Lou Ross of the Pythias presented watches to Ms. Patricia Ferrara and Mr. Arthur Wilde. Both are employed by Allentown Industries' production unit. . .

From **FRANKLIN COUNTY** comes the following news — The Franklin County Chapter has announced the appointment of several new people to their organization. The incoming Executive Director is Mr. Jay Walsh. Mr. Walsh arrives from Albany with an MSW in Administration. Also new is Mr. Richard Bates in the position of Community Residence Director. They are also happy to announce the appointment of Mr. Ellis Maroun to the position of Business Manager - Bookkeeper. Ellis comes with extensive experience in the field of hospital administration, having been responsible for the books of account at Mercy General Hospital in Tupper Lake. . . **FULTON COUNTY CHAPTER** heavy into all programs, as always, had an overnight camp from June 24-29 and is planning a day camp August 13-17. . . **GREENE**



ARC guest, Mrs. Eleanor Pattison, center, President of the NYS ARC with incoming Clinton County Chapter ARC, President, Kevin Ryan and outgoing Chapter President Edward McShane, Jr., at recent ARC Annual Meeting.



# are doing and saying for our children and adults



Peter Leon, 8, Poster Child of the Association for the Help of Retarded Children, New York City Chapter, shows his interest in City Hall surroundings during presentation of Mayor Koch's proclamation designating May as "AHRC Month" and noting the Association's 30th Anniversary. Participating are (l. to r.) Michael Goldfarb, AHRC Executive Director; Irene Platt, AHRC President; Dr. June Christmas, New York City Commissioner of Mental Health, Mental Retardation and Alcoholism Services, who represented the Mayor; and Michael Mascari, Assistant Commissioner of New York State Department of Mental Retardation and Developmental Disabilities.

Recently held Open House in each of their three community residences. . . . **ORLEANS COUNTY CHAPTER** recently was the recipient of several pieces of good news, the green kind . . . Open house sponsored by **PUTNAM COUNTY CHAPTER** at their new facility in Kent Center on April 29th. News of this event just missed the last issue of OCV. The new 13,000 square foot facility provides programming for 50 handicapped individuals. . . . 20-24 members of our **OT-SEGO COUNTY CHAPTER's** Day Training Program have been bowling at the Hartwick College Bowling Alley, regularly. . . . The **RENSSELAER COUNTY CHAPTER** has been busy of late with work on the development of 4 new community residences. Chapter Executive Director, Jim Flanagan reports that contacts with local officials in Troy, Sand Lake and North Greenbush have been very positive under the new site selection law. Rensselaer's Adult Services Program has also been awarded its second fee category increase in six months by the Office of Vocational Rehabilitation and is now expending its program offerings through grants from the Developmental Disabilities Act and the Office of Vocational Rehabilitation. The chapter is also awaiting delivery of four new vans, purchased through a grant from the Department of Transportation. A highly successful spring semi-formal dance was held in April by the ARC's evening social program, under the direction of Dave Annone and MaryAnne Donovan. . . . Have to mention the fine column called, "Why Fund Raising" by then President, Doris Skrzec of **ROCKLAND COUNTY CHAPTER** in their Spring newsletter. Tells it like it is. . . . We welcome an old friend, Francis B. Turner back as President of **ROME DEVELOPMENTAL CENTER CHAPTER**. . . . From the Executive Director's desk of

**SCHENECTADY** comes the following bit from Carl Hawkinson. "I am pleased to announce that we have received final approval of our State Aid Grant Application from OMR-DD for the Fort Hunter project. This means that we will receive \$111,000 which represents one-third the total cost for the acquisition and renovation of the facility. We are making final preparations to move our first residents into our new community residence on Myrtle Avenue in Rotterdam at the beginning of June. . . . **STEUBEN COUNTY CHAPTER**, working on that new facility, together with having an outstanding membership campaign, didn't

on May 17th. I remember it from last year and it was terrific. . . . According to information received in the news, **SULLIVAN COUNTY CHAPTER** will be receiving \$832,000 to pay one-third of the cost of a new building to house their vocational rehabilitation services. Executive Director, Marc Brandt stated that he anticipated the chapter would have 800 clients within the next two years. The total amount of the project will be approximately \$2.5 million. . . . **ULSTER COUNTY CHAPTER** got right down to the heart of it in a recent issue of their newspaper with the headline, The A.R.C.! What Is It? What Does It Do?, and then went on to tell just exactly what it was. Have to mention, Mr. Frank Giannino, a 26 year old marathon runner who is a recreational therapist for the chapter. He ran coast-to-coast in 60 days and 6 hours, setting a new national record, down from 61 days. Congratulations and do you have recommendations for what one does about blisters? . . . Excellent article about membership in the **TOMPKINS COUNTY CHAPTER** newsletter written by Chapter President, Walter Herr. He is hoping to gather support for their community residence proposal for the County Board. . . .

**WELFARE LEAGUE - LETCHWORTH VILLAGE** running an interesting addition to their newsletter. Had an article which indicated that anyone just interested in talking or lending or needing support while far away from Letchworth could get it by calling a member in the Miami, Florida area. Seems we're going national. . . . Now here's one for you. The White Plains Rotary Club got together on a Saturday in early June and built a portable, miniature golf course for the clients at **WEST-CHESTER COUNTY's** Katzenberg Training Center. That's really a very nice project. Those of us who need help with our putting will probably all want to visit Westchester soon. Last but by no means least, we want to mention the **WILLOWBROOK CHAPTER** held its Annual Luncheon on Saturday, May 26th at the New York Hilton. Over 400 people attended the affairs at which Eliu Howe was the guest of honor. The luncheon was chaired by Ann Barsky and Genevieve Camen. A new slate of officers, headed by returning President Anthony Pinto was installed on June 10th.



New popcorn machine at Wassaic, purchased by Community League.

## Schoharie ends ed program

The Board of Directors of the Schoharie County Chapter of the State Association for Retarded Children has discontinued its program for school age children effective June 30.

"The decision was made reluctantly after much deliberation and extensive consideration," Elizabeth L. Southard, executive director, of the Schoharie Valley Training Center said.

"It was made in the interest of quality educational programming for the multi-handicapped retarded children in Schoharie County; this is their primary concern," she added.

The space used for this education program at the training center between Middleburgh and Schoharie, will be used to expand the adult programs also operated by the chapter. The children will attend appropriate programs operated by the public schools. The role of the chapter will be to advocate for quality programming within the public school system. The directors will work with parents and the schools to obtain this for the children.

Three factors influenced the board of directors' decision:

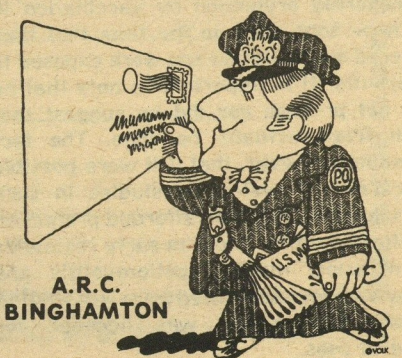
1) Enrollment has decreased until the prospect was for only five or six children to be enrolled in the 1979-1980 school year. The directors said they cannot "provide quality programming" in the "least restrictive environment" for so few children with so varied problems.

2) The Department of Mental Hygiene has issued a directive that it will not be responsible for any deficit in the educational program.

3) The State Association for Retarded Children was started to advocate for program for the retarded and arranged for children's programs when they were not being provided by the public schools. In Schoharie County the public schools are ready to provide these programs. The agency will return to its role as an advocate for children and as a provider of programs for adults.

Many people have inquired about what will happen to the building. Mrs. Southard said there are 46 adults enrolled in the rehabilitation and employment programs — the number of clients in these programs will be expanded. The Schoharie ARC has plans to expand and renovate the building to better accommodate this program to serve between 66 and 70 clients and to develop a day treatment program for 42 adults who cannot function in the workshop program.

"These people presently do not have adequate programs," Mrs. Southard noted. "However, they can be taught to function on a higher level and, in time, may even be able to try working in the workshop. At the least, they will be better able to care for their own needs and to function in their homes," she said.





## Hepatitis tests denied

In the last issue of Our Children's Voice, an article regarding the clinical testing of retarded children with hepatitis B vaccine, was printed.

Maurice R. Hilleman, Ph.D., Director, Virus and Cell Biology Research, Merck Institute for Therapeutic Research of Merck Sharp and Dohme Research Laboratories, has responded to this publicity by letter:

The original newspaper article, published on May 18, contained information not in accord with the facts, particularly with regard to the matter of purported tests of the vaccine in retarded citizens. I should state to you that there is no plan, there has never been a plan, and there will be no plan for investigative studies of unlicensed hepatitis B vaccine in retarded citizens!

Allow me to expand. This laboratory has been engaged since 1971 in research toward the development of a safe and efficacious killed vaccine for prevention of a very serious disease, hepatitis B. To date, we have prepared 11 lots of vaccine, all of which has been tested *in vitro* and *in vivo* for safety and potency including tests in chimpanzees. Five of the lots have been tested in man in more than 600 persons who were without hepatitis B antibody (susceptibles) and in more than 150 persons who already had antibody (immunes) and whose antibody was increased by vaccination. The vaccine proved safe and was effective in inducing antibody in these persons. Human subjects were first given the vaccine in November 1975.

The first human subjects who received the vaccine, except for two, were all employees of this Company who volunteered freely to receive the vaccine. These and all further studies have been carried out in normal persons with free and voluntary consent under the Investigative New Drug Laws administered by the Bureau of Biologics of the U.S. Food and Drug Administration.

We, and the Bureau of Biologics, regard the vaccine as proven safe and potent. The vaccine is now being tested in man to measure its protective efficacy. Some of the planned studies are in progress and others will begin soon, some under private sponsorship and some under government sponsorship. The studies planned, or in progress, are all in noninstitutionalized mentally competent persons who are at high risk to contamination with infected human blood or body secretions.

Might I comment briefly on Dr. Saul Krugman. The hepatitis issue had its origins at a workshop on hepatitis B that was convened by the Bureau of Biologics on January 18-19, 1979. During the last day of the meeting, Dr. Krugman, who is a renowned hepatitis expert, was Chairperson for the summing up. The question had been raised by one of the participants as to the feasibility for immunization of the mentally retarded against hepatitis B infection. Dr. Krugman observed that all such institutionalized persons are at high risk to hepatitis B infection, no matter whether these persons be mentally retarded or not mentally retarded. He commented on the logic and rationale of considering protection by vaccination in such persons prior to the time that they entered an institution and were exposed to hepatitis. It is important to note that he did not propose nor did he suggest that such trials actually be done. The fact remains, however, that if it were possible to carry out evaluative studies in such persons, they could be afforded protection against hepatitis B just as early recipients of measles, mumps, poliomyelitis and other vaccines benefitted from vaccination before the vaccine was licensed for general uses.



## For the new program

Undergoing renovation, this building in Arkville, was the Sanford appliance store. The building is being leased from Bruce Sanford by Broome Developmental Services and will be used for a community living schools program for severely retarded adults. The program will be operated by Delaware County Chapter of the Association for Retarded Children. ARC Executive Director Stephen C. Helfgott said, "These adults will receive daily training in self-care, daily living skills (making bed and preparing meals), language and communication, recreation, basic concepts and academics and socialization." Program will commence as soon as renovations are complete. Another location for the living schools program is Christ Episcopal Church, Walton.

## Travel training in N.Y.C.

Travel Training for the Handicapped, a New York City, Board of Education Program, has been validated as a Model Educational Program for New York State. This program has been in operation in New York City since the 1970-71 school year, and is the largest program of its kind in the country.

What is Travel Training? . . . Travel Training is a program designed to teach handicapped adolescents to travel independently. Mentally retarded and other handicapped students learn to travel on public transportation from home to an educational or vocational facility, as preparation for independence and expanded job placement potential.

How does it work? . . . Paraprofessional Travel Training instructors provide individual instructions to each student in the program. Skills such as street crossing, boarding and exiting buses and trains, and requesting assistance are part of the daily activities.

More than 2,000 mentally retarded adolescents in New York City, enjoy a significant degree of personal independence because Travel Training was part of their school curriculum.

This year the program has received a Title IV-C grant to demonstrate the program to local educational agencies throughout New York State, and to provide assistance to those school districts interested in replicating the program.

Title IV-C replication or mini-grants for start-up costs are available from the State. For more information, consultants from the Travel Training Program are available to discuss with you how to develop a Travel Training Program to meet the special needs of your community, and how to file a grant if necessary.

Please contact Margaret M. Grocé, Program Coordinator; or Madeline Bova, Project Demonstrator: Travel Training For The Handicapped, 8310 21st Avenue, Brooklyn, N.Y. 11214. (212) 266-0085.

# Funding change demand for community residences

A Statewide Survey on Staffing - Funding for Community Residences brought the unanimous response from nineteen agencies throughout New York State, that their organizations were not funded properly by the State to staff a twenty-four hour care facility properly.

The survey further showed that, if the funding ratio were changed, some of the staffing problems would be elevated due to increased funding.

Although there was not unanimity on what the funding should be, it was evident that it had to be changed.

The Survey also listed the information that the present funding does not permit the agency to comply with Wage and Hour laws. The recommendations that came out of this Survey conducted by the Chapter of the ARC, through James Elmore, Director of the Community Residence, are:

1. State should increase its share of funding community residences.

The present funding mechanism does not allow adequate funds to properly comply with Federal and State Wage and Labor Law.

Additional monies are needed to properly staff facilities and provide adequate On-Going In-Service Programs.

Services are mandated beyond the actual Program Budget and needs.

Finally, that there should be adequate allowance for fees for attorneys who are becoming more and more important if we are going to meet the Wage and Hour Law provisions as well as others.

These inadequacies are well recognized by the Commissioner of Mental Retardation who is working on a response to them.

## Workshop grads in private jobs

Vera Winters is a young adult whose life changed when she began her first job in the private employment sector.

She is one of 16 who were graduated recently from the job training program at the Community Workshop operated by the Columbia County Chapter, Retarded Children's Association. The slim attractive woman approached her first job with enthusiasm. She works at the Hudson Food Preservation Center as a cannery technician.

Her success after two years in the ARC's workshop program has made her "very happy," she said.

Jobs have been obtained for five of the 16 "graduates;" prospects for the others, working with the employee - employer replacement program of ARC, appear good.

The graduation ceremonies, like the program, were unique — a picnic on a Taconic State Parkway overlook, topped off with a congratulatory cake and many hand-shakes and smiles. Frisbee and baseball games added to the party atmosphere.

The diplomas were handed out by Brian Hughes and Sandy Lynn, key staff members in the placement program.

The job readiness program serves workshop clients the staff has determined are prepared for private work force. It lasts between four and five months, and its purpose is to place as many persons from the workshop into the competitive job market by gearing them on a job in their own skill area.

"From a young age, the mentally handicapped are told there are things they shouldn't or can't do," said Hughes, placement program director. "But given a realistic opportunity and encouragement, they can go a long way."

Persons at the workshop have been employed in the area as baker's helpers, kitchen aids, nurse's aides and cleaning service employees. The workshop even has a community cleaning referral service that cleans small businesses and homes.

The first step in getting a job begins when the client enters the workshop. He is given an extensive battery of tests that enables counselors to determine his strengths and weaknesses.

He is placed into simulated work conditions at the workshop. They work on subcontracted work for local businesses like Swiss Farms in Philmont, W.B. McGuire in Hudson, and IBM in Kingston.

The second step is skill training in the client's particular strong field. That may include sewing, upholstery, packaging, woodworking or a variety of other job skills.

The workshop is under the jurisdiction of the Columbia County Association for Retarded Children. The center has clients ranging from 18-72 years old. It serves 180 clients and employs a staff of 55.

What would make an employer attracted to hiring a mentally handicapped person? "Durability," said Hughes. "Of those clients who get jobs, 80 percent of them stay on that job or move to a new one. They're dependable and not many don't work out."

The final step in the program is obtaining a job. In the three and a half years of the program, it has graduated 75, 50 of whom have gotten jobs.

Once into the work force, the clients may become active members of the community.

"We have clients who are volunteer firemen, on bowling teams and involved with church activities," added Hughes.

Graduation day was capped off with the slicing of the cake from the Jersey Baking Company.

## What is Office of Advocate for Disabled?

On June 3, 1977, Governor Hugh L. Carey issued Executive Order 51 creating the Office of the State Advocate for the Disabled. The office was activated on November 1, 1977, and is the first independent state agency to exclusively concern itself with the needs, problems, and delivery of services for the disabled citizens of New York State. The Advocate's goal is to ensure that the disabled are afforded the basic rights, privileges, benefits and equal opportunities in education, transportation, recreation, housing, and employment which all citizens are entitled to. The Office provides a central referral and information service, ombudsman and counsellor assistance service, and also functions as special advisor to the Governor in analyzing and initiating legislation dealing directly with issues affecting the disabled.

The State Advocate for the Disabled, chaired by Narold Unterberg, has a main office (Two World Trade Center, Room 3712, New York, New York 10047) and an Albany office (Agency Building 2, Empire State Plaza, Albany, New York 12223). The Office has a toll-free hotline for the disabled and teletype service for the hearing impaired throughout the state. New York City residents should dial (212) 938-0186, outside the City, dial (800) 522-4369.



# Order ARC Christmas Cards TODAY!

## 1979 AWARD WINNERS

These card designs were selected from an Art Contest of Christmas subjects created by the retarded especially for this program.

25 cards for \$6.00  
Add \$3.25 for each 25 cards imprinted



Card No. AG9822W3  
"Snow-couple" by Eleanor Waldken of West Seneca; a repeat winner! Expresses the warmth of the holiday on white, textured paper. White envelope. Inside: "Warmest thoughts and best wishes for a wonderful holiday and a very happy New Year."



CARD NO. AG9821W3  
"Tree and Gifts" by Joseph Spencer of Wassaic. Reproduced in full colors of Christmas on white, textured paper. White envelope. Inside: "May your home be merrie and bright with the joys of the Season".

## PREVIOUS AWARD WINNERS



Card No. Z376-78  
Created by Eleanor Waldken, a resident of West Seneca Developmental Center. Friendly child with little bird. White envelope. Inside: A Holiday Wish that one day all children will realize their dream.



CARD NO. Z314-78  
Lovely, delicate water-color painting on a white background, framed in green. White envelope. Inside: "Holiday Greetings and Best Wishes for a Happy New Year".

25 cards for \$4.00  
Add \$1.00 for each 25 cards imprinted

## SPECIAL ASSORTMENT



Our own Special Assortment Box of 50 cards featuring original award-winning and best selling designs by retarded persons.

Box of 50 Cards and envelopes for \$7.50. Imprinting is not available for this assortment.

## ORDER FORM

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

Please send me the following  
cards by mentally retarded artists:

No. Boxes	Style, Price & Message	Amt. Enclosed
_____	AG9822W3: 25 cards at \$6.00 — Warmest thoughts and best wishes for a wonderful holiday and a very happy New Year.	_____
_____	AG9821W3: 25 cards at \$6.00 — May your home be merrie and bright with the joys of the Season.	_____

Add \$3.25 for each 25 of  
the above two cards im-  
printed

No. Boxes	Style, Price & Message	Amt. Enclosed
_____	Z376-78: 25 cards at \$4.00 — Wishing you all the Joys of the Season and Happiness in the Coming Year.	_____
_____	Z314-78: 25 cards at \$4.00 — Holiday Greetings and Best Wishes for a Happy New Year.	_____
_____	Add \$1.00 for each 25 of the above two cards imprinted	_____

No. Boxes	Style, Price & Message	Amt. Enclosed
_____	ARC: 50 cards at \$7.50. Special assortment featuring best selling designs by mentally retarded persons. Imprinting not available for this assortment.	_____

Specify imprint: \_\_\_\_\_

TOTAL Enclosed: \_\_\_\_\_

Your Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_ Zip \_\_\_\_\_



# Open doors, hearts to disadvantaged

This editorial on group homes is reprinted from the *Saratoga Springs, New York Saratogian*. It was published in early May. Does this sound familiar?

In principle, few would object to plans to improve the lot of the disadvantaged — as long as it doesn't involve their own backyards.

Such appears to be the syndrome in the Country Knolls North neighborhood in the Town of Malta, where the Saratoga County Association for Retarded Children hopes to establish a community residence for eight retarded adults.

With tempers running hot, a number of residents of the area turned out at a special town informational meeting Wednesday night, accusing the ARC and the town board of being "secretive" about the proposal and implying the establishment of a home for the retarded adults would diminish property values and damage the character of the neighborhood.

Nevertheless, we commend ARC Executive Director Karl Klein and Town Supervisor David Meager for holding firm and for conducting the special meeting to clear the air.

Klein cited studies that showed that such residences do not reduce property values and Meager declared, "I don't feel that morally it would be right for the chief elected official to take a stand in opposition in this proposal."

In fairness, not all the homeowners at the meeting objected to the plan and some even welcomed it. But those who are so much against the plan should follow Meager's example and look into their hearts and consciences.

Fear of those who are disadvantaged are self-perpetuating fears. Care and help for the retarded are the responsibility of society as a whole and are dependent on the acceptance and benevolence of any given community. The "not-in-my-backyard" posture will not make the problem go away.

The Country Knolls North neighborhood

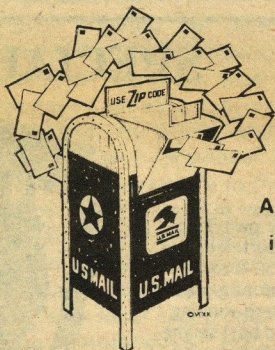
should be proud, not angry, to do its part in helping those who need care and support. The acceptance of such a community residence, in fact, should strengthen the fiber of the community, not weaken it.

We'd say Country Knolls North residents have some soul-searching to do.

## Parent advocates for public school

Other chapters please note. — New York City Chapter Education Committee, together with their professional Advocate, Ms. Catlin Donnelly, has started a very successful chain or network made up of parents whose children are in the public school. They serve as advocates to reach other parents entering the school system, and have a telephone exchange, assist them by going with new parents to the Committee on the Handicapped to give them moral support. These parents use all of the reprints the education committee has been distributing — how to write letters to officials, what to do when you go to your Individual Education Program conference etc.

That is why each chapter should reproduce this material and distribute it. More important is this personal contact of parent to parent — it is working most successfully in the bureaucratic maze of New York City, so it has to work in your school district. Won't you try this system with your education committee?



ARC needs YOU  
in Binghamton

## Neighborhood protection

This excerpt is from a column by Jim Fitzgerald of the *Detroit Free Press*.

Lately, it has become increasingly important that the differences between retarded and unretarded persons be made perfectly clear. Many retarded persons are now allowed to live in ordinary houses instead of dungeons. The law forbids cities from using zoning ordinances to discriminate against them. This means normal people must use other means to protect their property values.

The "other means" used in a Troy subdivision were gunshots. Someone smashed bullets into the living room of a home just after two retarded people moved in. No one was hurt.

This is a dangerous way to protect a neighborhood from handicapped people. Naturally, the normal people with guns want to be certain they are shooting at retarded people and not at each other. Maybe I can help.

Because of my background, I'm fairly expert at distinguishing mentally handicapped persons from the rest of the crowd. For over 20 years I lived a few blocks from Michigan's largest home for the mentally retarded. Every day I saw home patients who had "downtown privileges". They were in the same intelligence category as many of those retarded persons now being allowed to compete in Special Olympics and to live in ordinary neighborhoods.

It has been my experience that these retarded people, when they go out into the community, tend to be quiet. They never push anyone around, and they never complain when they get pushed. They aren't mean to people who aren't as smart as they are. They are kind to everyone they meet.

That's how you can tell them from normal people.

A quick test for the normal gun-shooting protectors of peaceful neighborhoods might be this: If no one shoots back, you're probably attacking the right people.

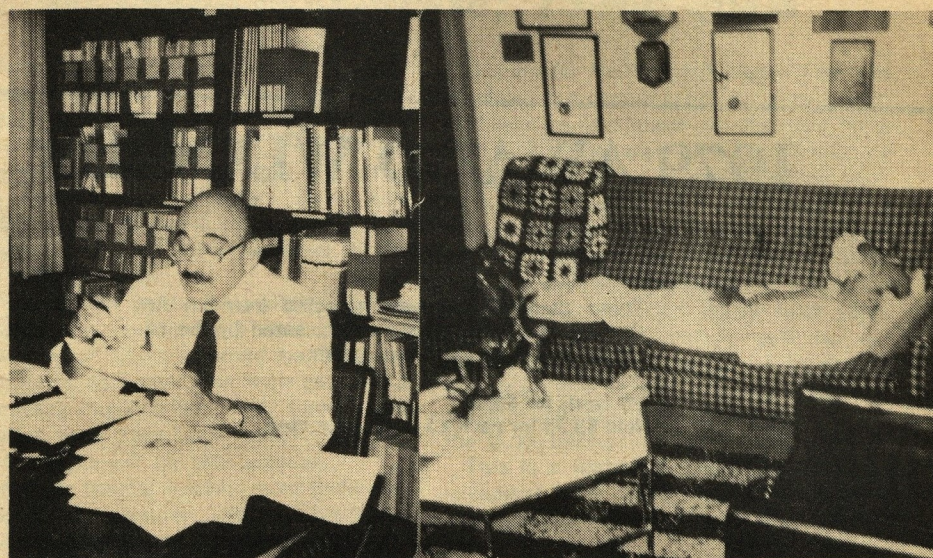
Go get'em, you brave champions of everything that's lousy in this world.

## Cuts force client layoff

A cut in state funds meant no more jobs for 41 trainees and 13 staff members at a workshop run by the Chumung County ARC.

The trainees, who suffer various degrees of mental retardation, were given sudden notice in early May that they will be out of a job, at least temporarily. The layoffs were made to save nearly \$18,000 a month, lost when the state Office of Vocational Rehabilitation (OVR) cut off funds.

In a related move, Executive Director of the Chapter, Michael L. Gordon, and William O. McGill, workshop director, were terminated from their positions. The shakeup followed a growing disagreement



THE FRUITS OF HIS LABOR

"BEFORE"

"AFTER"

## Fulton 9th Annual Fair a big success

The Fulton County ARC's Lexington Fair, held June 7, 8, 9 and 10, 1979, raised \$20,000.00 and attracted over 25,000 people.

The weekend extravaganza featured: Six Mile Lexington Run, A.A.U. Sanctioned, with 190 runners and a winning time of 30 minutes, 20 seconds.

Cavalcade of Champions, Drum and Bugle Corps competition held at Park Terrace Field in Gloversville, New York with six participating drum corps and over 2,000 in attendance.

Parade, 57 units, downtown Johnstown to Lexington Center.

One To One — Wilton Developmental Center, 80 clients and 80 volunteers.

Seven Storey High Hot Air Balloon Softball, Glove Inn Park — WGY Personalities vs. Went No Stars.

Finally, there was a wide variety of food, games and exhibits with continuous four-day live radio coverage by radio stations WENT and WIZR.

In addition, there was a flea market with 75 exhibitors with folk and country music, square dancing, captioned film for the deaf, 4-H demonstrations and exhibits, a Mime, Hugh T. Farley, State Senator, and a Lexington Benefit raffle drawing.

The purpose of the Fair included:

- 1) Raising funds for the Center.
- 2) Acquainting the general public with Lexington's retarded clients who attended the Fair throughout the weekend as workers, spectators, or through the One-to-One Program.
- 3) Creating a positive image about the retarded, emphasizing their attributes.

4) Educating the public about the activities of the Fulton County Association for Retarded Children.

All in all, a model for our chapters to follow if they have not already done so.

Congratulations Fulton County!

## ARC joins in media awards

Over 25 newspaper and broadcast journalists and editors were honored June 19th by One-to-One for excellence in coverage of issues involving retarded people. Ceremonies held at the McGraw-Hill building in Rockefeller Center drew over 230 journalists, editors, publishers, and radio and television station officials.

The judging panel was chaired by William B. Arthur, Executive Director of the National News Council, and included representatives from the New York and New Jersey Press Clubs, the National Academy of Television Arts and Sciences and agencies working with retarded people. Mr. Jerry Weingold, ARC Executive Director, represented the New York ARC.

Mr. Robert Greene, a double Pulitzer prize winner, addressed the winners and guests. Mr. Greene is the founder of the Investigative Editors and Reporters Association, which One-to-One works with to encourage on-going coverage of issues involving retarded people.

Among the winning members of the media were: *The New York Times*, *Newsday*, *The Jamestown Post-Journal*, "Good Morning America", *The Scarsdale Inquirer*, NBC-TV Weeknd, "One Day at a Time", and other print and broadcast presentations.

One-to-One Executive Director, Paul Dolan, told the winners that, "For too long retarded people have been confined to back wards and back pages. The struggle by retarded people to win dignity, proper housing and training will be the civil rights movement of the 1980's." Mr. Dolan stressed the risk of already established gains by advocates for the retarded being erased by government bureaucracies, self-serving agency policies, and erratic funding practices.



# ARC protests state workshops in community

*Unfair competition, says Weingold*

Increasingly, Developmental Centers throughout the State have been establishing and operating Sheltered Workshops in the community for residents of the Centers. This has brought a sharp protest from the New York State Association for Retarded Children.

These workshops are being operated by staff already on the payroll of the Developmental Centers thinking it unnecessary to figure their labor, supervisors and trainers in the price of the product. Furthermore, there is some question as to whether the workers are being paid the rate to meet the Wage and Hour requirements of the State and Federal Governments.

## NEWSPAPER ADS PLACED

Both Newark and Syracuse Developmental Centers have placed ads in newspapers and distributed brochures to prospective contractors for work without consultation with the community agencies already running workshops, many of which lack work, without regard to the well-being of such shops.

Furthermore, these vocational training centers run by Developmental Centers do not have Labor Permits as required by law for those run by the ARC and other agencies.

Some idea of how they are approaching the public is in an ad run by the Syracuse Developmental Center under the name "Precision Contractors" which in no way states who they are and offers industry the following: "The Public non-profit workshop employing 100 persons seeks

subcontract work from area business and industry". Work being sorting, benchwork, mailings - promotions, packaging - labeling, salvage - rework. All of them being done by sheltered workshops for the Mentally Retarded and especially the severely retarded in the community, run by community agencies under the supervision of The Office of Vocational Rehabilitation.

"To call a Workshop run by a State institution — 'public non-profit workshop' is misleading," to say the least, said Mr. Weingold. "It borders on fraud".

## COMPLAINT MADE TO COMMISSIONER

In response to a complaint to Commissioner Coughlin, the commissioner replied he saw no unfair competition in this kind of advertising. He did not, however, respond to fact that there is unfair competition because these shops are notorious for underbidding the community agencies.

If nothing else, since the community agencies are required to provide back-up services for these de-institutionalized clients as well as others, this power-push by the Office of Mental Retardation, through their Developmental Centers, is in fact taking bread out of the mouths of the very agencies they are asking to help them.

This Association is going to seek legislation, having protested to Senator Norman J. Levy, Chairman of the Senate Labor Committee, to forbid this practice under the Labor Laws.



Shown attending Buffalo Management Seminar are left to right — Joseph T. Weingold; Ellie Pattison; Paul Dolan, Executive Director of One-to-One; and Duncan Whiteside, Director of Training Session.

## ARC, One to One hold management seminars

The New York State ARC and One-to-One co-sponsored a three-day workshop on financial management and boards of directors on May 16, 17, 18 for the Western Region chapters in Buffalo.

The training program, funded by One-to-One, is part of a statewide effort that will continue in September in Syracuse and in December in Sullivan County. All chapters are invited to participate.

The seminar program focused on these issues: agency growth, financial planning, cash flow management, budgeting and government funding sources. The program stressed the various roles of Board officers and members, the Executive Director and the agency

financial officer.

Agencies participating in the program were asked to develop a three-person team of the Board president or member, the Executive Director, and the agency financial officer. Agencies work collectively and as teams on specific problems.

Mrs. Ellie Pattison, ARC president, and Jerry Weingold, Executive Director, welcomed the participants and joined in the workshops. Mr. Paul Dolan, One-to-One Executive Director, and Mr. Duncan Whiteside, Director of Management Training, served as resource people.

Ed Emmer of the state office is coordinating activities for the ARC.

## Group home operates without city approval

Eight mentally retarded adults moved in a one-family house in Yonkers recently.

The move was made without city approval on the basis that an operating certificate had been issued to the newly established residential community home by the State Department of Mental Retardation, said Charles Awalt, director of the Westchester Developmental Services. "The operating certificate is all we needed to move in," said Awalt.

For the past eight months, the state agency waited for the city to issue a building permit to make \$20,000 renovations to the house it purchased on July 6, 1978.

However, the permit was not issued because the renovation plans did not include a sprinkler system which the Fire Department required. The agency was told to seek a special exception from the Zoning Board of Appeals in compliance with Yonkers' group home ordinance.

Awalt referred the entire matter to the State Department of Mental Retardation because he claimed the state's law concerning community homes supercedes the city's ordinance passed last November.

The state legislature had established procedures protecting neighborhoods by requiring advance notice be given local officials by those seeking to sponsor the group home for mentally retarded. The law went into effect last July, when the house in Yonkers was leased from Mrs. Gwendolyn Kirsner of Bronxville. Since then the agency has paid \$1,700 per month rent on the empty house.

Prior to the passage of the state bill, the Department of Mental Retardation was permitted by the Willowbrook decree to select sites without permission of the municipalities.

The Willowbrook decree had ordered the state to transfer its institutionalized retarded to group homes in the counties from which the patients originated.

Awalt said he had met with representatives of the Park Hill Homeowners Association prior to signing the lease "and they did not oppose the home."

The new residents at the Rose Lane home formerly lived at Wingdale and attended school at the Mount Kisco Training Unit. "They will continue to attend that school," said Awalt. The adults, all 40 years and older, had previously lived at Wassaic Development Center, a state institution in Dutchess County.

"They have lived most of their lives in institutions" said Awalt. The home is being sponsored by the agency and the Young Adult Institute of New York City.

"The area is now organizing a Community Advisory Board composed of interested residents in Yonkers and will serve as a liaison with the staff and residents with an opportunity to lead normal, more productive and more meaningful lives through programs and services which will help them to achieve the growth of which they are capable," said Awalt.

The Yonkers Parks Department will provide recreational and leisure time activities, he said.

In a related matter, Awalt said the group home for the mentally retarded which was established more than two years ago at 199 Park Avenue also does not have a certificate of occupancy.

A temporary certificate has been issued to the "one-family community residential facility" by Stuart Rowe, then director of the Bureau of Housing and Buildings,

according to Vincent Pici, head of the city agency.

In November 1976, residents of Northwest Yonkers overwhelmingly voted in favor of the Park Avenue group home.

When the home's temporary certificate of occupancy had expired on July 5, 1977, after numerous extensions, Pici says the entire matter had been referred to the corporation counsel's office.

Awalt says he was summoned to court by the city but, on advice from the state attorney general's office, did not appear.

## Bill increases MR city employment

An Act to amend the Civil Service Law, in relation to the employment of mentally retarded persons, has been passed by the New York State Legislature. The act, which the state ARC has urged the Governor to sign into law, will increase the employment of mentally retarded persons in municipal governments from 100 to 200 positions. The law states that municipal civil service commissions in the state may, by rule, determine a prescribed number of positions, not to exceed two hundred, with limited duties which can be performed by mentally retarded persons who are found qualified to perform such duties.

Upon such a determination, these positions will be classified in the non-competitive class, and filled by persons who have been certified by the state education department as mentally retarded and qualified to perform satisfactorily the duties of any such position.

## Residents evacuate burning hostel in seconds

Eleven residents escaped injury when a fire swept through a vacant attic at the hostel for retarded citizens in the village of Ticonderoga recently.

The Amherst Avenue hostel, operated by the Essex County Chapter New York State Association for Retarded Children, suffered heavy damage to the roof and attic and water damage to the house's living quarters as a result of the blaze.

The fire, believed to have been caused by faulty wiring in the attic, broke out shortly after 7 p.m.

A spokesman for the ARC said the home's 11 residents, aged 21-60, were alerted by a fire alarm before anyone knew a fire had erupted in the vacant section of the building.

The spokesman said all the residents were out of the house within seconds and most of their personal belongings were recovered undamaged. The ARC residents regularly practice a fire evacuation plan.

All three Ticonderoga fire companies responded to the stubborn blaze, keeping dozens of volunteers busy for almost three hours.

Local firefighters were hindered by heavy smoke and the fire's fast start. The firemen used 13 air packs in the thick smoke.

A company from Crown Point stood by in Ticonderoga during the fire in case a second alarm was called or another alarm came in from another section of town.

The hostel's 11 residents were housed at other ARC facilities in Crown Point and Port Henry.

Ticonderoga fire officials investigated the cause of the fire.



# Rose Ball award to Senator Levy

Over nine hundred members and friends of the Nassau Association for the Help of Retarded Children helped to mark that organization's thirtieth anniversary at the AHRC Annual Rose Ball held on June 16th in the Grand Ballroom of the New York Hilton.

The event produced over \$300 thousand for the AHRC programs which provide service each day to twelve hundred mentally retarded children and adults. Along with the evening's dancing and entertainment there was a more serious note as Helen Kaplan, AHRC's Executive Director, presented the organization's Humanitarian Award to State Senator Norman J. Levy, citing him for successful

sponsorship of legislation which has aided all the vocational centers and sheltered workshops in the state. Senator Levy, it was pointed out by Mrs. Kaplan, has played a large role in the enactment of laws which have made possible many of the rights for the mentally retarded.

As AHRC celebrated its thirtieth anniversary at the Rose Ball, it was recalled that the organization, now numbering more than 8,500 families and with a budget of about \$5 million, started in 1949 with barely thirty families. Today, the Nassau AHRC is the largest county organization of its type in the United States and has served as a model for other groups concerned with the care of the handicapped.

## U.S. urges more for handicapped

The government entered a court suit recently seeking to force local school authorities to provide summer programs for severely handicapped children.

The Justice Department filed a friend-of-the-court brief on the side of parents of handicapped children who are seeking a court order requiring officials in Philadelphia to extend the normal school year to help children with severe mental and physical handicaps.

The government's brief said, "This case may significantly affect the manner" in which new regulations of the Health, Education and Welfare Department are applied throughout the country.

A trial in the case has been completed and a decision is being awaited from U.S. District Judge Clarence Newcomer of Philadelphia.

The case raises novel questions because HEW regulations, under a law passed in 1973, are due to have broader effect after June 1980, when school districts that fail to comply stand to lose federal aid. The regulations prohibit discrimination against handicapped individuals who participate in programs receiving federal aid. It is the interpretation of those regulations that is open to question in the Philadelphia case.

The Justice Department's civil rights division said recently that equal opportunity for the handicapped, in effect, means providing special treatment for them.

"The educational needs of the handicapped child are not necessarily identical to those of his or her non-handicapped peer," the department's legal brief said. "Rather, the education of the handicapped child can sometimes be accomplished only through additional or alternative educational services.

"The mere provision of the same educational program to handicapped and non-handicapped children alike would therefore not eliminate discrimination."

The department added that there must also be educational programs "tailored to the specific needs of each handicapped child."

There are approximately four million handicapped children among the more than 48 million pupils between the ages of 6 and 18 in the country. The Justice Department had no figures on how many states provide special summer programs for the handicapped.



Deane Pinsley, a member of the Westchester Rose Ball Committee, is flanked by State President Eleanor Pattison and Ned Pattison. (Photo by Doris Kirchhoff, Gannett Westchester Newspapers)

## SSI earnings test

The House of Representatives Ways and Means Committee has approved H.R. 3464, which is designed to remove work disincentives for disabled persons under the Supplemental Security Income program. The bill, introduced by Representative James Corman (D-Calif.), Chairman of the Ways and Means Subcommittee on Public Assistance, and Representative William Broadhead (D-Mich.), is similar to the so-called Keys Disability bill, which passed the House last year but was sidetracked in the Senate.

The effect of the Corman - Broadhead bill would be to phase out benefits to working disabled recipients at the same point where they are currently terminated for aged and blind SSI recipients. In other words, a recipient would lose one dollar in benefits for every two dollars of countable income in excess of the statutorily specified income disregards (i.e., the first \$20.00 of income from any source plus up to \$65.00 of any additional earned income).

At the current benefit level this would mean that a single disabled individual could earn up to \$478.00 a month before he or she would lose all SSI benefits, while the phase-out point for a disabled couple would be \$685.00 a month.

Under H. R. 3464, work-related expenses would be disregarded in determining a disabled individual's eligibility and benefit level under SSI. This extends the same privileges to other disabled as the blind now receive. In addition, employment -

related expenses, including the cost of intensive care, would be disregarded.

H.R. 3464 would also permit an SSI recipient to retain his or her disability status under SSI for twelve months following the termination of benefits due to earnings exceeding the SGA test.

Further, he or she would be considered presumptively disabled for an additional four years. Should the individual become disabled at any time during this five year period, he or she could re-establish eligibility without going through a second disability determination process.

Further features of the Corman - Broadhead bill include:

For purposes of determining parental liability the term "child" would apply only to individuals under age 18.

The severity of the debate within the Committee suggests that H.R. 3464 may encounter additional hurdles when it reaches the floor.

## Christmas winners

(Continued from Page 1)

and charming lady who enjoys special attention given to her. Eleanor has hopes of moving to a community residence in Batavia, New York, sometime this summer.

Staff of Wassaic Developmental Center were so proud of the artistic work of Joseph Spencer that a collection of his art was submitted. Apparently, the judges also recognized this young man's ability, for he was awarded second prize, a \$50 U.S. Savings Bond. Members of this association will have an opportunity to purchase his award-winning design which is being reproduced as one of the Association's cards for the 1980 Christmas Season.

His brief biographical sketch supplied by his Art teacher, Roxanne Appleton, tells us that Joseph is 29 years old and resided at Wassaic Developmental Center for 25 years. Joe began using his natural born art talent industriously last year when he began designing Christmas post cards to sell for the holiday season. This project proved to be very successful both for Joe's financial advancement, and for his developmental growth. We are looking forward to expanding Joe's talent into other art forms such as designing silk screen for T-shirts and helping with the completion of murals in various parts of this facility. Joe is also presently being considered for a work position as a teacher's aide where he will be able to share his talents with young children at our elementary school.

## Raise for Commissioner

Thomas W. Coughlin, former director of the Jefferson County Association for Retarded Children, was one of scores of beneficiaries of new pay hikes approved by the legislature recently.

As commissioner for mental retardation and developmental disabilities, Mr. Coughlin's salary was boosted, retroactively to October 1978, to \$54,739 from about \$47,500.

On October 1 this year, Mr. Coughlin's pay will increase to \$61,685.

He was among an elite of six commissioners — the others were health, transportation, corrections, mental health and social services — to draw top commissioner's salary.

Most other commissioners will have to live with \$57,500 annually beginning October 1.

## Albany's new building dedicated



Present at the Dedication are left to right — Frances Reville, Treasurer, ARC; Thomas A. Coughlin III, Commissioner OMR-DD; Ellie Pattison, President, ARC; Frank Sheridan, President Albany County Chapter; Hy Clurfeld, Sr. Vice President, ARC, and Joseph T. Weingold, Executive Director, ARC.



## MR/DD Advisory Council



Members of the Sub-Committee on Planning, convene at NYSARC state office to develop agenda. Shown left to right — Frances Reville, Chairperson; Matthew Janicki, OMR-DD; Ann Schoonmaker, EMC Institute; Peg O'Brien, OMR-DD.

## Community residence management

### training offered by college

Mater Dei College, Ogdensburg, New York, will begin offering an Associate in Science degree in Community Residence Management beginning in September, 1979. The new program will train managers and personnel for community residences for the de-institutionalized, half-way houses, transitional apartments and community-based residential services to the disabled.

Mater Dei is a co-educational college conducted by the Sisters of St. Joseph of the Diocese of Ogdensburg. Located six miles southwest of Ogdensburg, New York, its 211-acre campus overlooks the St. Lawrence River. It is fully accredited by

the Board of Regents of the State of New York, the Middle States Association of Colleges and Secondary Schools and is approved by the Bureau of Veterans Education. The College has a strong student financial aid program.

One of the consultants for the development of the program is Richard Laurin, executive director of the St. Lawrence County Chapter.

For further information or input to the program, please contact: Thomas C. Larkin, Co-ordinator, Mater Dei College, Riverside Drive, Ogdensburg, New York 13669. Telephone (315) 393-5930.

## Service Board meetings must be open to public

In the opinion of Robert J. Freeman, Executive Director of New York State's Committee on Public Access to Records, a community services board is a public body subject to the New York Open Meetings Law in all respects, (SS95-106).

The Law defines "public Body" as:

"... any entity, for which a quorum is required in order to transact public business and which consists of two or more members, performing a governmental function for the state or for an agency or department thereof. . . . ( 97(2)).

By separating the quoted definition into its elements, one can conclude that a community services board is a public body subject to the Law.

First, the boards in question consist of fifteen members (see Mental Hygiene Law, 41.11) that are required to act by means of a quorum. Although there may be neither a statutory provision nor a by-law that requires the presence of a quorum, 41 of the General Construction Law states in relevant part that:

"(W)enever three or more persons are charged with any public duty to be performed or exercised by them jointly or as a board of similar body, a majority of the whole number of such persons . . . at any meeting duly held upon reasonable notice to all of them, shall constitute a quorum and not less than a majority of the whole number may perform and exercise such . . . duty."

Therefore, although the boards may not be specifically required to act by means of a quorum, 41 of the General Construction Law mandates that all public bodies act only by means of a statutory quorum.

Second, it is clear that community services boards "transact public business." It is noted that I discussed the powers and duties of community services boards with representatives of the Department of Mental Hygiene and was informed that community services boards

perform either policy making or advisory functions, depending upon the nature of the local law enacted in the county in which they operate. In the case of Schenectady County, the community services board is a policy-making group that undoubtedly "transacts" public business.

Third, public business is transacted by the boards for both the state and a public corporation, a county.

In view of the foregoing, I believe that community services boards are subject to the Open Meetings Law.

With respect to executive sessions, 97(3) of the Open Meetings Law defines "executive session" as that portion of a meeting during which the public may be excluded. Further, 100 (1) describes the procedure that must be followed prior to entry into executive session. Specifically, the cited provisions state that:

"(U)pon a majority vote of its total membership, taken in an open meeting pursuant to a motion identifying the general area or areas of the subject or subjects to be considered, a public body may conduct an executive session for the below enumerated purposes only, provided, however, that no action by formal vote shall be taken to appropriate public moneys. . . ."

Moreover, the subjects that may be discussed behind closed doors are limited to eight categories of discussion that are listed in paragraphs (a) through (h) of S100(1).

Finally, S103 of the Law describes three exemptions. The only exemption which might arise in the course of discussion by a community services board is S103(3), which deals with matters "made confidential by federal or state law". Since records pertaining to patients in Mental Hygiene facilities are confidential, discussions regarding specific patients would be outside the scope of the Open Meetings Law.

## Restrictive covenant held bar to group home

A State Supreme Court justice, deciding that a sixty-year-old restrictive covenant has priority over public policy, has issued a permanent injunction against the use of a single-family home in an exclusive area of the Bronx as a group home for mentally retarded children.

This was a proposed home for children (not adults) and was to provide "treatment, shelter, rehabilitation and furnishing of special services".

Justice Joseph DiFede ruled that the use of the residence as a group home for eight children was clearly prohibited by the covenant established in 1919 for the Spuyten Duyvil area of Riverdale. He emphasized that his findings were based only upon the covenant, not the zoning regulation covering the thirty-three-home enclave over-looking the Hudson River and bordered by West 231st and 232nd Streets.

In reviewing the case in this decision, *Tytell v. Kaen*, Justice DiFede acknowledged that the "more enlightened strategy and procedure" on the part of the state to remove emotionally disturbed children from "destructive warehouses little better than concentration camps. . . in favor of appropriate community facilities" is appropriate.

In the same vein, he said, the State Court of Appeals has held that a group home consisting of surrogate parents and seven children unable to live with their natural families was the functional and factual

equivalent of a natural family, but the four-judge majority in that case, *Group House of Port Washington v. Board of Zoning and Appeals*, Town of Hempstead, specifically limited its holding to "particular facts" before it, dealing only with foster children and a zoning ordinance.

What convinced the Bronx justice to issue a permanent injunction was his conclusion that the home could be characterized as a health-related facility, not only falling within the covenant's restrictions, but also requiring a special permit to qualify under the zoning regulations.

The individual defendants, Herbert and Lila Kaen, who would be the surrogate parents for eight mentally retarded children seven to fourteen years old and Working Organization for Retarded Children, the nonprofit organization which supports the group-home approach, raised the various statutory and constitutional defenses in their motion for dismissal.

These included the public policy factors in the Social Services and Mental Hygiene Laws which establish group homes, the contention that the children and the husband and wife who would care for them constitute a single family as defined in the restrictive covenant, constitutional protections under the Fifth and Fourteenth Amendments, and appellate holdings allowing groups of children to qualify as families under local zoning ordinances.

Justice DiFede held, that these arguments fail to overcome the validity of

the covenant.

"The argument submitted by plaintiffs that the proposed group home is clearly not a private dwelling as required by the covenant appears to be well-founded", he wrote. "The group home is, in fact, a creature of statute, publicly funded and publicly monitored. That the term 'private' was carefully used in the covenants is patently clear".

Perhaps an over-riding factor in his decision to permanently enjoin the defendants was his conclusion that the group home would be a health-related facility providing "treatment, shelter, rehabilitation and the furnishing of special services," clearly prohibited by the

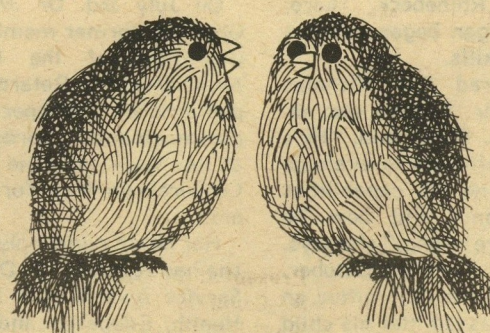
covenant.

The plaintiffs were represented by Wein, Lane and Malkin; Mr. and Mrs. Kaen, by Robert Mishkin; and WORC by Murray B. Schneps.

The restrictive covenants argument had been raised before elsewhere and efforts had been made to get Senator Padavan to amend the site selection law to include the prohibition against use of restrictive covenants to prevent the creation of group homes.

Such a prohibition is included in the model law on site selection as developed by the American Bar Association. So far, efforts to convince Senator Padavan have been unavailing.

Be where the ACTION is on October 18- 21.





# Craig resident sues

## Locked in shower 8 years

A mentally retarded resident at the Craig Developmental Center in Sonyea, who claims he was kept locked in a shower room for eight years, has sued the state and the Center in Federal Court.

The suit alleges that August Barthalamane, a resident at the center for 33 of his 40 years, spent eight years locked in the shower room sleeping on a tile floor without any mattress.

He was allowed out of the shower room only at meal time and shower night when the other residents took their showers there, according to the suit.

The suit says, that after a complaint last June, he was kept in the room but it was not locked and he was given a mattress and two sheets.

Last month, just before the suit was filed, he was suddenly transferred from the shower room to another building at the center.

The suit claims, that as a result of living in inhumane quarters, Mr. Barthalamane has suffered physical, emotional and mental deterioration.

The suit also claims that during his 33 years at the center, he has received virtually no training or instruction in personal hygiene, daily living skills, communication skills or manual dexterity.

The suit further claims that very few, if any, of the residents housed with Mr. Barthalamane in the center's west wing have received any skill training.

Whatever training they do receive is "totally inadequate," according to the suit, because there is not sufficient staff

and the staff is not adequately trained for the west wing.

The suit alleges that the center's treatment of Mr. Barthalamane violates the federal Rehabilitation Act of 1973 and the Developmentally Disabled Assistance and Bill of Rights Act.

It also allegedly violates the Civil Rights Act of 1871, the 1st, 8th and 14th Amendments to the Constitution and the state mental hygiene law.

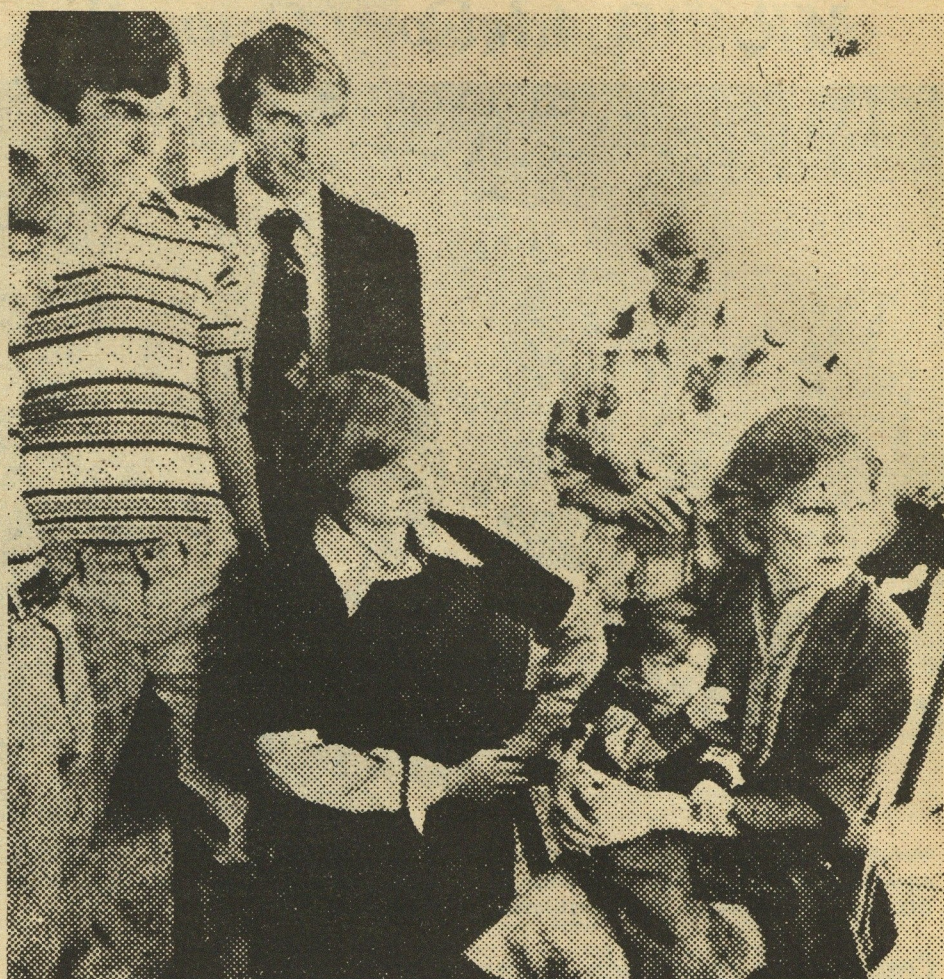
The suit was filed April 2 in Buffalo by Buffalo attorney Bruce Goldstein for Mr. Barthalamane and the Protection and Advocacy System for Developmental Disabilities.

It names as defendants Commissioner Thomas A. Coughlin III of the state Office of Mental Retardation and Developmental Disabilities and Center Director, Dr. Nadine Hunter.

It alleges that they and their predecessors knew about Mr. Barthalamane's condition.

The suit alleges, that after some center employees told the Protection and Advocacy System, a public interest law group for the disabled, about Mr. Barthalamane, the employees were hit with disciplinary proceedings, promotion denials, job transfers and poor performance ratings.

The court has asked for an order providing Mr. Barthalamane with humane living conditions and an adequate trimming program along with \$20,000 in damages as well as an order barring the center from retaliating against employees for informing authorities about conditions.



## First lady listens

Rosalynn Carter rocks with Michael Johnson, 3, during a visit to the child's home in Concord, N.H. Parents, Helen and Richard, spoke with the first lady about the need for alternative care for retarded children such as their son. Michael's brothers, Matthew and Mark, and sometime babysitter, Ann Yeaton, look on.

## Dad fights for handicapped son

The future of an 11-year-old handicapped boy is the issue in a battle between his father, Nicholas Santoro, and the Red Hook Central School District.

Santoro has requested that his son be removed from a Board of Cooperative Educational Services (BOCES) classroom for Trainable Mentally Retarded (TMR) youngsters and placed in a classroom where he can study academic subjects as well.

In a special meeting, the school board reserved decision on the subject pending further evaluation of the child's capabilities.

In the TMR classroom, Nicholas receives group speech therapy but no occupational or physical therapy and no academic training.

But the Red Hook district's Committee on the Handicapped has recommended that further evaluations be made before the child is moved.

"Nicholas has been stagnating at BOCES for the last five years," Santoro declared. "His time is being wasted. He could be doing academic work and he isn't," Santoro said.

Santoro has hired attorney Caroline V. Rider to assist his challenge. According to Ms. Rider, Santoro discovered that his son was fully capable of learning to read when Santoro took Nicholas to the Nexus Learning Center in Rhinebeck. There, director Barbara Morgan began tutoring Nicholas in reading skills.

"When he discovered that Nicholas could learn to read, Mr. Santoro was absolutely enraged," Ms. Rider said. "He's been trusting school officials to evaluate Nicholas and determine his capabilities and teaching programs and now he discovers that they were wrong," she says.

As a result of his discovery last October, Santoro complained to the Committee on the Handicapped and asked that his child be placed instead in the BOCES North Road facility multiply handicapped class.

"The North Road site offers all the therapies recommended by Nicholas' doctor in addition to academics," Ms. Rider explained. "That's the only site where the full program is available," she said.

The Red Hook committee met with Santoro and his attorney, at which time the committee reviewed reports by several professionals who examined Nicholas at Santoro's request.

Mrs. Morgan reported that Nicholas was learning to read under her tutelage. Mrs. Georgia Sullivan, regional advocate for Protection and Advocacy Systems for Developmental Disabilities reported that, at the request of Santoro, she had observed Nicholas in his classroom and that he received little or no one-to-one attention.

"There are 30 kids and two teachers in the TMR classroom. That may be an acceptable pupil-teacher ratio but with 30 kids, there is too much opportunity for distraction," commented Ms. Rider.

Santoro and his attorney are hoping that the Red Hook Board of Education will reject the committee's recommendation for an evaluation prior to removing Nicholas from the TMR classroom at BOCES.

## Dr. Mary Goodwin dies

On July 3rd, Dr. Mary Stuart Hooke Goodwin, former member of the Board of Governors of the New York State Association for Retarded Children and a pediatrician and specialist in childhood communication disorders, died of cancer at the Mary Imogene Basset Hospital in Cooperstown, New York. She was 71 years old.

Her death came only a few weeks after she had received the Distinguished Public Service Award from the Department of Health, Education and Welfare.

In making the Award, Secretary Califano said, "because of Dr. Goodwin's

"That child is 11 years old, and a child with a handicap learns more slowly. Nicholas has no time to waste," Ms. Rider declared. She said that, if the board refuses to move Nicholas immediately, she is afraid Santoro may file suit against the board. "He's ready to go to a civil rights suit, he's so angry," Ms. Rider declared.

Santoro has said he hopes the board will see his point. "I'm tired of being pacified. I want the child moved immediately. His time is important to me," he declared.

According to law, handicapped children must be evaluated every third year, Ms. Rider indicated. Nicholas was due for evaluation this year. "But we want him moved before the evaluation. If the school district is really interested in the child, they won't rush through an evaluation just for the purpose of saying, 'We were right, he should stay where he is,'" she said.

David Machell, chairman of the Committee on the Handicapped, has said he cannot comment on the Santoro case.

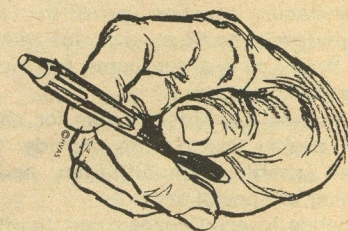
"I am bound by law to protect the confidentiality of the case or else the district is open for lawsuit," Machell said. "This puts us at a definite disadvantage since we cannot discuss or respond to the situation," he said.

dedicated work, the medical profession and the American public are now more aware of the facts concerning autism, and the special compassionate approach that this condition requires. This award honors her unique contribution to autistic children and their families, and her work with children with learning disorders and developmental disabilities of all kind."

From 1968 to 1971, she and her husband, the late Dr. T. Campbell Goodwin, pediatric consultant to the New York State Department of Mental Hygiene, attempted to improve the treatment of institutionalized patients.



Sign up today!



## Herkimer Swim-a-thon

Herkimer County ARC is all set for the annual swim-a-thon.

This year, the swim-a-thon will be held during the month of September to help maintain and expand the involvement of all area students and residents. The swim-a-thon is an event to help raise money for the Herkimer County Association for Retarded Children's projects. Last year, the area participants helped raise over \$8,000 which went towards many new activities sponsored by the ARC.

This year, the swim-a-thon will be held September 22 at Herkimer County Community College pool from 8 a.m. to 5 p.m. and September 20 at the Little Falls YMCA pool from 2 p.m. to 8 p.m.

This type of fund raising activity is dear to your Executive Director's heart, a swimmer from way, way back.



## A salute to John Regan

In early July, they came from all over — from far and near in New York State, from Georgia, from Ohio, and from the local community — almost four hundred of them, to attend the reception and Annual Dinner Meeting of Monroe County Chapter, A.R.C., which this year became a glorious celebration in honor of John Regan and his family. Most came early and remained until the benediction. The reception was held in a separate room, where throngs of people consumed punch and tasty hors d'oeuvres, and chatted with John and Mary Lou Regan.

Mrs. Jobina Bruinsma accompanied her son, Mark, at the piano for his vocal rendition of "How Great Thou Art." Following this stirring invocation, Logan's excellent buffet was enjoyed at tables decorated with small centerpieces of silk daisies, made by Anne Shannon and members of the planning committee.

In her opening remarks, retiring President Dorothy Alger greeted the diversified groups of guests, with a special welcome to Mr. Joseph Weingold, Executive Director of the State Association; Mr. John Bertrand, assistant to Mr. Weingold, and Mrs. Bertrand; Mrs. Eleanor Pattison, President of the State Association; to Executive Directors Anthony Terranova, Les Rivkin, Frank Capone, and Joan Mayer; and to Shirley Reynolds of Kenmore, Vice-President for the Western Region, and Mr. Reynolds.

The Annual Business Meeting of the Chapter began with the presentation of Scholarship Awards by Mrs. Barbara Mitacek, who presented the first four certificates to: Stephen K. Brickman, Daniel Osborn, Abigail Rose, and Amy Sutliff. Barbara then introduced James Mroczek, Acting Executive Director of A.R.C., who announced the surprise award which is to be given annually in an amount totaling \$250 more than the regular amount. Known as the John A. Regan Scholarship Award, it was presented this year by Mr. Mroczek to Kelly Ann Myers. Thus began the surprises which were to overwhelm our retiring Executive Director throughout the evening.

The next surprise was presented by Anthony Terranova, President of the Executive Directors Association, in the form of a plaque which read:

**N.Y.S.A.R.C.  
Executive Directors Association  
Presented to John A. Regan  
In Recognition of  
His Leadership, Professional  
Expertise, Friendship and  
Support  
7-8-79**

Mrs. Ellie Pattison, President of the N.Y.S. Association for Retarded Children, Inc., gave a brief but warm tribute to John, in which she commented on his contribution to the improvement in the quality of life for the retarded. A recitation of a poem created by Gloria, from the Board of Directors. Space permits only the last stanza: "This is brief and incomplete, but what we want to say, is 'Thank you, John' for all you've done to guide us on our way. To John, who's here with Mary Lou and children numbering four, Meg, Beth, Mark, Kevin, Niece Adele (in spirit) and good friends by the score, We know your future labors in writing, teaching, golf, will prove to be successful, but save some time to loaf. To help out with the latter are fantastic gifts for you: a small TV, a future trip — a cruise or flight with Lou. And finally — (read in unison) To benefit our A.R.C. — this really is the end — the special John A. Regan Fund, which only you can spend."

Dorothy explained that \$3500 was voted by the Board of Directors as a fund to be used for the Agency's benefit in ways suggested by John to the Executive Committee of the Board. Maintenance or expansion of the fund may occur through contributions specified for the John A. Regan Fund. John's response to all of the surprises was heartfelt and spontaneous. He thanked everyone — parents, clients, staff, board members, community people, his associates at the Sigl Center and throughout the State — and especially his family, for their tolerance and for the many thousands of hours they had enabled him to give in service to the retarded.

## Another task force meeting



A task force focused on children who are mentally retarded with developmental disabilities was held by Parsons Child and Family Care Center in Rensselaer County. From left: Henrietta Messier of Rensselaer, Janet Marchese, Parent; Ellie Pattison, N.Y.S. ARC President and Tom Regan, Director of the Parsons Regional Adoption Program.

## Association officers



New officers of the Rome Developmental Center Chapter, ARC, include, from left: Ethel Lombard, recording secretary; Francis Turner, president and Mrs. Barbara Turner, treasurer. Ms. Maryellen Spellicy is vice president.

## New faces among execs

A number of changes have taken place within the ranks of local Executive Directors within the past several months. The departure of John Regan from Monroe County Chapter marks the departure of one of our longest tenured Executive Directors. John, having been in his position for some 16 years, has been replaced by Mr. James Mroczek, who previously served as the Chapter's Assistant Executive Director.

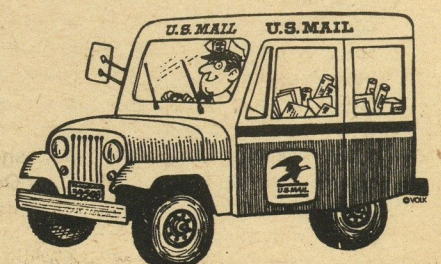
Another long time Executive Director, Mr. Michael L. Gordon has resigned his position in Chemung County Chapter, and will be replaced by Mr. William Haberlin. Mr. Haberlin, who has his Masters Degree in Rehabilitation Counseling from West Virginia University, has been employed for the past 7 years as Program Coordinator and Assistant Director at the Kennedy Center Workshop in Bridgeport, Connecticut. It is anticipated that he will begin his employment around August 15th. Mr. Gordon had served with Chamung County for some 10 years.

Additional changes reported to the State Office as of this writing, are: the resignation of Tom Rick from Livingston-Wyoming Chapter with Mr. Ben Penner serving as the Acting Executive Director;

Wayne Rowe will be leaving Orleans County Chapter in August — no replacement has yet been named; Mr. James Wilson has joined Schuyler County Chapter as their Executive Director; Dr. Paul A. Buck has been named Executive Director in Tompkins County, and in Yates County, former exec. Donna Pollard has moved to the Program Director's position with Mr. William Bub taking the Executive Director's slot.

Finally, Ulster County Chapter has announced the resignation of Mr. Frank Freda, effective August 24th. No replacement has yet been named for that position.

Register for The Convention NOW!



John Regan and outgoing president, Dorothy Alger, at Monroe County Chapter's salute to John and Dorothy.



# 1979 CONVENTION PROGRAM

October 18-21 ----- BINGHAMTON

## Register Here

TO: Broome-Tioga Chapter, ARC  
Broome County Health Plaza  
Front Street  
Binghamton, N.Y. 13905  
Attn.: Brenda Hawley, Registration Chairperson

Please accept my reservation for the following Convention events:

Registration	\$8.00
Tour (please indicate)	\$2.00
A. Broome-Tioga ARC Center	
B. Broome Developmental Center	
Luncheon	\$ 7.50
Dinner	\$12.00*
Total	

\*Dinner will be \$14.00 if not registered by October 5th.

Name \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
Phone \_\_\_\_\_

TO: Holiday Inn - Arena  
2 - 8 Hawley Street  
Binghamton, N.Y. 13901

Gentlemen:

Please reserve the following accommodations for me at the Convention of the New York State ARC, October, 1979.

Single at \$25 \_\_\_\_\_  
Double at \$32 \_\_\_\_\_  
Date of Arrival \_\_\_\_\_ Departure \_\_\_\_\_  
Name \_\_\_\_\_  
Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### CONVENTION PROGRAM

#### STATE CONVENTION

OCTOBER 18-21, 1979

THE YEAR OF THE CHILD — THIRTY YEARS OF SERVICE

#### Thursday, October 18th

4:00 - 9:00 p.m. — Registration (\$8.00)  
8:00 p.m. — Meeting of the Board of Governors

#### Friday, October 19th

9:00 a.m. — All Day — Registraton  
9:00 a.m. - 1:00 p.m. — Board of Governors Meeting continues.  
1:00 p.m. — Lunch (Open)  
1:30 p.m. — Tours (\$2.00)  
A. Broome-Tioga ARC Center  
B. Broome Developmental Center  
2:00 - 5:00 p.m. — Training Session-One-To-One, "Finances and Management" Chapter Officers and Executive Directors  
5:00 p.m. — Dinner (Open)  
8:00 p.m. — Convention Convenes

#### Saturday, October 20th

7:30 - 9:00 a.m. — Special Buffet Breakfast  
9:00 a.m. - 2:00 p.m. — Registration  
9:00 a.m. - Noon — General Session Continues  
12:15 - 1:30 p.m. — Luncheon (\$7.50)  
2:00-5:00 p.m. — Workshops  
1. YOUTH — David Lewis, Chairman  
2. Institutions — Karin Burgess, Chairperson  
3. Membership — Dorothy Ganin, Chairperson  
4. Education — Betty Pender, Chairperson  
5. Public Information — Mary Kallet, Kate Klein — Co-chairpersons  
6:00-7:00 p.m. — Reception  
7:00 p.m. — Banquet (\$12.00—)  
10:00 p.m. — Dancing  
— Banquet \$14.00 if not pre-registered

#### Sunday, October 21st

9:00 a.m. - Noon — Meeting of Newly Elected Board  
12 Noon — Adjournment

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

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New York, New York 10010

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