



# Our Children's Voice

Retarded Children Can Be Helped

Vol. XXX, No. 3

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

September 1978

## ARC programs successful

# Voc. Rehab. bills signed

## Long range work funding strengthened

Two of the most important bills of the New York State ARC Legislative Program have been passed by both houses as of this writing (June 27th). Both bills were signed by Governor Carey as this issue went to press.

These bills strengthen the programs and financing for long range employment of the severely handicapped, known throughout the state as SEP.

The first bill mandates that education pay \$1500 PER YEAR for EVERY client in long range employment in rehabilitation facilities. The present law, in existence since the late '60's, permitted payments up to \$1500, but only in one year. The agencies receive \$1200 (the first year) and thereafter about \$1000. In spite of many protestations to OVR and the commissioner of Education, this figure remained stationary in spite of increased costs, cost of living increases and growing agency budgets.

Last year, they threatened to cut this back even further and it was only rescinded after a large demonstration by the handicapped on the steps of the Capitol.

The present bill (s. 7486C Padavan — M. Murphy) mandates \$1500.

### WAITING PERIOD ELIMINATED

The second bill eliminates a regulation we have been unable to change over the years. This regulation, in effect, creates a waiting period of almost two years before the client is eligible for long range employment. From the time vocational rehabilitation, personal adjustment and other training ceases, to the time the client is eligible for SEP is at least a year under this regulation. It finally took legislation to do away with this waiting period (S. 8101A Norman Levy; Amatucci).

Since almost all rehabilitation agencies in the state are affected by these programs, a Coalition of Rehabilitation Agencies was formed early in the legislative session so all the agencies could act in concert. It was because of the enormous efforts of these agencies, their concerted action, and the understanding of Assemblyman Arthur Kremer, Chairman of the Ways and Means Committee in the Assembly, and John Marchi, Chairman of the Finance Committee in the Senate, that these were successful.

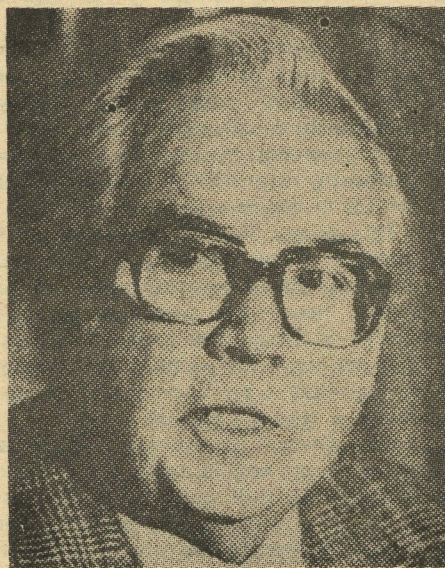
The \$1500 bill was in the Senate on the last day they met before recessing and only a Message of Necessity from the

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L. to R. Governor Hugh L. Carey, Assemblyman Arthur (Jerry) Kremer, Chairman, Assembly Ways and Means Committee, and Joseph T. Weingold, Executive Director, New York State Association for Retarded Children at the signing of the bills increasing state aid to long range employment clients to \$1500 and removing the two-year waiting period. It is the culmination of a long up-hill struggle, happily resolved.

## Sen. Conklin retires from Albany seat



William T. Conklin

After twenty-two years, when a skeptic told him to enjoy his first term as a State Senator because, "you probably won't be back," William T. Conklin of Brooklyn, Deputy Majority Leader of the Senate, acknowledged on June 19th that he would not seek re-election.

At a news conference, Senator Conklin who is 70 years old, said he was closing the book on his senatorial career because he wanted to "relax a little bit," and spend more time with his family after years of strenuous political effort to retain his seat in the predominantly Democratic district,

something that he has done with enormous success.

Before publicly announcing his retirement, Bill Conklin, a member of the State Association for many years, wrote a personal letter to our executive director announcing what he was going to do.

In part he wrote:

"I entered the Senate 22 years ago desiring to leave a mark in areas of great concern to me, the most crucial one being the needs of our retarded and handicapped children. I set up goals in my own mind and often, in the face of difficulties, worked hard to realize them.

Today, I am proud of what has been accomplished, a separate department for the mentally retarded is now part of our state government. My P.K.U. (phenylketonuria) legislation has already succeeded in saving many thousands of new born infants from a life of retardation (a law which has since been adopted not only across our nation but by governments of many others), and a hostel program to house the retarded and handicapped in their own communities is thriving and growing.

I am happy to say that I am ending my legislative career with much gratification, satisfaction, and in good health. And I want you to know that I am most appreciative of the help and support you have given me in the past. Even as I look forward in the new year to spending more time with my family, I will not soon forget what people like you have enabled me to accomplish."

## Zoning bill in

A bill which, in effect, eliminates the problem of zoning prohibitions against use of any housing for group homes for the mentally disabled has finally passed both houses of the Legislature. It is S. 8213B Padavan and A. 30039A McCabe. As this issue went to press, this bill was also signed by the Governor.

The pertinent section of the bill states "The community residences established pursuant to this section and family care homes shall be deemed a family unit for the purposes of local laws and ordinances."

For this, however, we had to pay a price which may result in delay of the establishment of such group homes.

A sponsoring agency must notify the chief executive office of the municipality in writing of its intentions, etc. and include in such notice a description of the nature, size and the community support requirements of the program. The municipality shall have 40 days upon the receipt of such notice either to approve, suggest other sites or object because it would result in a concentration of community residential facilities for the mentally disabled, etc., or that the nature and character of the areas within the municipality would be substantially altered.

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

If the municipality suggests other sites not satisfactory to the sponsoring agency, the municipality shall have 15 days to suggest alternative sites.

The municipality has 15 days to appeal to the commissioner by a hearing officer and conduct a hearing within 15 days of such request.

The commissioner has 30 days to make a determination.

Finally, the review of the commissioner's decision may be had in a proceeding, pursuant to Article 78 of the Civil Practice Law and Rules, within 30 days of the determination of the commissioner.

If this was all added together, we have 40, 15, 15, and 30 or a total of 100 days.

If a 78 proceeding, that is, going to court to mandate the commissioner, is instituted by the municipality, in our opinion it should not stop the agency from proceeding with the creation of the group residence.

But, in any case, it can be clearly seen the price we had to pay for the elimination of zoning in this state was to give 100 days

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## Senator Bill Conklin

With the retirement of Senator William T. Conklin, "Bill" to us, from the New York State Senate, this Association and the mentally retarded everywhere have lost the legislative help of a giant.

It would take more than this column, and much of this newspaper, to list all the legislation with which he was connected that affected the lives of our children and ourselves. The testing for PKU, immunization for rubella and mumps, more recently his concern for hypothyroidism, the right of education and training in our public schools and institutions, expansion of education to 21, mandatory transportation for the handicapped children, breaking up of the giant bureaucracy of the Department of Mental Hygiene, the hostel program, and many, many others attest to his skill and success.

More than that, Bill Conklin is the father of a mentally retarded son and, as such, has been keenly aware of all the problems of the parents as well as the children. He was always accessible, never refused time for a meeting, consultation, advice and sponsorship of most important legislation which sometimes took years to accomplish and on which he never gave up.

I first met Senator Conklin on the train going to Albany one morning when he had just been elected to the Senate. He heard me haranguing some of the legislators and came over to me and introduced himself and told me of his interest. Since then, it has been a symbiotic relationship from which I know I derived much knowledge and which helped my growth in this organization.

We have been blessed in this movement with people, especially in the legislature, who have been our champions. I recall Senator Earl Brydges who finally became Majority Leader in the Senate, Assemblyman Stanley Steingut, before he was speaker when these two together introduced bill after bill at our behest and fought for them up and down the line. After that, Senator Conklin took over the chairmanship of the Joint Legislative Committee on Mental and Physical Handicap where so much of the successful legislation was incubated. Then, after him, Senator Niles, now also retired.

These were all giants in our field, in my opinion not yet honored enough in this state or on a national level. As one of them, and equal in stature to all, steady in his devotion, skilled in his craft, and with deep human understanding is William T. Conklin, Bill.

We all owe him the greatest vote of gratitude we can possibly give. In this, our own Governor Carey should join because it is because of Bill Conklin, I believe, that Carey is Governor. It is simple. If Bill Conklin had opposed Carey for Congress in his own district he would have beaten him. If he had beaten Carey for Congress, Carey would never have become a candidate for Governor.

So there it is. Not only do we owe you a vote of gratitude, Bill, but so do all the Republicans as well and, of course, all the Democrats.

Bill Conklin may be out of the Senate, but he is not out of our lives or the life of our Association.

## Gov. breaks ground for Westchester D.C.

### Weingold suggests fuller program

After more than 5 years of hesitation, planning and replanning, the State has finally moved with the development of the land in White Plains, Westchester County to implement a Westchester Developmental Center to serve the parents and children of the County.

The plan calls for the construction of 6 group homes, 2 at present to be operated by the ARC. There are no further plans for these 30 acres.

There is a definite need, according to Joseph Weingold, for a residential facility for at least 100 severely and profoundly retarded persons, residents or former residents of the County.

In a letter to Commissioner Coughlin, Weingold outlined this development plan: "As I understand it, the plan is to build 6 buildings, each to house approximately 10 persons which would in effect be group homes to be operated by the state, and turned over, if possible, to a voluntary agency to operate. This is just fine as far as it goes. There is, however, a great need in Westchester, as, indeed, other places, for a 24-hour service, primarily medically

and rehabilitation oriented for severely and profoundly retarded children who cannot remain at home, and who do not fit into the concept of hostels as we have developed them. A voluntary agency, in our opinion, would not have the experience or the personnel to properly treat and help these children.

We suggest, therefore, rather than declare much of the Urban Development land in White Plains surplus, that you consider the construction of an ICF-MR for 100-150 residents to serve the severely and profoundly retarded who need this kind of service in Westchester County.

This is not much different from the concept of the Children's Psychiatric Center, built so beautifully to answer a special need. The programs would be similar to those in the regional centers in Connecticut, with which I am sure you are familiar. I am especially thinking of the New Haven Regional Center.

In addition, I believe some of the land could be utilized to build a community center that would serve the 60 persons in the group homes you are building there, staff, retarded of the whole community that can reach there, where they would have available to them recreation, gymnasium, swimming pool, auditorium, meeting rooms for the community, etc. and it should be open to the whole community.

From the P.R. point of view, I think this would be a tremendous thing. In addition, you would be serving the severely and profoundly retarded population of Westchester who really have no place to go, except to institutions in which you are now struggling for standards, such as Letchworth and Wassaic.

I urge as strongly as I know how, to seriously consider this proposal before disposing of the property in White Plains."



## At Madison dinner

At ARC dinner — numerous dignitaries were present at the Madison County Association for Retarded Children's 10th anniversary dinner at Dibble's Inn, Vernon. Among them were, from left, Joseph T. Weingold, executive director of the N.Y. State Association for Retarded Children, Sen. Martin S. Auer, R-C, 49th district; Sen. William T. Conklin, R-C, 21st district, Brooklyn, deputy majority leader in the State Senate; Louis Neveu, president of the Madison County ARC, and Assemblyman Clarence D. Rappleyea, R, 122nd district.

## A Parent's Jeremiad

I am sound of mind and able bodied.

I am possessed of eyes that see,

ears that hear,

and a tongue capable of clear speech.

I have limbs and appendages which function well.

I am not limited in mobility or thought.

With the exception of those temporary and minor infirmities

which affect us all, I enjoy reasonably good health.

Only my heart is broken, and the pain is, at times,

unbearable.

Morton Posner — 1977  
Dedicated to the Blessed  
Memory of Michael  
Edward Posner

## Our Children's Voice

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NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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the big N.Y.S. ARC STATE CONVENTION

*Values, potential, love*

# The mongoloid person as teacher

These excerpts from a recent lecture by Dr. Thomas J. Weihs, Superintendent of the Camphill-Rudolph Steiner Schools, in England, and delivered at Trinity College, are worthy of deep pondering:

In the past, we used to believe that the doctor had to do something for his patient; the teacher had to do something for his pupil. Now we realize that the patient also does something for the doctor; the pupil does something for the teacher.

In this same way, I want to tell you what mentally handicapped people can do for those of us who are associated with them, those of us who give up the prejudice that ours is a one-way relationship.

There are some things people who are mongoloids do not achieve, no matter how old they get. They never learn that one must buy something cheap and sell it expensive in order to make a profit. They never learn to argue intellectually.

But they do develop an indiscriminate power of love and of gentleness. To them every adult man is like their father, every adult woman like their mother, every child, like their sisters or brothers.

You and I probably know what it means to love and to meet no response. Our love freezes. Not so the person who is mongoloid. He has the unbelievable potential to go on loving.

Could it be that people who are mongoloid appear on this earth to show us a different possibility in the human existence? To show us values, forgotten and neglected?

As we observe them, we see that what appears first as a handicap gradually reveals itself as an exaggerated form of a particular human trait that is in all of us.

They reveal to us the child in us. Some of us, even at the ripe age of 60, have not lost access to that original child in ourselves. These fortunate ones are the richest among us.

Some mongoloid people reveal in us our "head nature" — sensitive, princely, wanting to say what should happen rather than doing anything to make it happen.

They show us the way we feel on waking early in the morning.

Other mongoloid people are all limbs. They are willing to work, to serve; they have the greatest difficulty in grasping ideas. They are strong but slow.

They show us our own "limb nature," the way we feel in late evening when tiredness overtakes us.

There are still others in whom left and right seem too far apart, as if each half wanted to go its own way. Sometimes they cannot speak, though they can hear and understand.

Their "mid-line defect" shows us that our face is formed by the fusion of two halves, and that it is our ego that brings the two halves together into one.

There are some who are spastic. They show us how over-sensitivity and over-anxiety can freeze our own movements.

**In Sum:**

People who are mongoloid can teach us.

As we associate with them, we can see that the totality of their development begins to unfold itself as the discernible majesty, as the tremendous vista of the human potential.

We become enriched in self-knowledge in our encounters with these "handicapped" people.

## D. D. bills reported out

### DIFFER ON DEFINITION AND APPROACH

A tragic, if irreconcilable, difference appears in the committee reports of the House of Representatives and the Senate in reporting out the Developmental Disabilities Act amendment of 1978. The House bill (HR 12326; House Report 95-188) retains the "specification of certain categorical conditions" and rejects a functional definition. On the other hand the Senate bill (S.2600; Senate Report 95-890) changes the definition of developmentally disabled from a categorical definition to a functional definition. This means that mental retardation, cerebral palsy, epilepsy, etc. will no longer be identified as such in the act.

Furthermore, the Senate bill abolishes the National Advisory Council on Developmental Disabilities whose responsibilities are to be taken over by the Federal Council on Handicapped Individuals, an amorphous idea where the mentally retarded will be submerged once more.

This change alone would expand the target group by 300,000 to 400,000 individuals with very little if any increase in funding, now so woefully inadequate.

The ARC has taken the position that the definition should not be changed. The bill, of course, now goes to conference where anything can happen.

Senator Edward Kennedy protested most vigorously in the subcommittee against this change in definition but did not succeed.

In a letter to Senator Kennedy, Joseph T. Weingold, executive director of the New York State Association for Retarded Children, wrote, "I think that this is a tragedy that is going to become worse and worse as time goes on. It seems to me that all the gains we have made 'by taking our children out of the closet' will gradually be whittled away by the voracious appetite of other handicapped, served under any number of other Federal laws, to latch on to this small, although important program."

In a letter to Dr. Richard C. Scheerenberger, president of the A.A.M.D., Mr. Weingold, Chairman of the Legislative and Social Issues Committee of the A.A.M.D. wrote, "In my opinion S. 2600 is a bad bill. Its thrust is definitely away from any concentration on the mentally retarded and developmentally disabled."

"It is only through highlighting what we are, and what we need that we have been able to achieve what we have. The time has not yet come when we are so accepted by the community, and our rights so observed, that we can afford the luxury of anonymity and loss of identity in the amorphous mass of handicapped individuals."



## Assemblyman Kremer honored at Rose Ball

Assemblyman Arthur J. Kremer, Chairman of the New York Assembly Ways and Means Committee, who received the 1978 Humanitarian Award at the Nassau AHRC's Annual Rose Ball held in late June at the New York Hilton, greets State ARC Director. Jerry Weingold and his son, Johnathan. Nearly 1,000 members and friends of the Nassau Chapter attended the dinner-dance which, together with its journal, raised about \$250 thousand. The event is a high point of the Nassau AHRC social-philanthropic calendar and together with the Chapter's other community fund raising activities helps to provide over 6,000 hours in daily programs to the children and adults served by the Nassau Chapter.

## Howse, Mascari named by Carey

Governor Hugh L. Carey recently announced the appointment of two persons in the State Office of Mental Retardation and Developmental Disabilities to direct services for New York City and Long Island.

Jennifer L. Howse of Manhattan was named Associate Commissioner for the New York City-Long Island County Service Group. Michael Mascari of Brooklyn will be the joint Assistant Commissioner in the Mental Retardation Agencies of the State and New York City. Mayor Edward I. Koch of New York City joined in the appointment of Mr. Mascari.

Dr. Howse has been Executive Director of the Willowbrook Review Panel since its creation under the Willowbrook Consent Decree in 1975.

A graduate of Florida State University where she earned a doctorate in language development, Dr. Howse was director of the Florida Developmental Disabilities program and director of the technical assistance division of the Department of Health and Rehabilitation Services in Florida. She also served as a consultant to several national organizations concerned with the mentally retarded.

One of her duties will be to find homes in the surrounding community for residents

of Willowbrook — renamed last month as the Staten Island Developmental Center to get away from its past image as a "house of horrors." An order in Federal Court in Brooklyn requires that the center be cut down to 250 residents, all Staten Islanders, in 1981 — it now has 2,100, down from 5,341 in 1972.

In her new post, Dr. Howse will be one of four regional associate commissioners across the state in the reorganization that set up the Office of Mental Retardation as a separate agency when the old Mental Hygiene Department was split up effective April 1.

Mr. Mascari, former assistant director of the Mental Retardation Bureau of the New York City Department of Mental Health, is acting head of the New York City-Long Island County Service Group Office of the State Office of Mental Retardation and Developmental Disabilities.

The proposal for the joint assistant commissionership was worked out by Thomas A. Coughlin III, State Commissioner for Mental Retardation and Developmental Disabilities, and Dr. June Jackson Christmas, New York City Commissioner of Mental Health, Mental Retardation and Alcoholism Services.

Register  
for

Rochester



## Family Care, Chapt. 620, 621 community suit filed

As a result of hard work and persistence, twelve parents of retarded persons who reside in the Bronx have filed a class action suit against the Department of Mental Hygiene and the Department of Social Services. The suit was taken out on behalf of themselves and all others of similar situations who live in New York City. Their attorney is Stephen M. Latimer, Esq., Bronx Legal Services Corp. C, 579 Courtlandt Avenue, Bronx, New York 10451.

The charges brought up by the parents are that they are "not eligible for payment pursuant to Social Services Law, Section 138-a ("Family Care Money") or pursuant to Chs. 620 and 621 of the Laws of 1974 ("Ch. 620 and 621 Money") which are program and residential monies "because their mentally retarded children have not been admitted or discharged from any state institution for the mentally retarded during the statutory period."

The parents are seeking equal protection under the law, and therefore, are asking for "equalization of benefits for their retarded children to bring them to parity with the formerly institutionalized children." The parents base their arguments on the following facts:

- 1) Equal protection of the law must be granted to citizens within New York State.
- 2) The "degree of care and expense of caring for formerly institutionalized persons are substantially similar to that required for persons who have never been institutionalized."
- 3) "The policy of providing substantial financial assistance to certain parents of mentally retarded children while denying assistance to plaintiffs whose children have the same needs and are at the same developmental stage as the formerly institutionalized children bears no substantial relation to the statutory objectives" and discrimination results since greater opportunities are available for programs and residential alternatives with the Family Care and Chapter 620 and 621 monies.

The parents do not seek to take away benefits from the Willowbrook class, but

## Quie amendment withdrawn

In the last issue of OCV, we reported on an amendment by Congressman Quie that would phase out Title I of 89-313, under which many of the programs operated by the ARC are funded. The purpose behind this amendment was to transfer the \$113 million of funding in this program to 94-142, Education of all the Handicapped, which is under-funded.

The Association wrote to the New York State members of the House Committee on Education and Labor protesting this. We are pleased to write now that the Quie Amendment has been withdrawn.

"I am pleased to advise you that the House Education and Labor Committee did not accept this amendment, and I voted against it when it came before the Committee. At the very least, P.L. 94-142 is not nearly advanced enough to provide the kinds of assistance which Title I has provided for the handicapped child."

"I would be most surprised to see this amendment reappear on the floor." Thus wrote Mario Biaggi, as well as Congressman Weiss and Congressman Zefteretti.

Thank you to the New York State Delegation and Congress.

ask to be given payments for their retarded children at the "same time and in the same amounts as payments are made to parents of formerly institutionalized retarded children. The parents have not only received the unanimous support of the Bronx Mental Retardation Council, but the Bronx Mental Retardation Council is seeking the support of the other borough Mental Retardation Councils in this effort. Parents and agencies are urged to write their support for the lawsuit and a reversal of the family care and Chap. 620 and 621 regulations which prevent community or never-institutionalized mentally retarded individuals from receiving these monies.

Please write your local legislators in support of the community based lawsuit filed by Steve Latimer and for changes in the discriminatory family care and Chapter 620 and 621 regulations.

1. Write local legislators
2. Write: Honorable Hugh Carey, Governor of New York, Executive Chamber, 1350 Avenue of the Americas, New York, N.Y. 10019.
3. Thomas Coughlin, Deputy Commissioner for Mental Retardation and Developmental Disorders, Department of Mental Hygiene, 44 Holland Avenue, Albany, New York 12229.

## Louis Striar dies

Louis Striar, a pillar of the Association's New York City Chapter, died recently. Striar, a former resident of Douglaston, Queens, joined AHRC in 1963. His contributions were many and significant. He was elected to the Board of Directors in 1964. His commitment to the Association was not simply an individual one. Rather, it was a concerted family commitment for Striar, his wife, Libby, and his children. They all entered the mainstream of AHRC activities in the same spirit that characterized their father's involvement.

Since 1963, Striar filled nearly every post of importance in the organization. For many years he served as Financial Secretary, while during other years, he served as Treasurer. For a number of years he was chairman of the Building Advisory Committee. He also acted as Dinner Chairman of the Association's Annual Dinner in 1970. He was chairman of the Workshop Committee for many years.

Striar's commitment to the retarded extended even beyond the bounds of the New York City Chapter. When he retired in 1976 and moved to Ft. Lauderdale, Florida, he continued to participate in the development of services to the retarded in that state while maintaining his useful role within the New York City Chapter. He was proud of his affiliation with the Ex-Caliber Developmental Center, which is part of the range of services offered by Broward County ARC.

His participation was crucial in the design, development and utilization of the Mayflower Avenue facility. His relentless interest in the Melvin W. Kraus residence was directly responsible for the quality of that facility.

But most of all, he served as a tireless force for good within the Association. He often said of himself, "I'm a gadfly," in which role he frequently compelled those around him to question, to think, and to evaluate the real consequences of their actions as they related to the retarded. His brusque manner was tempered by humor while the intensity of his vision was touched by the deep pleasure which life brought to him. As proud as he might have been of his achievements on behalf of the Association, he was proudest of all of the achievements of his son, Martin.



Proceeds from the 3rd annual Unity Life Tennis Tournament went to the Association for Retarded Children. Linda Schoenwald, tournament director, and David Hawkins, producer of the television presentation of Onondaga Community College, visit with two students from the Onondaga Association for the Retarded, Kim Darby and Michael McClenthan.

## 3rd Tennis Tourney raises funds for Onondaga ARC

Exciting tennis and superb organization proved an unbeatable combination as Unity Mutual Life Insurance Company sponsored a third annual Tennis Tournament for the benefit of Onondaga ARC.

"Love Enough to Go Around" saw three action-packed days of mixed doubles play in mid-April at Limestone Tennis Club in Manlius, an eastern suburb of Syracuse. One hundred sixty players competed, with 32 teams each in Amateur A and B categories and 16 pro teams.

At the completion of the tournament, Unity Life President John F.X. Mannion presented proceeds of \$6000 to a smiling Don Boudov, Executive Director. The funds were raised through team entry fees and special solicitation of business and

industry. In an appeal letter to previous donors and players, Mr. Mannion wrote: "ARC has become special to Unity Life. Our experience with the Association in our first two benefit tournaments has moved us from simple admiration for their fine work to a feeling of deepening friendship with the ARC family."

ARC volunteers worked side-by-side with Unity employees throughout the tournament.

The Sunday finals were videotaped in color for cable television by the Radio-Television Department of Onondaga Community College.

Since its inception as a fund raiser in 1976, the popular sports event has raised \$12,000 for ARC and become the tennis tournament players and fans have come to look forward to.

## Wayne Pres. named to Community Services Bd.

Wayne County's former Mental Health Board now will be known as the Wayne County Community Services Board and will have 15 members instead of 9.

Marion Supervisor Douglas Orbaker, chairman of the board's Public Health Committee, said the name change "is in line with what the state has been doing for the past couple of years in the whole field of mental health and related services."

He said, "Two years ago the Newark State School name was changed to Newark Developmental Center. This, as I see it, is the same type of change. It's a change for the better to show that the board is supposed to be handling situations that involve not only mental illness but retardation, developmental disabilities, and alcohol and substance abuse."

He said the larger board would "broaden the base of representation" from the community in planning and carrying out programs specified under the law.

Among the six new members is George Denniston of Palmyra, President of the Wayne County ARC Chapter.

The newly named board will form subcommittees for mental health, mental retardation and developmental disabilities, and alcoholism and substance abuse. Members of the subcommittees will be appointed by the Board of Supervisors.

## Essex opens group home for "geriatrics"

The historic St. Frederic Hotel, in the Glens Falls area, has been sold to the Essex County Facilities Inc., an arm of the Essex County Association for Retarded Children.

The facility is now used as a geriatric group home for 10 mentally retarded adults with the minimum age of 50 years. The residence is staffed 24 hours a day by live-in residence managers. In addition, developmental aides assist in providing training in community living skills, socialization, personal hygiene, communication, and recreation. The initial residents are from Sunmount Developmental Center in Tupper Lake. The former hotel is the fourth such home operated by the ARC. There are two residences in Port Henry and another in Ticonderoga.

Those living in the community residence attend a day activity program in Port Henry five days a week, Monday through Friday. There, training is provided in functional academics, community orientation, physical activity, recreation and socialization.

The ARC has received a contract from the state Department of Mental Hygiene for \$84,000 to fund the project for the first year.

# M.R. hostels blend well

The turmoil engulfing a proposal to establish a home for mentally retarded adults in Germantown has spotlighted similar hostels in Hudson and Chatham. There, participants in the program, with scant attention from neighbors, have achieved their goal to live independent or semi independent lives in the community.

In attempting to dispel apprehensions voiced in Germantown, officials of the Community Resident Program cite their past success in providing supervised residential alternatives for mentally retarded adults who otherwise would be cloistered in institutions or boarded in family care homes.

Eighteen adults currently are residing in hostels at Hudson and Chatham, existing harmoniously within the community and diligently working to help support themselves while enthusiastically learning new skills, which for some is the final step to their own apartment.

## NO PROBLEMS ARISE

The fears and misconceptions that the mentally retarded pose a hazard to the community have failed to materialize in the first year and half of operation, bolstering the program's premise that "Many retarded people are able to hold jobs and become contributing members of society."

The Community Residence Program is operated by the Columbia County Chapter, New York State Association for Mentally Retarded Children, Inc., which was chartered a dozen years ago "to assist the mentally retarded in every manner possible."

The residence program is one of three projects operated by the chapter, according to the Chapter's Executive Director Jan Wheeler, who noted her group also runs a summer day camp and a sheltered workshop and rehabilitation facility for disabled adults.

"We all want a place of our own, to be surrounded by people and things that we care about," according to Neil Pollack, director of the Community Residence Program.

## NEED FOR ACCEPTANCE

"We all want to feel that we belong," he said, quickly adding, "and the mentally retarded are no exception, they have the same need for acceptance as anyone else."

Pollack, quoting from a Program information pamphlet, continued, "They have the same right to their place in our society, a right to participate as far as possible in the real world."

A community residence, which provides a homelike environment with guidance and supervision, is one way to give mentally retarded people a chance to live their lives with dignity, he said.

The concept of community residences was developed a decade ago but did not become a reality in Columbia County until the summer of 1976. Then 10 persons were placed into an aging, two story former nursing home on the fringe of Hudson's upper Warren Street business district.

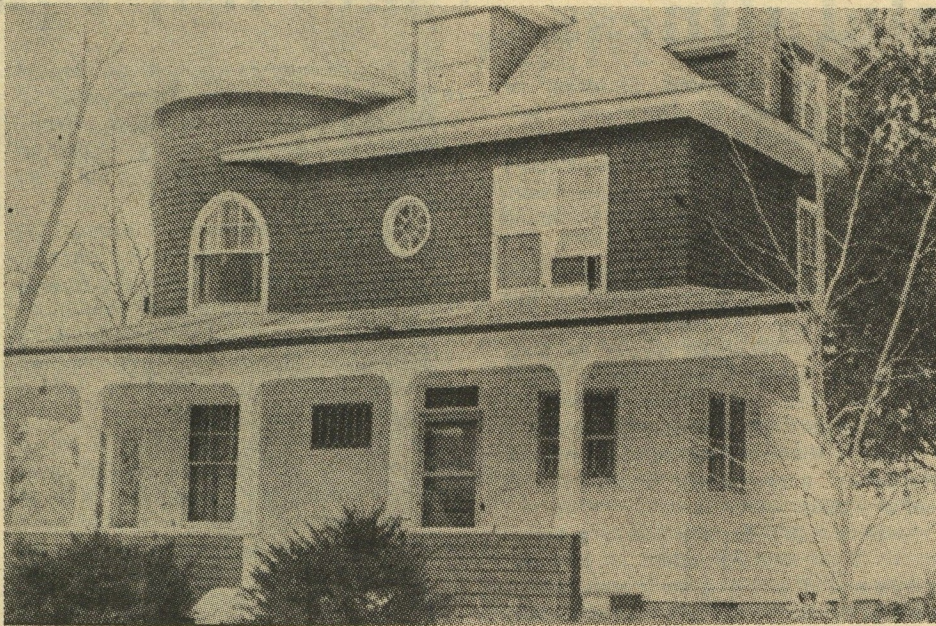
A year later, the Program opened its second hostel, a spacious, two and a half story Victorian house on a middle-income residential street in Chatham.

## RESIDENTS ENTHUSIASTIC

Pollack's enthusiasm for the program is shared by the residents of the hostels, who have varying degrees of disabilities.

Some need a great deal of individual attention while others are virtually self sufficient, Pollack said.

"The homes for some are the final stop before they are permitted to venture into the community to live in an apartment by themselves or with others with supervision



This two story home at Payn Ave., and Elm Street, in Chatham was established as a hostel for eight mentally retarded adults last summer by the Community Residence Program.

(from the Program) based around the individual's needs," the director said.

"For others, the homes provide a long term, family type environment in which they can live out their lives," he said.

The Hudson hostel is designed as a transitional facility with residents expected to achieve, within a one to three year period, the skills necessary to live in an apartment, such as one of the eight currently supervised by the Program.

Chatham's hostel, as the one in Germantown, will house residents who probably will remain in the hostels for the rest of their lives, Pollack said.

"Freedom" is the word most used by the residents when asked to define what the hostels mean to them, "freedom to do things for themselves, freedom to be individuals, freedom to learn new things."

Every resident questioned enthusiastically expressed a preference for the hostels over their former family care homes or institutions, about which some did not even want to talk.

Most of the residents of the two hostels range between the ages of the mid 20's to early 50's and are motivated by a desire, some more than others, to eventually be independent.

## GOOD NEIGHBORS

In relation to the community, the program has maintained a virtually unblemished record. Persons living near the hostels generally describe the residents as "good neighbors."

Ghent Supervisor Martin Tuczinski said he had not paid "too much attention" to the hostel situated several doors from his home, "and I've heard very little comment about it from others in the community."

The 10 room Hudson hostel also has attracted little attention from neighbors, mostly business offices that operate during the day while residents are at work.

One neighbor, Dr. Sanford Ullman described the hostel as an "excellent neighbor" noting the residents had been helpful in snow removal, quiet and courteous.

The Program plans to have five hostels in operation by 1980, contending community residences are more economical than institutions while enabling mentally retarded to live near their loved ones.

However, Pollack concluded, the most important aspect is that "Community care gives someone who is mentally retarded the opportunity to share the world around him and to make the most of his life, within the limits of his handicap."



The former Kring Nursing Home at 816 Warren Street was the first hostel in Columbia County opened a year and a half ago by the Community Residence Program. The home shelters 10 mentally retarded persons.

# Poison may cause mental retardation

It's deadly poison, especially to unborn children.

You can't see it, smell it or taste it.

And it's all around us — in ever-increasing amounts.

Methylmercury pollution is a worldwide problem that nobody pays much attention to until a disaster occurs, according to Thomas Clarkson, director of the University of Rochester's Environmental Health Sciences Center.

And as with many man-made environmental disasters of the past, "You have to have dead bodies on your hands before you can prove that something's gone wrong," Clarkson said.

Methylmercury pollution is a byproduct of industrial waste, and UR researchers have been awarded a \$249,265 federal grant to study the effects of the poison on unborn generations.

They hope they'll also be able to develop a means of detecting low levels of mercury in the environment and find out what constitutes a safe level of exposure. Dr. Byung Ho Choi said.

Choi is principal investigator for the research project and professor of pathology at the university.

Choi said his main concern is for the unborn children of pregnant women who eat mercury-contaminated food.

A woman might not be affected by the contamination, he said, but her fetus is at greater risk. Such children are likely to be born dead or with such defects as cerebral palsy or mental retardation.

"In cases of less severe poisoning during pregnancy, an infant may appear completely normal at birth, only to develop psych-motor deficit as the nervous system matures. Yet we have little knowledge of the nature of the abnormalities," Choi said.

Choi and an associate investigator, Dr. Lowell W. Lapham, have developed painstaking procedures for tracing the path of methylmercury in the brain to find out how it affects the central nervous system.

By analyzing portions of brain tissue from mercury poison victims, and by studying the effects of the substance on laboratory animals, they've found that it turns normal brain cell patterns "inside out," Choi said.

It appears that a fetus is at greatest risk between the eighth and fifteenth weeks of development, he said, when brain cells are "migrating."

Because "the early effects of the poisoning are almost impossible to detect," Clarkson said, "the emphasis should be on prevention — to keep exposure down."

Methylmercury is the organic form that mercury takes when it interacts with microorganisms in sludge and water.

Dumped into a lake or stream, the substance permeates the flesh of fish.

People and animals who eat the fish can be poisoned — depending on how much is consumed over how long a time.

We all have a certain amount of the chemical in our diet, Clarkson said. But the danger is that by eating the flesh of poisoned animals, we'll exceed the level our bodies can handle.

Clarkson said rain and snow also can be a source of methylmercury. Pollution from oil and coal burning industries interacts with the moisture in the air and can fall back to earth in the form of "acid rain," he said. Traces of methylmercury have been detected in the snow run-offs into lakes and streams in the Hudson Bay area of Quebec, Canada, he said.

# Mental retardation is not mental illness

Responding to an editorial in a recent edition of the Poughkeepsie Journal entitled "Dumping Patients," Charles T. Weatherford, Jr., wrote this letter to the newspaper:

"In regards to your editorial of May 2, 1978 entitled 'Dumping Patients.'

I feel it is important to point out that the hearing held by Senator Perry for the State Senate Democratic Task Force on deinstitutionalization, was directed at patients released from psychiatric centers for the mentally ill and not residents released from developmental centers for the mentally retarded.

In my testimony before Senator Perry, I pointed out that the mentally retarded residents of Dutchess County are often tarred with the same brush as the mentally ill.

I know of no resident released from Wassaucott Developmental Center into Dutchess County who is not at rehabilitation programs; Dutchess County

Association for Retarded Children, or programs provided by Community Services ably headed by Sue Neal.

Since the retarded of Dutchess County are in programs and under supervision, they are extremely unlikely to be found wandering the Main Mall.

As has been seen in the papers, the Association for Retarded Children has been endeavoring to open a Community Residence for retarded adults in East Fishkill for many months. Much of the opposition has been fostered by the inability of political figures and the public at large to discriminate between mental retardation, a permanent disability, and mental illness, which is not.

I wish to thank Senator Perry publicly for his clear understanding of this difference and for allowing me to speak at the hearing, in spite of the fact that the issues of the hearing did not involve the mentally retarded."

Mental retardation is not mental illness.

## Zoning for M.R. group homes limited by states

Although it has been shown that litigation can be used successfully to invalidate restrictive zoning ordinances, preemptive state legislation could be the most viable way of insuring that local governments will not be able to exclude group care facilities from desirable locations.

According to a study by the Wisconsin Council on Developmental Disabilities, made in January 1978, 11 states now have state zoning laws that allow community residential facilities in residential areas, and bills are pending in eight states.

### STATE LEGISLATION ON ZONING

Laws were enacted in California, Colorado, Minnesota, Montana and New Jersey prior to 1977. In 1977, laws were passed in Michigan, New Mexico, Ohio, Rhode Island, and Virginia. The Wisconsin statute was signed March 1978.

Bills are pending in: Arizona, Florida, Massachusetts, Maryland, New Jersey,

New York, Pennsylvania and South Carolina.

### AN AFFIRMATIVE LEGISLATION AND INFORMATIONAL APPROACH

Although a few successful cases have been litigated that affirm the value of community facilities, exclusionary zoning, as it affects the handicapped, can best be dealt with through the enactment of federal or state statutes preventing local municipalities from excluding residential facilities at will. This, in turn, can be accomplished only by educating the public, and the lawmakers to the dire need for these facilities and, in light of the long-since discredited alternative of warehousing, of the moral obligation of the community to guarantee the right of individuals to live in residential communities in the least restrictive setting possible.

## Albany M.H. Assn. criticized at public hearing

The public hearing of the Albany County Mental Health Association recently drew criticism from speakers that recommendations of outside agencies are not being taken into consideration.

In this first of its kind meeting, spectators waited patiently for a question and answer period. They then opened up on Dr. Gordon Cohen, coordinator of mental health services for the mental health board, Dr. Walter Osinski, director of Albany County mental health services and Dr. Ebon Plager, a member of the mental health board.

A social worker contended the board meetings "are not open to the public", and plans drawn by people interested in mental health and retardation are "totally ignored by the board."

Henrietta Messier, active in both the Albany County and state associations for retarded children, said she believed many programs have developed in Albany County "in spite of the mental health board rather than as a result of the board." "We want to be of assistance, but we always feel we are being held at arm's length," declared Mrs. Messier.

Many of the spectators criticized what they considered the lack of much Albany County funding in mental health services. Dr. Cohen, Plager and Dr. Osinski disagreed.

This public hearing was the first of its kind for the Albany County Mental Health Association.

## Cameron is Top Citizen

George Cameron, the first president of the Clinton County ARC Chapter, has been named "Top Citizen" by the International Woodmen of the World.

The Chapter and its members have joined in honoring Cameron by citing his pioneering efforts on behalf of the retarded.

## Willowbrook

# State must pay lawyers

Civil rights lawyers who have won major reforms at Willowbrook Developmental Center said they will likely ask New York State to pay them more than \$1 million in legal fees for six years of work in the court case.

The lawyers' statements followed U.S. District Court Judge John R. Bartels' ruling that four public attorneys groups representing the institution's mentally retarded residents are entitled under a 1976 federal statute to "reasonable" payment since the start of the class-action suit against the state in 1972.

Bartels, in a seven-page decision, called the residents' lawyers "prevailing parties" in the dispute — responsible in large sum for reversing a situation that allowed nearly 6,000 people to languish for years on the institution's overcrowded, filthy ward floors.

The state Attorney General's office, which had opposed the motion to award legal fees, refused comment on the ruling or the probable demand of close to \$1.2 million that would be siphoned from taxpayer money.

An appeal, however, was expected to be filed by the state, with months of in and out-of-court wrangling preceding any lump-sum payments.

Four of the residents' attorneys have worked roughly half time for the past six years on the Willowbrook case, according to Christopher A. Hansen, a lawyer for the Mental Health Law Project.

At the rate of between \$100 and \$150 an hour, a sum to which Hansen and other attorneys said they feel entitled, legal and paralegal fees would total \$1.2 million.

The final cost will be decided by the state and the residents' attorneys and would be paid by the Comptroller's office. But New York taxpayers would ultimately bear the costs.

"These cases," Hansen said, defending receipt of attorneys fees, "cannot be done without extraordinary resources and enormous amounts of time.

Cases like Willowbrook are to be encouraged, he added, "and the award of fees permits our attorneys to go on and take a similar case on behalf of the mentally retarded or mentally ill."

In the precedent-setting Willowbrook case, the state agreed, in 1975, to reforms that have changed the nature of publicly run institutions nationwide.

Jack Bernstein, an attorney for the group representing the state Association for Retarded Children, said the federal court's ruling "has shown the rest of the legal profession, particularly the private bar, that fees are possible when you represent people whose rights are being abridged."

"To me, to have the private attorneys realize they too can represent disadvantaged people is more important than the money," Bernstein added.

He said that his firm, System of Advocacy for the Retarded, will not benefit, but that the awarded fees will go into "more and better programs" for the developmentally disabled.

"And this ruling only takes into consideration fees for services rendered up to

## Mrs. Allen on

## Rome Board

Gov. Hugh L. Carey announced the appointment of 21 persons as members of boards of visitors at various mental institutions, including James G. Allen of Lyons Falls to the board of the Rome Developmental Center. Her reappointment is for a term ending Dec. 21, 1981. Mrs. Allen is a former president of the Lewis County Association for Retarded Children.

now," Bernstein noted. "I assume additional issues will come into it through 1981, and we will continue to generate attorney fees.

"Maybe the state will learn there's a less expensive way than going to court," he added.

By 1981, as called for under the 1975 court judgment, Willowbrook, which now has 1,600 residents, is to be dismantled to the point where only 250 people, all native Islanders, remain.

The Attorney General's office, which represents Gov. Carey and the executive branch, as well as the mental hygiene agency and its designated leadership, had argued against the awarding of fees on the ground that the state has a constitutional obligation to protect the public treasury.

The state also had maintained that substantial relief had already been provided for the Willowbrook residents, with millions of taxpayer dollars going to improve conditions there, and with the creation of a court monitor to oversee the institution's workings.

But Judge Bartels nevertheless rules for the residents' attorneys, saying that Hansen and Bernstein's groups, as well as the New York Civil Liberties Union and the Legal Aid Society were owed "reasonable counsel fees for services rendered" since the state was first called to account for conditions at Willowbrook.

Hansen said he and the other attorneys expect to sit down with state officials "sometime in the near future" to try to work out a "fair entitlement."

If the state refuses to bargain, however, the attorney general likely will go back into federal court, asking for another hearing before Bartels.

Bartels' order was based in large part on the 1976 Attorney Fees Act, passed by the Congress as an encouragement to private law firms to take on civil-rights disputes.

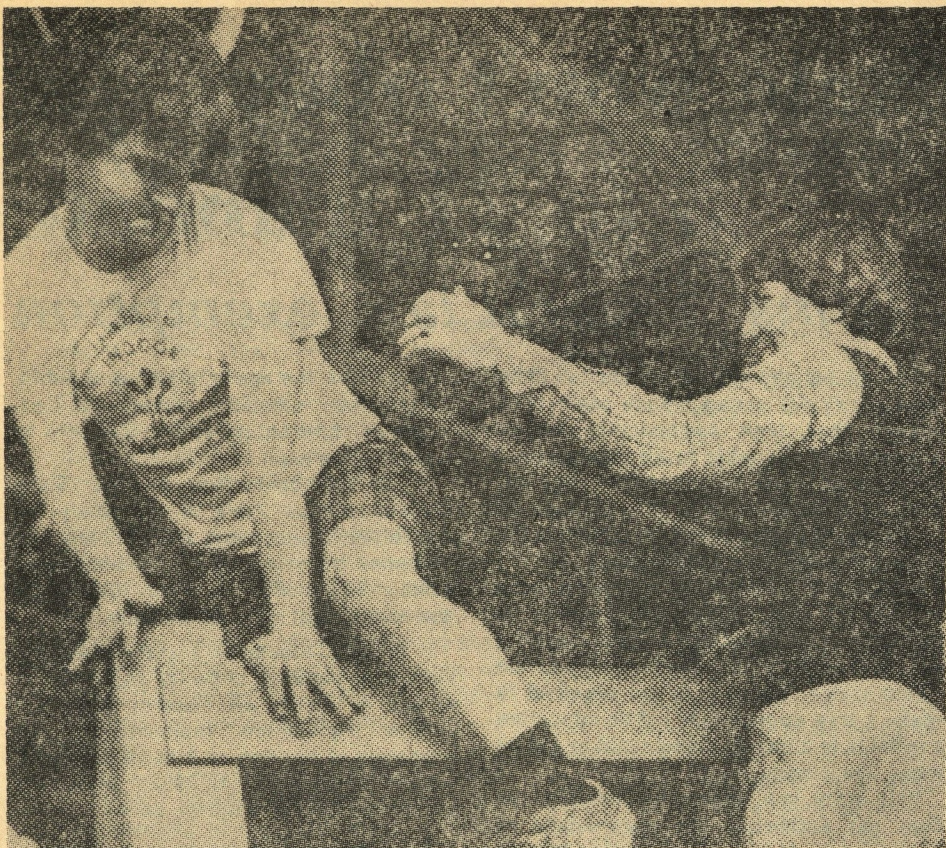
## Cab company files novel suit

The Yellow Cab Company of Greater Buffalo and Madison Taxi of Buffalo have filed a law suit to bar the government from purchasing vehicles for community organizations that provide free transportation for the handicapped and elderly. The firms claim they unlawfully were denied an opportunity to bid for transportation contracts as they claim is provided by law. The cab companies claim that 14 of 28 community groups already have vehicles purchased with federal funds while the remaining 14 have applications pending with the government. They claim the government's action of bypassing businesses engaged in providing transportation in favor of purchasing vehicles outright is a denial of due process and violates the Constitutional requirement of protection under the law. Among those being sued are: Brock Adams, secretary of the U.S. department of Transportation; Richard Page, administrator of the Urban Administration; William C. Hennessey, commissioner of the New York State Department of Transportation. The New York State Association for Retarded Children, Erie County Chapter, Niagara County Chapter find themselves in good company with the United Cerebral Palsy, Buffalo Goodwill Industries, and many others.

This is a novel suit, indeed, and if carried to its logical conclusion, according to our legal advisors, could lead to a lawsuit by taxicab companies against the city providing bus or subway transportation.

See you in Rochester!





Tommy Miller of Hudson is a winner in the fourth annual indoor Olympics for the mentally handicapped as he completes the obstacle course. The sponsors, Albany Lodge 540 of the Knights of Pythias and the United Order of True Sisters, Abigail 3, planned the events at the New Scotland Avenue Armory in Albany to be non-competitive and to meet the needs of each participant. Nearly 400 persons, aged 5 to 60, jumped hurdles and bounced on trampolines.

## Thrill of victory

### Applause

From testimonial dinners to concerts to sporting events, it's the universal sign of recognition — the sound all performers love to hear.

And the jubilant sounds of clapping hands, shrieks, laughter and cheers filled Albany's New Scotland Avenue where 300 to 400 sports enthusiasts jumped hurdles, overcame obstacles and bobbed on trampolines at the Fourth Annual Indoor Olympics for the Mentally Handicapped.

If the participants — aged 5 to 60 — have a more supportive audience than their peers, it is their fans in the Albany City Lodge No. 540 of the Knights of Pythias and the United Order of True Sisters, Abigail No. 3, who organized and sponsored the event.

Mentally, and sometimes physically, handicapped participants from nine Capital and counties took turns in a dozen indoor events, ranging from agility runs to high jumps, performing maneuvers with a multi-colored, grounded parachute, to tossing softballs and shooting basketballs.

Whether they performed with the skill of veterans or hesitantly approached the events as novices, participants each received the same awards of a patch designed by students of the Rensselaer Columbia - Greene Counties Board of Cooperative Educational Services (BOCES) and a T-shirt commemorating the days' activities.

But the job of participating and the pressure of receiving encouraging cheers and smiles were clearly the top prizes of the day.

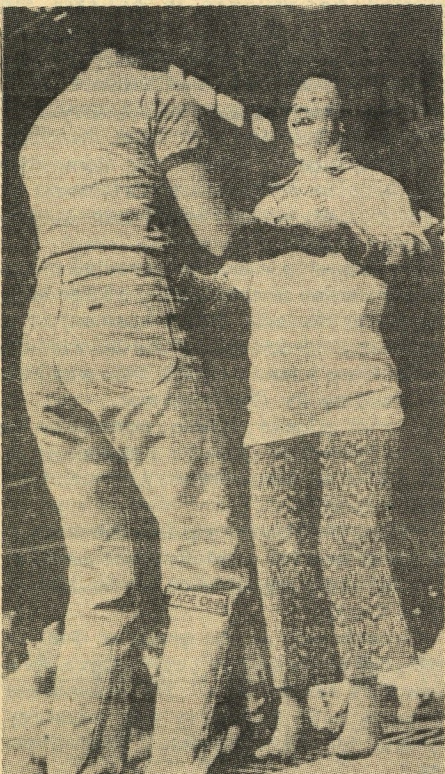
The events, stressed planners, were non-competitive, designed to meet the unique needs of handicapped participants. Each participant completed against himself or herself — striving to improve individual physical skills.

"We don't want any losers," explained Pythias member Mardy Allen, a senior fraud investigator with the Albany County Department of Social Services. "They're all winners here. In the eyes of the public, they're losers to begin with. But each of these kids is gifted. You should see some of the poetry (of theirs) I've read. I couldn't do as well," Allen said.

The non-competitive atmosphere seems well-suited to participants, who take at least as much pleasure in the efforts of their peers as they do in accomplishing their own feats.

In one event, a small, blonde, long-jumper still gripped the hand of the spotter who had aided her and gleefully kissed it before she got in line for her next turn.

After exposure to a single meet, it isn't hard to find extra helpers, said planners, who receive volunteer assistance from area Boy Scouts and their leaders, physical education teachers, employees of the Albany County Social Services Department, and students at Christian Brothers Academy.



**THE THRILL OF VICTORY**  
Brenda Nero, right of Berne, Sports a T. shirt from last year's indoor Olympics as she and Albany Association for Retarded Children worker, Susan McGreevy, jump on the trampoline during this year's event.

## Trust invasion nixed Surrogate rules public has right to institutional care

Incapacitated persons are entitled by right, not privilege, to have the state assume the cost of their institutionalization, and trusts of which they are life beneficiaries may not be routinely invaded to pay for this care.

Bronx Surrogate Bertram M. Gelfand reached this conclusion recently in rejecting a claim by the State Department of Mental Hygiene to direct a trustee of a life beneficiary's \$62,000 trust to invade and deplete the corpus to pay \$119,000 owed for thirty-one years of institutional care.

The ruling is in direct conflict with decisions over the years ordering invasion of trusts to meet the needs of life beneficiaries on the basis that public policy prohibits the state from assuming the cost where a trust is available.

Since the cases were decided against the use of public funds where a trust exists, he said, "public assistance has evolved from being a 'gift into a 'right' which must be provided by state and local government to all who show need, without even regard to the capacity of their respective taxpayers to generate the required revenue to pay the mounting cost of this right."

He also stressed the testator's intent in the 1924, later amended, will, knowing his daughter — one of five children — had a

disability and would require medical care and institutionalization. He noted that the testator's other children receive their bequests outright at the age of 21, while the daughter was made a life beneficiary of an equal amount.

"With absolute specificity, the instrument, (the will) reflects that it was the desire of the testator that, to the extent the corpus was not required to provide the life beneficiary with that which she would not otherwise receive, he wished the corpus to pass to her distributees. . ."

"Under no stretch of the imagination could it be interpreted that the testator would desire to pay the immense cost of his daughter's care in preference to having society share this burden."

The Surrogate also noted that, if the testator were alive, he would have no obligation to provide for the cost of his daughter's maintenance who is over 21 (she is 77) nor does any statute exist that would require him to make his daughter a beneficiary of his estate. The state, concluded Surrogate Gelfand, presents neither statutory nor common law authority which would justify impressing on a testamentary trust a greater obligation than the testator would have if alive.

## Triple split pros and cons

Guarded optimism mixed with a liberal sprinkling of downright skepticism appears to be the prevalent attitude of mental health advocates toward the newly reorganized state Department of Mental Hygiene.

While state officials claim the triple-split will result in better service to the disabled clients served by the department, mental health advocates representing consumer groups and local agencies are adopting a wait-and-see attitude.

Eleanor Pattison of West Sand Lake, wife of U.S. Rep. Edward Pattison and senior vice president of the New York State Association for Retarded Children, has been a long time proponent of the reorganization. But she readily admits, "it's going to be a rough year" for the three new agencies.

"I see a lot of flaws," Mrs. Pattison said in a recent interview, citing in particular what she views as inadequate coordination among the three agencies to deal with the problems of the multiply-handicapped.

"But I think we're just going to have to try and make it work," she added.

Like Mrs. Pattison, Christopher Ross of Buffalo, president of the statewide Association of Boards of Visitors of Mental Hygiene Facilities, is concerned about coordination among the three agencies.

But as the head of the boards that serve as patient advocates at developmental and psychiatric centers across the state, Ross also is worried that the reorganization will create additional administrative expenses at the cost of patient programs.

Although department officials insist the reorganization has been accomplished at minimal expense and with no administrative staff increases, Ross remains skeptical.

"I just don't see how you can avoid the additional cost with three separate offices each minding their individual stores," he said. "I think they're looking through rose-colored glasses."

For Dr. Gordon Cohen, deputy director

of mental health services for Albany County, the chief concern is the dilemma of dealing with three agencies instead of one.

Although he agrees with department officials that the massive size of the old department made it "too unwieldy," he is worried about the additional expense and confusion of preparing budgets and vouchers in triplicate to seek state reimbursement for county programs.

"Locally, it's going to be much more complicated and create more problems," Cohen said.

He said officials of many county mental health services are equally concerned, and that a bill is already pending in the state Legislature that would reimburse localities for the additional expense incurred in dealing with the three new department agencies.

Jerry Weingold of New York City, executive director of the N.Y.S. Association for Retarded Children and one of the staunchest supporters of the reorganization, also is guarded in his appraisal.

Despite a whopping \$234 million increase in the budgets for the three agencies, Weingold said the mental retardation budget still falls far short of the funding needed to support the beefed-up community services touted under the reorganized structure.

"I don't think the governor's budget has given mental retardation the chance it should have had," Weingold said. "Tommy Coughlin (acting mental retardation commissioner) has the cards stacked against him this year with the budget."

But Weingold said his prediction for a funding shortfall has not completely dampened his enthusiasm for the reorganization.

"I am optimistic," he said. "I don't think it's going to be easy. But I don't think it's going to be any worse just because we're separated."

## How to charge discrimination

The Rehabilitation Act of 1973 (Section 504) prohibits discrimination on the basis of physical or mental handicap in programs receiving federal financial assistance.

Prior to filing a complaint, one should attempt resolution through informal means or through a grievance procedure, if one has been established. Under the Section 504 regulations, recipients of federal funds who employ 15 or more persons must adopt a grievance procedure. It is not necessary, however, to exhaust grievance procedures before seeking recourse with HEW.

This is a model of the form a discrimination complaint should take:

1. Name, address and telephone number of complainant.

2. A description of the handicapping situation of the person discriminated against. Example: Individual has a physical and mental impairment which substantially limits one or more life activities. Or, individual has a record of such an impairment or individual is regarded as having such an impairment.

3. The description of the nature of the handicap.

4. Name of the person or persons discriminated against with address and telephone number.

5. Discriminating recipient, names and addresses.

6. Description of the nature of the discriminatory acts.

7. Dates discrimination occurred.

8. Additional background information, if available.

9. Names of the person or persons harmed by the discriminatory acts.

10. A summary of the attempted resolution of the complaint to date.

11. Name, address and telephone number of person or persons to be contacted for further information with regard to the complaint.

Copies of relevant correspondence with recipient institution or individual representatives concerning the matter should be attached. A statement that the information is true and correct with signature and date is necessary.

Complaints should be addressed to John Wodatch, Office of New Programs, Office for Civil Rights, HEW, Washington, D.C. 20201.

## NLRB turns down collective bargaining for disabled

In a ruling with far reaching consequences, the National Labor Relations Board has denied the petition of a division of the International Brotherhood of Teamsters to represent certain disabled employees of Goodwill Industries of Southern California.

The Teamsters sought to represent a proposed bargaining unit consisting of 650 drivers, helpers, and mechanics employed at Goodwill's Los Angeles facility, all of whom suffer from disabilities which limit or prevent their opportunity for competitive employment. The employer contended that a collective bargaining order would be improper because Goodwill is a charitable nonprofit organization and because its "clients," as Goodwill terms its handicapped workers, are not employees under the National Labor Relations Act.

The Board found that Goodwill is a network of independent charitable organizations which generate income through the sale of discarded items refurbished at Goodwill's plants. Goodwill's primary purpose, however, is to provide rehabilitation to persons whose physical, emotional and social handicaps render them ineligible for employment in private, competitive industry.

The Board rejected Goodwill's arguments that its status as a non profit organization whose commercial activities are ancillary to its rehabilitative objective made an assertion of jurisdiction improper. Because Goodwill satisfied standards for retail enterprises, the Board refused to decline jurisdiction under the Act. In addition, handicapped "clients" were found to be employees for purposes of the Act, in that they are paid a wage for work of recognized economic value. However, the Board indicated that the nature of the employer-employee relationship at the Goodwill facility was unique and required analysis before the appropriateness of collective bargaining could be decided.

The Board found that clients referred to Goodwill for employment all suffer from some employment disability, which may be a mental or emotional disturbance, an

educational limitation, or a penal record. Once placed in a job, clients are permitted to work at their own pace. All employees receive the same hourly wage, and disciplinary infractions are handled by counseling, rather than punishment. Where job adjustment is poor, a Goodwill worker is likely to be transferred to another division at the facility, rather than be dismissed. Social service, medical vocational and legal counseling are provided by the employer.

Goodwill's ultimate goal for a handicapped employee is his successful placement in private industry, and a job placement service is provided. However, Goodwill does not pressure reluctant clients to leave, and reserves a percentage of its jobs for long-term placement. If adjustment to a new job is poor, clients placed in private industry may return to Goodwill within the first month of their outside employment.

Against this background, the Board held that collective bargaining between the Teamsters and Goodwill would neither effectuate the policies of the Act, nor be appropriate, because Goodwill's primary objectives were the converse of the usual employer's. The Board indicated that Goodwill's employment practices more closely resemble those of a vocational clinic than those of a viable business concern.

Further, the Board determined that Goodwill's unprecedented concern for the welfare of its handicapped "clients" vied with, and to an extent supplanted, the union's traditional objective of securing better working conditions for its members. For example, the Board hypothesized, collective bargaining might secure for workers the advantage of higher pay at the expense of the employer's counseling services or a reduction in the number of available jobs.

Finally, the Board dismissed the Teamsters petition. Although members of the proposed bargaining unit were found to be employees under the Act, the Board refused "to distort the unique relationship between Employer and client" and undermine the realization of Goodwill's rehabilitative goal.

## State won't obey 3 to 21 mandate Claims Federal law exemption

P.L. 91-142 and regulation Section 212a.300 specifically states "Each state shall insure that free appropriate public education is available to all handicapped children age 3 to 18 within the state not later than September 1, 1978, and to all handicapped children age 3 to 21 within the state not later than September 1, 1980."

Although a number of bills have been introduced, the Legislature refuses to recognize this Federal mandate claiming exemption through another regulation which states, "A state is not required to make a free appropriate public education available to a handicapped child in one of these age groups if:

"(I) state law expressly prohibits, or does not authorize, the expenditure of public funds, to provide education to non-handicapped children in that age group; or (II) the requirement is inconsistent with a court order, etc."

Under New York State law, kindergarten classes are being provided in the regular public schools; blind and deaf children are being referred to state schools

almost from the age of birth; and public schools may establish classes for handicapped children under the age of 5 to receive state aid.

It is the contention of the State Association that there is absolutely no prohibition against this and, in fact, the education from the age of 3 to 18 is passed before September 1, 1978, obviously something that will not be done.

It is the Association's claim that the state is in violation of 94-142 and in grave danger of losing all Federal state aid unless legislation mandating such education from the age of 3 to 18 is passed before September 1, 1978, obviously something that will not be done.

The argument of the state is that the regulations limit this requirement "to the extent that the requirements would be inconsistent with state law or practice..."

This mandate is not inconsistent with any New York State law or practice; and on the contrary it is consistent with a practice in this state, if not law.

## Protection and advocacy system now in operation

At last, the Protection and Advocacy System for Developmental Disabilities, Inc., an offshoot of SOAR, the Advocacy System operated by the State Association for 2½ years, is in operation and functioning under the direction of Jack Bernstein.

Two of their recent successes are decisions won by them in appeals before the Commissioner of Education on behalf of mentally retarded children. One dealt with the review of the determination of the hearing officer with regard to the appropriateness of an education placement within the New York City School system, which the parent challenged and successfully had reversed. In that case, the petitioners (parents) were reimbursed for tuition for their daughter's placement in a private school, and the expense of a private tutor, because of the City committee's failure to notify them that they were entitled to address the committee and because of the inappropriateness of the classes which were subsequently recommended.

The second case involved a review of the determination of the hearing officer with regard to the education placement of a mentally retarded child in the Central Islip Union Free School District. This was also reversed by the Commissioner.

An indication of the help rendered by the P & A System is shown in these excerpts from a letter, by a mother, in the Buffalo Newspaper:

"Some time ago, I was in a dilemma as to how to help my mentally disabled child. I called every organization I could think of, to no avail.

Through luck or the grace of God, or both, one of the parties I called gave me a New York number to call. This brought me in touch with Protection and Advocacy System for Developmental Disabilities, Inc.

I talked to Dorothy Greenwald and no one ever really understood as this woman did. I and my child were treated with kindness and understanding. My faith in human nature was restored."

Since that letter, the P & A System has opened these six regional offices:

**ALBANY:** includes Albany, Rensselaer, Saratoga Schenectady, Southern Washington, Fulton, Montgomery, Schohaire, Otsego and Delaware Counties  
Vicki White, Regional Coordinator  
101 State Street, Room 614  
Albany, N.Y. 12207 518-434-3575

**BUFFALO:** includes Erie, Niagara, Chautauqua, Cattaraugus, Alleghany counties.

Joseph Gerkin, Attorney  
Kathleen J. Murphy, Regional Coordinator  
1490 Jefferson Avenue  
Buffalo, N.Y. 14208 716-883-4424

**ITHACA:** includes Broome, Tioga, Cortland, Tompkins, Chenango, Chemung, Steuben, Southern Cayuga, Southern Seneca, Schuyler

Marcy Silverman, Regional Coordinator  
301 Elm Street  
Ithaca, N.Y. 14850 607-272-9217

**PLATTSBURGH:** includes Essex, Clinton, Franklin, St. Lawrence, Warren, Hamilton, Northern Washington, Northern Herkimer counties.

Dale Moose, Regional Coordinator  
39 Clinton Street  
Plattsburgh, N.Y. 12901 518-561-8135

**ROCHESTER:** includes Monroe, Orleans, Genesee, Livingston, Wayne, Ontario, Wyoming, Yates Counties.

Marcia Slutzky, Regional Coordinator  
42 Pinion Drive  
West Henrietta, N.Y. 14586 716-334-4210

**SYRACUSE:** includes Onondaga, Northern Cayuga, Northern Seneca, Oswego, Madison, Oneida, Lewis, Jefferson, Southern Herkimer counties.

Colleen Perkins, Regional Coordinator  
State Tower Building, Suite 317, Room 6  
Syracuse, N.Y. 13202 315-471-3321.

Diane C. Perreira, Director of Social Services is located at the New Paltz office, 104 Deyo Hall, State U. at New Paltz, New Paltz, N.Y. 12561, 914-255-8662.

# Commission monitors care quality

A part of the package passed last year, along with the Mental Hygiene Reorganization Act, was a bill creating a Commission on Quality of Care for the Mentally Disabled composed of three persons appointed by the Governor with the consent of the State Senate.

Members will serve full time and be appointed for a period of five years each.

Among the functions and powers of the Commission are the responsibility to advise and assist the Governor in developing policies, plans and programs for improving the administration of facilities for all mental disabilities and the delivery of services to the mentally disabled.

The law gives the Commission the right to visit, inspect and appraise the management of those facilities, whether state or locally operated, with specific attention to safety, security and quality of care provided.

The commission may place a member of its staff to monitor any facility which it judges as presenting imminent danger to health, safety or welfare to its patients or residents.

The law also requires the Commission to establish procedures which will assure effective investigation of grievances of patients and residents of facilities and of conditions affecting such patients and residents including allegations of patient abuse and mistreatment. In addition, the commission would also set up a mechanism for speedy and impartial review of patient and resident abuse and

mistreatment allegations called to its attention in writing.

In addition to responsibility for overseeing the quality of care in department and community programs, the Commission will provide staff and other necessary assistance to boards of visitors to assist them in performing their functions or conduct orientation, training and educational programs for members of the boards.

Within the Commission, there will be a board of visitors advisory council composed of 15 members of the boards of visitors appointed by the Governor. At least seven members must be parents or relatives of patients or former patients. The Council will advise and assist the Commission in developing policies, plans and programs for improving its performance.

The Commission will also include a Mental Hygiene Medical Review Board composed of seven members including specialists in forensic pathology, forensic psychiatry and internal medicine. It will be responsible for investigating any unusual or other-than-natural deaths of patients or residents of mental hygiene facilities.

Facility directors, or others in charge of mental hygiene facilities, will be required to report to the Commission and the Medical Review Board the death of a patient or resident. Similarly, every allegation of abuse or mistreatment of a patient or resident must be reported to the Commission.



## Christmas Giving

William Lee, chairman of Sibley's department store, presented Dorothy Alger (far right), president of the Association for Retarded Citizens' Board of Directors, with the proceeds, in the amount of \$11,688, from the Buy an Angel, Be an Angel project. On hand, representing the Association's workshop groups who assembled the angels were Marilyn Feeley and Craig Cielinski. "Never has the community responded with such warmth and love," proudly declared Lee in referring to the thousands of consumers who donated to the cause by buying the gold and red holiday angels.

## Gouverneur D.C. residents finally find new home

Residents of Gouverneur Developmental Center, a satellite of Willowbrook Developmental Center, after many years of seeking, have found a new home.

The Gouverneur Developmental Center was in an old hospital of the City of New York condemned over and over again as a fire trap. The new facility is to be housed on three floors of Flower and Fifth Avenue Hospital on East 105th Street, Manhattan, a new Catholic run facility. It will be the most expensive home for the retarded in New York State, and perhaps in the country.

The program, to be operated by the Mental Retardation Institute of New York Medical College, Dr. Margaret Giannini, Director, is under the control of the Archdiocese of New York. It has been awarded a yearly medicaid rate of \$89,425 a patient, three times higher than that granted any state institution.

A spokesman for the State Health Department said recently that the medicaid schedule is "tentative" and based on the serious nature of the patients' condition.

Gouverneur residents are multi-handicapped, severely retarded persons in need of "specialty rehabilitative care," said the spokesman.

The Archdiocese of New York took over the Flower Fifth Avenue Hospital, which was in financial trouble, in an agreement ratified in January by the Board of Directors of the New York Medical College.

Dr. Margaret J. Giannini, Director of the MRI said that the Flower Fifth program would offer a full range of services including medical and recreational therapy for the residents whom the state concedes have been neglected for years.

She also predicted the residents would be transferred to small community residences by 1981, as called for under a court order.

More than 200 state workers at Gouverneur Unit are scheduled to be transferred to other state facilities, said John P. McKenna, personnel director for the State Office of MR-DD.

**Editors Note:** The medicaid rate in day treatment centers for the mentally retarded operated by the ARC is \$28.00 a day but, of course, that is not under the Willowbrook Decree.

### Respite home in Utica

Oneida County Executive William Bryant has directed that steps be taken to open a respite care home at Broadacres skilled nursing facility in Utica.

Bryant told Mental Health Commissioner Louis Patrizio to go ahead with plans to open the facility although the state hasn't yet approved the county's 1978-79 mental health plan. Once approved, 50 percent funding for the home would be released.

The respite care home would provide temporary care for mentally retarded children and adults, thus providing temporary relief for their families.

## N.Y.C. Chapter plans 5 new residences

The AHRC Department of Residential Services will soon be expanded to include five new group homes in addition to Fineson House and the Melvin W. Kraus Residence. When opened, these five new homes will increase the service capacity of the department from forty-one residents to a total of ninety-five residents.

Two of the new homes will be located on Staten Island. One of these will house eight adults from the borough and from Willowbrook Developmental Center.

The second of the Staten Island residences will be a traditional home on the grounds of Willowbrook. It was previously the Director's home and has been renovated to accommodate nine adults. At this home, residents will be prepared to move into a community residence within a period of a year and thus make room for other transitional residents.

The third new group home will provide

an opportunity for a new and exciting area of residential service. It will be the first group home for adolescents between the ages of 12 and 15. Renovations for this home, which will house ten residents, were completed early this year.

Two additional residences for adults are planned. In Astoria, Queens, renovations are in progress for a group home servicing twelve adults, and, in the Bronx, it is expected that renovations will shortly begin on a home for fifteen adults, including two wheelchair-bound residents.

Future plans include the development of independent apartment living programs to provide an exciting opportunity for those residents who have outgrown the group home and who are ready to live more independently. The apartment living programs will be closely linked to the ongoing programs, and will require a supervisory staff whose responsibilities will include ensuring that a structured transition is made, and that day-to-day help and guidance are available to the apartment residents.

### Greyhound announces policy

The National Association of Motor Bus Owners has announced that Greyhound Bus Company will now offer transportation free of charge for anyone accompanying a handicapped person on a Greyhound bus. This policy is being initiated to make it possible for handicapped people to receive any assistance they might need while using this means of transportation. It is hoped that other bus companies will also institute this policy in the near future.

### No N.Y. members on Carter's M.R. committee

At long last, and after considerable prodding, the President has appointed 7 new members to the President's Committee on Mental Retardation.

In what seems to have become standard procedure for all presidents, not one is appointed from New York State, and since the first appointment to this committee in the '60's, no one from New York State has been on it.

The members appointed came from Tennessee, Puerto Rico, California, Colorado, two from the District of Columbia, and one from Ohio.

### Weingold appointed

Your executive director, Joseph T. Weingold, has recently been appointed Chairman of the prestigious Legislative and Social Issues Committee of the A.A.M.D. This is the committee that presents policy alternatives to the A.A.M.D. Council for discussion and possible adoption.

At present, it is working on a policy statement on zoning and other matters, including national health insurance, use of human material for experimentation, and other significant matters.

# CHAPTER NEWS *What our chapters*



Schuyler County Chapter officers with State Vice-President, Ellie Pattison. Left to right (seated) Mrs. Pattison; Joyce Palmatier, President; Tom Brown, Vice President. (standing) Kit Palmatier, State Board Rep.; Richard Peet, Treasurer; and Marge Cole, Secretary.

As many of you have noticed, for a long time we tried to find ways to let a different chapter lead off this column each time. However, as we have now grown to 61 chapters, it would take us so many years to accomplish that we've given up on it and switched to an alphabetical format. It's rather a treat, therefore, to be able to include three chapters in our take-off item, noting that **ALBANY, RENNELAER and SCHENECTADY CHAPTERS** all recently shared in over \$1800 from the Capitol Newspapers through one of their subscription drives. Our thanks to the newspaper . . . While we have these chapters in mind, we will mention that **RENNELAER** has been doing some very active fund-raising, including a May 6th walk-a-thon. Haven't heard how it did but we hope it was extremely successful . . . **SCHENECTADY, IN THE MIDST OF A 25th Anniversary celebration**, published a very interesting booklet on their 25 years in existence. Programs growing yet today, as witnessed by the movement of 26 clients from their present Maple Ridge Center to their new Fort Hunter building within the past few months . . . **CLINTON COUNTY CHAPTER** very pleased over their new facility. Early this year, the Chapter moved their adult programs from their former Lakeside School building to the Franklin Building right on Route 9. In addition to picking up a new home, they have begun a green house at the new facility. . .

**COMMUNITY LEAGUE** following up their usual active times with fund raising. Had a Spring weekend in April at Browns in the Catskills, and a Sunday luncheon and dance at the Waldorf's Hilton Room in May. 150 turned out for this interesting event. The Chapter wants to thank their fund-raising Committee: Beverly Epstein, Ruth Zeins and Manon Aaron for their efforts . . . **CORTLAND COUNTY CHAPTER**, swiftly getting their first community residence in shape for opening, announces that Karin Burgess has been appointed Acting Executive Director of the Chapter as they move toward this long awaited project . . . It is difficult to believe that **ESSEX COUNTY** has come so far in their time within the Association. Their monthly newsletter always brimming with new expansion and

new activities is proof of how much can be done for the mentally retarded in a very rural setting. Perhaps the best story of growth can be told in the brief Chapter history by Jenifer Halasz, Treasurer-Membership. It reads: A group of friends met around a kitchen table in 1967 with a common concern: the lack of special classes in the county for the retarded. A pioneer class in Willsboro, taught by Georgianna Anson had closed in 1960 with angry words by school board and parents. The retarded child was kept home, out of sight, or placed in a regular class and taught little or nothing. Reverend Paul Ives, Margaret Kolodzy, Helen McDonald, and Eileen Platt were among those who worked to found the Essex County Chapter A.R.C. The first year there were 23 members. That year also a special education class began in Elizabethtown, taught by Ms. Anson, the only certified special teacher in the county. Last year, our Chapter had 219 members. Our goal this year is 300 members: there are 81 new friends out there we are waiting to hear from. Come in! . . . By the way, **ESSEX COUNTY** recently let the cat out of the bag. We didn't know that their Executive Director, Chuck Hayes had left bachelorhood last December. You don't

mind if we announce it to 30,000 friends, do you Chuck? . . . **FULTON COUNTY CHAPTER** looking forward to a summer day camp during the month of August, playground activities all during the summer and over-night camping for two nights for some of their clients. Busy as always . . . **GREENE COUNTY CHAPTER** also planning for their six-week summer camp. Ran a bike-a-thon, their 4th annual, on May 20th . . . Our thanks to the Chapter for encouraging their legislators to pass this resolution on April 20th: "Now, Therefore, Be It Resolved, that the Board does hereby proclaim the months of April and May as Greene County A.R.C. Membership Months, with the hope that our citizens react to the need and become members of this worthy Association." . . . Just going to prove that anyone who wants to, can help mentally retarded people. Pupils in the kindergarten through fourth grades of the Margaret Tuger Elementary School in Herkimer New York are taking part in a continuous paper drive on behalf of **HERKIMER COUNTY A.R.C.** We appreciated the pictures of the young fellows who had collected the most papers showing us how its done . . . **LIVINGSTON-WYOMING CHAPTER** has their new monthly publication absolutely filled with activities both in terms of staff and clients. Interesting to note that, at their Warsaw Branch on Hilltop Industries, they have started a farm program and will be selling produce from their garden at a road-side stand this summer . . . **MADISON COUNTY** celebrated a 10th Anniversary on April 15th. Had quite a line-up of celebrities with our own Executive Director, Joseph T. Weingold, included. In addition, they had State Senators William T. Conklin and Martin Auer, Assemblyman Clarence Rappleyea and Hyman Miller, Tom Coughlin and a very special guest, Mr. Pierrepont T. Noyes, Chairman of the Board and President of Oneida Limited Silversmiths, through whom the Chapter has received so much work in their workshop. Mr. Noyes was presented with the Industrialist of the Year Award for his support of the Chapter's workshop since inception in 1972. It was fun reading the 10 year highlights of the Chapter presented in their Anniversary newsletter, especially the remembrances about the early meetings when we were trying so hard to get the Chapter off the ground. A nice piece of work in Madison . . . **MONROE COUNTY CHAPTER** with their newsletter, as always, loaded with information on expanding programs. Several persons doing lawn mowing in their home areas as an interesting job. If you haven't already seen it, write and request a copy of the April issue of the

**MONARC** and review the Chapter's policy statement with regard to the use of their name for fund-raising. A good statement . .

**MONTGOMERY CHAPTER** has received two 30-passenger buses equipped with wheel chair lifts to help transport its 120 clients . . . June 17th was the date, and New York Hilton the setting, of **NASSAU COUNTY CHAPTER'S** Annual Rose Ball. This always festive occasion seems to get better every year and 1978 was no exception. Their very interesting news letter just too full of information to cover it all but must say that I was caught by the write-up that thanks the Bellmore-Merrick Auxiliary and the bazaar they sponsored, **NASSAU COUNTY CHAPTER** was made \$32,000 richer. Great work! . . . Our friend Senator Conklin was present at the Annual Dinner of the **NIAGARA COUNTY CHAPTER** where he was presented with the Chapter's Humanitarian Award, an excellent selection . . . **ONTARIO COUNTY CHAPTER** trumpeting its new program with a headline "A Dream Come True." This of course speaks to their efforts to open their first community residence which they hope will be functioning by September of this year. An interesting side light — **ONTARIO COUNTY CHAPTER** is sponsoring a special group for the developmentally disabled in the 14th Annual Seneca Lake



At Rome Developmental Center Chapter's the Chapter's award for her efforts on Executive Director John Bertrand and Ch



Kate Klein (1), outgoing President of St. Lawrence County Chapter, receives the Keith Bush Memorial Award at the Chapter's Annual Dinner. Mrs. Klein's daughter, Peggy, (holding plaque) and son, Karl, were present for the ceremonies, assisted by State Board Member Grace Jenack. (St. Lawrence Plaindealer photo).

Trout Derby. Had a nice turn-out at the Annual Dinner at June 14th where Doctor Sam Abbott received an award as "Volunteer of the Year" in the Chapter . . . A thank you to the Ontario Shores Chapter of the Sweet Adelines for finding their way into the hearts of the **ORLEANS COUNTY CHAPTER** and who presented the Chapter with a check toward their annual summer camp, Camp Rainbow . . . Another singing group who gave pleasure to one of our Chapters, was the Hostel Singers in **OTSEGO CHAPTER**, who entertained at the Chapter's May 18 Annual Meeting. We are happy to say **OTSEGO COUNTY** has apparently won a long and difficult battle. Recently there has been considerable publicity in their local newspapers about them being disenfranchised from their workshop location at Homer Folks Hospital . . . It appears at this time, however, if they will be relocated, the County will have to find another suitable location . . . Kate Klein, the out-going president of **ST. LAWRENCE COUNTY CHAPTER**, received well-deserved recognition at the Chapter's annual meeting when she was presented with the Keith Bush Memorial Award. This award

# ers are doing and saying for our children and adults

is given on an annual basis to a person who has helped to advance the purposes of the Association. It is for dedication and perseverance to that end. A special part of the award to Kate was that her daughter Peggy and son Karl were able to be present at the ceremonies. Karl, as you may know, is the Executive Director at our **SARATOGA COUNTY CHAPTER**. ARC seems to run in the blood . . . **SCHUYLER COUNTY CHAPTER** is doing all it can to obtain a contract with its local Community Services Board and begin programs for the mentally retarded of their county. Very much enjoyed having Northeast Regional Vice President Ellie Pattison at their May meeting . . . **SUFFOLK COUNTY CHAPTER** delighted with being able to open their Riverhead facility in April of this year. This will provide needed space for 50-75 clients in that area. With programs stretching from Niagara Falls to Riverhead, we can certainly say we are serving from sea to shining sea, or from sea to shining lake, perhaps. . . Thanks to the students of Middle Island Middle School who, in April, put on a dance marathon on behalf of **SUFFOLK COUNTY CHAPTER** and raised \$9,000 for the Chapter . . . Not to be outdone by **ORLEANS COUNTY CHAPTER**, **SULLIVAN COUNTY CHAPTER** recently was the recipient of the funds raised by the



Pauline Nearing (1), secretary of A.D.K. Sorority presents a check to Sullivan County Chapter. Staff members Richard Swierat and Sarah Barrett look on as Kathleen Drugan accepts the check on behalf of the Chapter.

planning by the new Office of Mental Retardation and Developmental Disabilities. The program was shared by Associate Commissioner Zygmund Slezak, an old friend of A.R.C. Ann McDonnell, who many of you will remember as our charming Mistress of Ceremonies at the Westchester Convention, was elected president replacing our dear friend Doris Hosmer . . . And wrapping up this time with news from **WELFARE LEAGUE, LETCHWORTH VILLAGE CHAPTER**, we find them busy as always, although it is only now late Spring, making plans for their Annual Luncheon which will be Saturday, November 18th. It will be their 39th Annual Luncheon and we know it will be its usual great success. Congratulations to Dorothy Gasman, immediate past president of **WELFARE LEAGUE**, who was presented with a plaque by the League in gratitude for her years of service as the Chapter's president. Dorothy has been replaced by Bernice Volaski. In addition to everything else, Dorothy Gasman was appointed by the Governor to the Board of Visitors of **LETCHWORTH VILLAGE**. A great way to close one career and begin another.

## 1978 Lexington Fair raises almost \$18,000



Part of the crowd at the Lexington Center Fair.

A very successful four days were the end result of many months' hard work and planning by the Lexington Center staff and other volunteers for the 8th annual Lexington Fair held at the Lexington Center in Johnstown, Thursday, June 8th through Sunday, June 11th. An estimated 20,000 people visited the Fair during its four day run, netting an approximate \$18,000.

One of the highlights was the "One-To-One" with volunteers assisting clients from the Wilton Developmental Center on Saturday. One hundred and twenty five clients were transported from Wilton to the Fair and one hundred and thirty five volunteers responded. Two local radio stations, WIZR, Johnstown and WENT, Gloversville provided continuous (over 50 hours) live coverage, while an area TV station, WRGB, Channel 6, Schenectady, supported the event with news coverage.

Live entertainment was enjoyed by the spectators every day of the Fair. Vocalists, musicians, instrumental groups, and many other types of entertainers performed for the crowds. One of the main attractions for the children was Ronald McDonald, who after appearing in our Saturday parade, presented a magic show. A large Flea Market, tractor pulls, sky divers, hot air balloons, games, contests, and a fantastic array of food, drew many visitors to the Lexington

grounds. On Saturday, members of the Fulton County Hairdressers Association did free hair styling for as many as 100 enthusiastic people.

On Saturday, spectators lined the sidewalks of Johnstown to watch the 7 division Lexington Fair Parade. One of the parade's features was a float carrying local children and the "Mini Animal Petting Farm," which was set up on the grounds later for all to visit. The Parade also included four area high school stage bands, the Mayors and Aldermen of Johnstown and Gloversville and several unusual entries such as Dracula. That evening, on Knox Stadium Field in Johnstown, the Lexington sponsored drum and bugle corps competition, known as the Cavalcade of Champions, was held. This event alone attracted 5,500 spectators.

Lexington Center was very fortunate, as they have been in the past, to receive the support of the community and surrounding areas. Volunteers gave of their time answering phones, and helping with various jobs where they were needed. Area merchants and businessmen donated equipment and prizes. Lastly, the public itself cannot be overlooked. The response, as always, was tremendous. An estimated 800 people braved a very rainy opening night. As the weekend went on, the weather cleared and the numbers attending grew to make it a very happy and successful 1978 Lexington Fair.

## 450 swimmers raise funds for Herkimer



Come on in! These swimmers were among those participating in the Herkimer County Chapter, Association for Retarded Children, swim-a-thon VI, held at the Herkimer County Community College Pool.

Approximately 450 swimmers helped to raise \$21,458 for the Herkimer County Chapter of the State Association during a three-day swim-a-thon held at the West Canada Central School, Little Falls YMCA and Herkimer County Community College swimming pools.

According to Judy Sprague, Swim-a-thon chairman, the event was a success because "we had a good committee this year."

People came to participate from as far east as Albany and as far west as Syracuse.

Some of the races showed great community interest as, for example, between representatives of the Armed Forces, the Principals Race for principals of schools, Law Enforcement Race won by the Ilion Police Department, the Jaycees versus Jayncees Race, a battle of the sexes, Mayors Race, and the Knights of Columbus Race. The winners were awarded certificates by Edward Hays, local president of the ARC.



ter's Annual Dinner, Mrs. Louise Mirachi receives s on behalf of residents, flanked by Assistant Chapter President Ethel Lombard.

Catskill Chapter of the Sweet Adelines whom we thank for their kind contribution. We also received a picture of a memorial gift from the Alpha Delta Kappa Honorary Sorority for Teachers and Educators being presented to the **SULLIVAN COUNTY CHAPTER** ARC's day treatment center, and we thank the Sorority for this . . . **TOMPKINS COUNTY CHAPTER** getting closer and closer to their community residence. Delighted to announce they have office space in Ithaca donated by a long time friend and life-member of the Chapter, Dorothy Saperstone. Thanks Dotty! . . . **WARREN-WASHINGTON CHAPTER**, being extremely active in the field of advocacy, has created an Advocates Committee and we were delighted to see that the Glens Falls Foundation cared enough to make a contribution of nearly \$1,000 to the Committee. It's great that this very active group is blending right in with the Chapter. Our globe-trotting Executive Director, Joseph T. Weingold also took time from this busy schedule to attend the annual Meeting of our **WESTCHESTER COUNTY CHAPTER** on June 13th. Mr. Weingold was speaking at the meeting on his approach to

## Story of Sharon

# Retarded woman denied hemo-dialysis

Sharon, a beautiful 26 year old girl of American Indian descent, functioning at a retarded level, recently died because society, with all its might, denied her a kidney machine.

Sharon was born to an American Indian parent. When she was three months old she was the victim of child abuse, causing her to become a ward of the state. From institution to institution she finally was placed at West Seneca Developmental Center where she spent a considerable number of years, finally being placed in a foster home where she found love and happiness.

Sharon was not severely retarded, she functioned as a 12 year old. She could take care of herself, read and write, partake in simple conversation, knit and crochet beautiful things. She touched the heart of everyone with whom she came in contact.

Seven months ago, Sharon came to St. Jerome Hospital in Batavia suffering from failing kidneys — a neglected case. Dr. S. P. Dhanda, Batavia surgeon, operated on her successfully but unfortunately, as he writes, "the kidneys kept deteriorating." The only way she could be kept alive was to utilize an artificial kidney machine. This treatment was necessary twice a week, and at a later date, a kidney transplant may have been necessitated.

Three years ago, St. Jerome Hospital applied for a kidney machine but this request was denied on the ground that this treatment is available in Rochester and Buffalo.

Since hemodialysis was not available at Batavia, Sharon was sent to Strong Memorial Hospital for treatment. This treatment was denied to her for the following reason.

1. Her mental retardation. She had no concept of disease and no understanding of the rigors of hemo-dialysis.

2. She had no support from her family.
3. Chances of rehabilitation are poor. They felt that she would end up in an institution anyway.
4. She has only the mental capacity of less than a 5 year old.

Even though \$5000 of Sharon's own money could be used to buy a kidney machine to save her life, it could not be used in St. Jerome Hospital because of the rules and regulations imposed by the federal and state government and by other committees. Dr. Dhanda could not find a nursing home to accept Sharon and her machine. He could not find a home who would take in her and her machine. "Alas, Sharon could not have a kidney machine." And, finally, on May 3rd, she spent a day with her foster parents, and on May 5th had an enjoyable dinner with her friends at the home for retarded children. She returned to the hospital and, on May 7th, quietly died.

Dr. S. P. Dhanda, the Batavia surgeon who took care of Sharon at St. Jerome Hospital wrote to The Batavia Daily News on May 31st, "I demanded the life of Sharon . . . I sought her life from this community, from the state, from the federal government, and lastly from God. I was let down by all."

"Because of our rules and regulations imposed on people by the community, by the government, and by tens of hundreds of committees, Sharon was doomed to die."

Whose responsibility was it to keep Sharon alive? If she was a ward of the state, was it not the State's responsibility? And what of Strong Memorial? Did Strong Memorial have the moral right to deny hemodialysis to this girl because others might profit more from it?

At any rate, Sharon is dead.

## The Edu-Letter

The Education Committee of the New York State Association for Retarded Children has initiated a new publication — the Edu-letter keeping you informed of the current interpretations of the rules and regulations, successful experiences of encountering the Committee on the Handicapped, examples of how to go through Due Process, etc. It is serving as a valuable exchange of information in the area of education.

If you are interested in receiving this newsletter, please sign your correct name, address and telephone number on the tear-off below, and return immediately. Feel free to duplicate this tear-off and sign up any other persons who may wish to receive this valuable newsletter.

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

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

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

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

Return to:

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

## Dreams Can Come True

By Johnny Brewer

(Son of Ruth Brewer — Chenango County)

Guess who came for Christmas, then stayed right on through January and February? Me — that's who!

My name is Johnny Brewer — and I'm back home to live

Even tho' the folks at "Craig" and a Foster Grandma tried to give,

Me, necessities and tender loving care.

Every day in every way, while I lived up there.

January 31st, Mom gathered all her strength and drove me, 80 miles northwest.

I have to hand it to her, she tried her very best.

But when she started to say, "Good bye," I wrapped my arms around her, a tear was in my eye.

Mom said, "This just won't work, I must take him back.

My heart tells me I'm on the right track. He'll enter school and be home at night, and for just several hours a day, he'll be out of our sight.

We've tried 5 years of his living away, Now it's time for him to come home to stay.

We'll always be grateful for all you've done

But now I'm well, It's up to us, because he's our son.

You have him toilet trained and on regular instead of baby food.

Provided education, recreation, soothed him during a crying mood.

Bathed him, taking care of scratches, fevers and a bruised toe.

We're thankful you helped him develop and grow."

Family cooperation is the key, Dad promised, "That's the way it will be.

I'm retired and John's no trouble, You can continue your service, but be back on the double."

Of course he was kidding about her rushing,

Cause he knows she'll be late, red-faced and blushing,

As she explains long meetings and visits with residents she's come to love,

Dad will ask, "Any car trouble?" Mom answering, "No, God watched over from above."

Changing schools won't be peaches and cream,

But it sure comes close to answering My Dream.

## Buy our candles!

Fourteen retarded people craft exquisite candles in the Candle Shoppe of the AHRC Training Center and Workshop in New York City. Esthetically and technically professional, the sturdy but graceful three inch by three inch candles come in eight rich colors wafting eight delicate scents. Some are smooth in texture and some honeycomb. Most are embossed with a frieze of frisky abstract elves called Waxwicks. The candles are packed in sturdy, handsome boxes, each candle individually wrapped in cellophane, each box with delightful literature. The candles come in four different assortments, each with eight candles. The assortments cost from \$8 to \$10 for the eight candles. They make attractive gifts and fund raising items.

For information and order forms, write or call Joel Nitzberg, The Candle Shoppe, AHRC Training Center and Workshop, 320 W. 13th Street, New York City 10014. Telephone: (212) 691-2100.

## Help! Help us find OCV

The Association is trying to complete its file of "Our Children's Voice" for the library and is missing two or three back issues. Would you old timers check and see if you have the following, which you could contribute to our collection? We will send you back a photocopy of anything you send in, so your archives can be kept complete. We need —

Vol II Number 3 (1950)

Vol II Number 6 (Dec. 1950) —

Vol III Number 2 (1956)

— We're not sure this one was ever printed, but if you have one, it would confirm its existence.

Please send to:

Library

New York State A.R.C.

175 Fifth Avenue — Room 1000

New York City 10010

## Life....the greatest gift

On January 25, an A.R.C. client named Alice was taken ill suddenly at the Al Sigl Center site of the Association for Retarded Citizens. Despite prompt action by the A.R.C. Staff and others from the Center, Alice lost her fight for life on Saturday, January 28.

Alice did not die in vain. Her parents concluded about a year ago that, in the event of their death, their organs should be donated to people in vital need. In anticipation of this possibility in Alice's case, her parents acquainted the hospital officials of their wishes, and a plan was formulated. Dr. Frank Thomas, of the Medical College of Virginia, flew to Strong Memorial Hospital Saturday night to remove Alice's heart for a transplant at the College's hospital in Richmond, Virginia. The recipient, a 46 year old man with a history of heart trouble, was reported in stable condition following the transplant operation, which lasted four hours.

Dr. Allyn May, of Strong, who removed the kidneys, said both recipients at Strong were doing well. The heart operation was the first long distance transplation to involve a Rochester hospital. The decision to donate Alice's organs was made a few days ago when the family realized Alice would not live.

Alice had recently moved into an A.R.C. community residence, where she was very happy and learning to be increasingly independent. Alice was a giving person, and it was characteristic of her that even in her death, she was able to give the greatest gift of all — Life — to three persons.

Our sympathy is extended to Alice's family, and to all her friends. We shall miss one with whom we were privileged to work and play for even so short a time.

## "Try Another Way" workshops presented

Four, two-day regional workshops on the use of a unique instructional system were sponsored by the Bureau of Program Development.

This instructional system can be utilized to teach moderately, severely and profoundly handicapped individuals to perform complex tasks. It has proven effective with profoundly disabled people who had been previously regarded as unteachable.

Workshops were presented in Syracuse, Buffalo, Albany and on Long Island. Approximately 100 people participated at each session including teachers, therapists, administrators and trainers in the State Training Network. Additional information concerning workshops can be obtained from the Bureau of Program Development, OECHC, Room 117, 55 Elk Street, Albany, New York 12234.

For Christmas

# Order your ARC cards NOW!

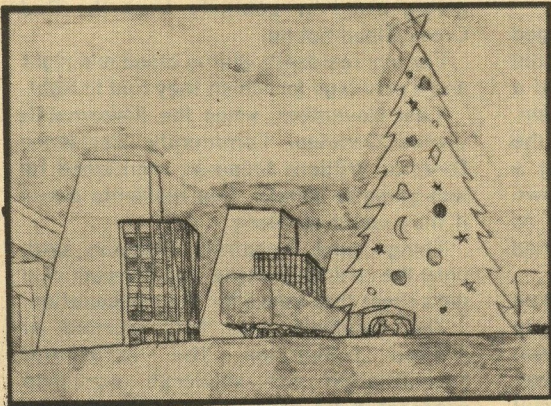
## 1978 AWARD WINNERS

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

25 cards for \$5.00  
Add \$3.25 for each 25 cards imprinted



**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.

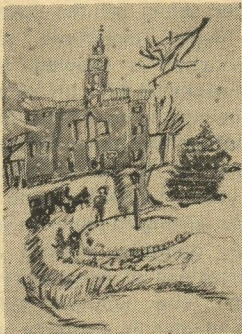


**Card No. Z314-78**  
Created by David Hoffman, Schoharie County. City scene. White envelope. Inside: "Season's Greetings with Peace, Health and Happiness throughout the New Year"

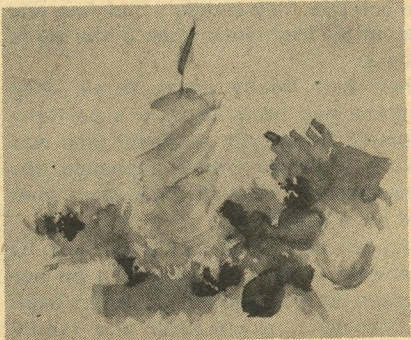
## PREVIOUS AWARD WINNERS

Designed by the retarded and produced to help the retarded.

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



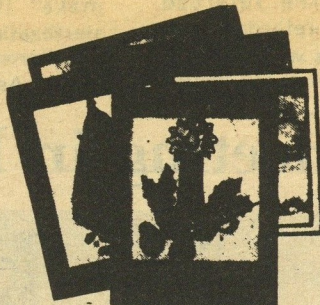
**CARD NO. 57802W1**  
Charming, colorful old fashioned scene complete with horse drawn carriage and snowfall. White envelope. Inside: "Wishing you all the Joys of the Season and Happiness in the Coming Year".



**CARD NO. 57803W1**  
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".

## SPECIAL ASSORTMENT

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



Order - Card No. ARC  
Box of 50 Cards and envelopes for \$5.95. 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
_____	<b>Z376-78:</b> 25 cards at \$5.00 — A Holiday Wish that one day all children will realize their dreams	_____

_____	<b>Z314-78:</b> 25 cards at \$5.00 — Season's Greetings with Peace, Health and Happiness throughout the New Year	_____
_____	Add \$3.25 for each 25 of the above two cards imprinted	_____

No. Boxes	Style, Price & Message	Amt. Enclosed
_____	<b>57802W1:</b> 25 cards at \$4.00 — Wishing you all the Joys of the Season and Happiness in the Coming Year	_____
_____	<b>57803W1:</b> 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
_____	<b>ARC:</b> 50 cards at \$5.95. 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 \_\_\_\_\_

## Dilemma of sterilization

Six years ago a Williamsville woman took her 14 year old daughter Ann, who had been retarded since birth, to the hospital to be sterilized. The day after the operation, the mother recalled, "was the most horrible day of my life."

This woman is just one of many parents of retarded children who have faced, or are facing, the emotionally wrenching decision of sterilization of their children.

Add legal questions to the terrible emotional dilemma and the result is a problem that has caused more than a few sleepless nights.

The woman and her husband had postponed surgery to have the girl's uterus removed even though Ann had repeatedly been disturbed over her menstrual cycle. Then one day they couldn't find Ann and began to get frightened when it started to get dark.

When Ann finally came home, they found she had been alone in a partially completed house with a painter who was working. Although nothing happened, she and her husband began to think about what could have happened.

After talking with the girl, who has an IQ of between 60 and 75 depending on her mood and the test, and getting letters from a gynecologist, psychiatrist and family doctor as well as a hearing with a hospital board, the operation was decided upon.

For the mother, there was a dual depression of having put her daughter through major surgery and a personal feeling of loss.

"I did what had to be done," the woman said, "but I also felt a tremendous loss. Being a woman and being Jewish you tend to think in terms of generations."

"The thought of that being the end of the line, the thought of breaking off an extension of myself, left me very empty."

The question of sterilization of the retarded is complex. The retarded, especially the marginally retarded, often can live near-normal lives which include love, marriage and a normal sex drive.

But caring for a child often is beyond their capabilities, and would, in fact, make their lives less enjoyable, the mother said.

The catch is that a retarded adult who chooses not to have children cannot just walk into a hospital and become sterilized. Unlike a normal person, a request for sterilization by the retarded results in court appearances and much red tape.

"When adults go in for surgery, they sign an informed consent form," the mother explained. "When you have a mentally incompetent person, that person cannot sign this thing relieving the doctor of responsibility."

"The law protects these (retarded) people, but in protecting them it has taken away some of their rights."

Even when all the court appearances and legal questions are met, and sterilization is allowed, fear of liability often makes it difficult for parents to find a doctor willing to do the operation.

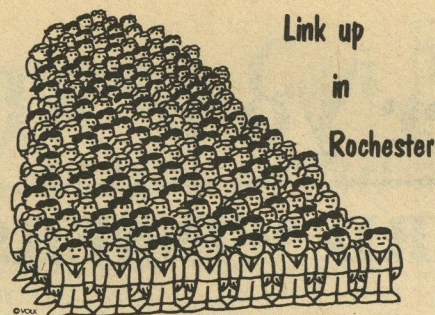
Another Williamsville woman arranged to have her 23 year old daughter sterilized last year. It took her nine years to find a doctor willing to perform a tubal ligation.

"My daughter doesn't understand the implications of pregnancy and having a child," the woman said. "My own gynecologist is Catholic and refused to even discuss it (sterilization). He turned green when I asked about it."

Finally after nine years of an off-and-on search, she found a doctor willing to perform the tubal ligation. But the refusal of doctors to perform the operation, either on moral or legal grounds, made a difficult situation even worse, she said.

"It's very difficult to walk in a strange doctor's office and tell him what you want," she said.

A recent Supreme Court decision that said judges are immune from liability in allowing sterilizations won't do much to make it easier to arrange for sterilizations, according to Roger Stone, an attorney with the Erie County Mental Health Association.



## Residents donate blood

Residents of Livingston Community Residence at 62 Center Street, Geneseo, have reversed the conventional attitude toward giving blood.

Many people have to be coaxed into giving blood by publicity from the Red Cross Bloodmobile.

For our residents, giving blood is a right and a privilege for which they had to fight.

Last November, when the Bloodmobile visited Geneseo, Community Residence Director William Shipman mentioned he was going to donate. Two residents asked if they could go along.

Things went smoothly, Shipman said, until the residents came into the part of a data sheet that asked for their occupation.

The residents said they worked at Hilltop Industries, the vocational rehabilitation and sheltered workshop program in Mt. Morris and South Warsaw run by the Livingston - Wyoming Association for Retarded Children.

The residents, both men, were refused because they lived in an "institution." Shipman insisted the Hilltop program and the community residence aren't institutions and said his friends were members of the county community.

The residents then became the subject of a phone call to Bloodmobile headquarters in Rochester, Shipman said. An attendant asked if the Bloodmobile should accept a donation from the "mentally retarded."

Shipman protested the use of this label. When one of the rejected donors asked if he did not have the right to give blood and the other asked if something was wrong with his blood, Shipman resolved to take action.

Red Cross regulations indicate that anyone who hasn't been declared mentally incompetent has the right to give blood, Shipman found.

He said it is general medical knowledge that there is nothing different about blood from "labeled" donors. There is no more connection between intelligence and blood than there is between talent and blood, he said.

Shipman pursued the matter to higher levels of the Red Cross and promised to take legal action, if necessary.

Last Friday, at a Bloodmobile visit to Central Presbyterian Church, Shipman and three occupants of the community residence visited the Bloodmobile again.

They each gave blood.

## Impartial hearing officer list required

According to the office for education of children with handicapping conditions of the State Education Department, local educational agencies must maintain a list of persons to serve as impartial hearing officers. The list must include a statement of the qualifications of each such person.

Also, local educational agencies must secure written consent from parents or legal guardians before initial placement of a child in a special education program. Written parental consent is also required before initial preplacement evaluations.

## Private schools cost less

A New York City Comptroller's audit has disclosed it is far cheaper for the city to send handicapped children to private schools than to educate them in its public schools.

The reason, said Comptroller Harrison J. Goldin, is that the state gives a greater amount of aid to private schools for the handicapped, even though tuition and transportation for their students are paid for by the city's Board of Education or the state's Education Department.

The 154 page audit, analyzing the cost and financing of special education, comes at a time when a record number of handicapped children — about 56,000 — are expected to be enrolled in the city's public schools as a result of new Federal laws that require schools across the country to educate children they have previously ignored.

By September, the Board of Education must complete the immense task of absorbing all of the city's children with physical, mental or emotional handicaps. Currently, only 5,000 handicapped children are attending private schools.

Mr. Goldin said last week that a "dramatic disparity" in the state's formula permitted it to be fixed at a specific maximum for children in public schools, but allowed the state to pay half the "excess costs" above a base amount for children in private schools.

"Were the same kind of aid for excess costs available for children in public schools, nearly \$50 million in extra aid would come to the city to finance special education," Mr. Goldin said in the audit. He urged legislators to eliminate the inequities in the aid formula so that the city got its fair share. The Mayor's expense budget has included additional funds for the rising number of handicapped children scheduled to be enrolled in the public schools next September.

Handicapped children generally require smaller classes, often more than one teacher and more than one assistant in a classroom, special equipment and transportation. Their education is usually extremely expensive and the state, not the Federal Government, picks up the bulk of the bill.

For example, in 1975-76 the overall costs of educating a severely handicapped child for one year, including transportation, was nearly three times as expensive as educating a nonhandicapped child in the public schools — \$7,143, as compared with \$2,401.

Auditors found that the net cost to the city to educate one severely handicapped child in 1975-76 in the public schools would be \$3,005 a year after state aid was deducted. The same student enrolled in a private school for the handicapped would cost the city \$1,496 after state aid was deducted.

The audit criticized the Board of Education for failing, until last year, to estimate the cost to the city of special education programs. The same criticism was implicit in an independent audit that disclosed last March that poor management and administration of the program for the handicapped had led the public school system to the point where it did not know it had 9,000 empty seats for 9,000 handicapped children on waiting lists.

Doctors and hospitals still are concerned over their liability in sterilization operations, he said.

"There's a great deal of concern over the ethics of sterilization," Mr. Stone said. "The Supreme Court decision was very narrow. It probably won't do much to loosen things up."

## Annual meeting in Rensselaer



James Flanigan, executive director, David Wilkie, past president, Joseph T. Weingold, executive director, State Association, and Russell McGarth, president.

## Property values stable near hostels

Records in the city assessor's office in Watertown, New York show there has been no erosion of property value in the five neighborhoods in Watertown where the Jefferson County Association for Retarded Children operates hostels.

The records show more than 200 property transactions in the neighborhoods since the first hostel opened more than five years ago, and that values have remained steady or increased.

Copies of the deeds demonstrate no erosion in the value of the property, property assessments on the parcels either remained steady or been increased to reflect the new purchase prices.

When parcels were sold more than once since ARC hostels were opened in the neighborhoods, with but a few exceptions, the second sale brought a higher price than the first.

# BOOK REVIEWS: Learning by Doing

By Mary F. Tomaselli

## Children of Skylark Ward

Rogovin, Anne. *Learning by Doing: An Illustrated Handbook For Parents and Teachers of Children Who Learn Slowly*. 2nd ed. Oak Lawn, Ill.: Ideal Publications, 1977. 233 pp.

This book is veritable cache of ideas for teachers of educable mentally retarded adolescents. Amply illustrated with photographs and drawings, the book is arranged by school subject, e.g. Language, Math, Music, Home Economics, Citizenship, etc. All the activities discussed are drawn from the author's experience as a special educator in the Buffalo public school system. The main focus of most of the activities is to help mentally retarded teenagers develop self-care skills for greater independence of function in society. There are lessons on telling time, use of reference tools (telephone book, dictionary), First Aid, household skills (cooking sewing, etc.), reading sings, etc. The sections on Language and Reading offer some innovative classroom or group activities such as use of comic strips to stimulate reading, creating a classroom newspaper, choral speaking, picture notebooks and field trips.

Most of the activities can be adapted for use of parents for their children at home, e.g. the classroom newspaper becomes The Family Reporter.

The language of the text is simple (possibly too simple at times) and straight forward.

The book is spiral-bound, and the sections are tabbed for easy use and accessibility.

Review of Ann Hale's *The Children of Skylark Ward*. London, New York: Cambridge University Press, C. 1978. 134 pp.

This is a personal account of the author's experiences while teaching severely multiply handicapped children and adults in a hospital setting in England.

The book is intended for student, lay-person and professional alike, but, in this reviewer's opinion, is best read by parents and students in training.

For parents, the positive view of caring for, and "educating", these profoundly handicapped persons in a residential setting, will be uplifting. For students, the descriptions of the extent of each resident's handicap, the group activities and individual child-based programming will serve as introduction.

The chapter on "The Child's Awareness of Self" gives particular insight to the author's need to develop with her own emotions, body and sexuality before she could deal effectively with her handicapped pupils. Although the author touches on this point only briefly, it is perhaps the most important point made in the book, especially for those who are contemplating a career in the care of the severely handicapped.

Although the literature of mental retardation and physically handicapped has always been overwhelmed with personal narratives, some good, some bad, there is always room for one more. One more good one, that is.

# LETTERS

## We need communities that care

I am the parent of two retarded children and one mentally ill child. I speak to all who have the opportunity to read this paper. Both of my retarded sons are now deceased but their lives, in spite of being shortened, gave much joy to those who knew them regardless of their handicaps.

I am sad their lives were so limited but I am also relieved, since they are no longer alive and will never give vicarious pleasure to the inhuman persons who mistreat children, dogs, cats and handicapped people who can't help themselves. How can a person who is in his right mind "beat a retarded person with a pipe once or twice a day?" This was the latest horror story reported in the June issue of "Our Children's Voice." These horror stories give me nightmares at night, just the thought that situations like those in the stories exist! It is something I cannot understand and how can anyone who has a loved one who is handicapped?

The New York Times article of May 28, 1978 is an example. It is not only the individual but the whole system of social workers without consciences and a system where the handicapped persons can only be called victims are put into situations where they are preyed upon day and night. What kind of ungodly, inhuman civilization do we have in this modern day and age when there is so little compassion and care extended to the less competent among us?

If I thought that my fifteen year old, son who is mentally ill, would ever be part of this terrible delivery system of mental health services that would mistreat him so inhumanely I would try to make certain, if within my power, that he would not outlive me to suffer from such treatment!

In a state that spends as many dollars as New York on mental health, it isn't just a matter of money. Everybody from the youngest child to the oldest citizens must start developing care and compassion for their fellow man. We can no longer absolve

our consciences by saying "I pay my taxes." Caring, understanding and acceptance are things that separate us from the animals of the world. Until we are willing to completely return to the animal way of life and kill our defective individuals at birth then we must develop a better system of showing we care about life in all its forms.

I can't help but believe that each parent of a handicapped person has a special role to play in their own communities. This is where you can, on a one-to-one basis let your neighbors, your local merchants, your fraternal organizations, your church, etc. know that the mentally retarded or mentally ill person is just that, a person. All too often, as parents, we don't expose the handicapped person to life as we do our normal children. This is where you can change attitudes, by personally involving your community.

I am not advocating something I don't do myself. My son swims at the local "Y," attends Sunday school and church services, goes shopping and is quite visible in all phases of his village life. I would like to think it has made a difference in his acceptance here in our community. Sure, some of you will say it is easy for a child who can walk and appear more normal than some, BUT for fifteen years I had children who had NO SPEECH, NO HEARING, were confined to wheelchairs, children who had seizures and severe physical impairments BUT they were still taken out into the community, to parks, to see Santa Claus, to shop, to do all the things we could with them to give them a taste of life but also to have people around them accept them.

Yes, we need community programs but more than that we need communities that care and understand the needs of the mentally handicapped person. Shirley J. Martin, (Mrs. T.E.)

## How we help

**Edward H. Schieber, with the Air Force, expresses his thanks to the New York State ARC for helping him and his wife with special education placement for their daughter:**

During May 1978, my wife contacted your office concerning a problem we were encountering with the Air Force. The Air Force was attempting to involuntarily separate our family, because they were unable to provide special education for our daughter in Izmir, Turkey.

Geraldine Sherwood, of your office, was extremely responsive to our needs and provided information which was in-

valuable. At her suggestion, we contacted a Mr. Carl Fogelberg, "of Protection and Advocacy System for Developmental Disabilities Inc." Mr. Fogelberg's efforts on our behalf appear to have been successful and I expect to be accompanied by my family to Naples, Italy where educational services are apparently available.

My family and I would like to express our sincerest appreciation to your office staff, particularly Geraldine Sherwood, for the time and effort expended on our behalf. Once again our thanks to all concerned.

# Outstanding OMR employees honored

Twenty-two employees of the Office of MR-DD were honored by the Association in ceremonies in the Blue and Gold Room, Empire State Plaza in Albany on June 15th. The honorees were individuals selected as the Outstanding Employee in each of the Developmental Centers, the Institute for Basic Research and the Central Office. As in the past, the Association will present each employee with a certificate and a check for \$100, and will have a nameplate bearing the employee's name inscribed on plaques to each of the Developmental Centers.

John Bertrand, Assistant Executive Director, represented the Association at the Awards Ceremony. A certificate for each employee was also given to them by

Thomas A. Coughlin, III, Commissioner of the Office of MR-DD.

The Outstanding Employees are: Elaine Marston, B.M. Fineson; Mary Marable, Bronx; Angelo Campagnola, Brooklyn; Janet Stevens, Broome; John Schirmer, Craig; Marian Mentley, J.N. Adam; Eva DeJesus, Letchworth Village; Dorothy Fulton, Manhattan; Justine Staggert, Monroe; Mylo DeMarree, Newark; Frank Bilka, O.D. Heck; Susanna Moskin, Rome; Florence Kahee, Staten Island; Krystine Silvers, Suffolk; Susan Edwards, Sunmount; James Mueller, Syracuse; Robert Coons, Wassaic; Alice Bender, Westchester; Wasyl Regula, West Seneca; Clarence Latimer, M.D., Wilton; Thomas Bonamo, Institute for Basic Research; and Salvatore Mazzaro, Central Office.

## You just can't win!

In 1974, the New York State Association for Retarded Children protested to the then Governor Wilson "inhuman treatment of the mentally retarded in the state institutions."

In a telegram to the Governor, the Association cited an overdose of 3,000 mg. of a tranquilizer given 28 year old Mary Madden, a patient at Syracuse State School. As a result of this overdose Mary Madden was seriously injured. Thereafter, Vern Madden, formerly a member of the New York State Board of Governors, brought suit against the state on her behalf and was awarded \$8500 by the Court of Claims. Judge Vincent Delorio ruled that the state was negligent in allowing an

untrained therapy aide to give Mary Madden at least 30 and possibly as much as 90 times the prescribed dose of concentrated liquid Thorazine.

Immediately thereafter, however, on June 1st, the voracious Department of MR-DD filed a claim for treatment of Mary Madden in the sum of \$6,550 "in order to maintain her Medicaid eligibility and to pay for past care and maintenance." This, in spite of the fact the judge ruled the state was negligent in a drug overdose case, and in fact Mary Madden had received very bad care, indeed.

You just can't win. Or maybe you can, if you fight.

## Buffalo group home wins in court

Supreme Court Justice Norman J. Wolf Jr. has granted permission to James P. English to operate a home for mentally retarded adults in the town of Evans, near Buffalo, ruling that such use of the building is in compliance with the town's zoning ordinance.

An application filed by Mr. English with the town building inspector for permission to use the home for mentally retarded adults was denied.

Mr. English then asked the Town Board to grant a variance, but after two hearings the request was denied.

Subsequently, a group of owners of adjacent property who objected to Mr. English's plan were given permission to intervene in the courts.

In that same decision, Justice Alfred M. Kramer authorized the State Department of Mental Hygiene to intervene on behalf of Mr. English.

Justice Wolf said the question before the court was whether the occupants of the home would constitute a family as defined by the zoning laws. He said there is substantial case law which holds that a group such as Mr. English plans to accommodate — 15 adults — would comply with the law.

He noted that the occupants would be permanent residents and commented that "it is only when group homes and community residences are established to house transients or persons for short terms that they are not considered families."

# YOUTH REPORTS

## LARC ADVISOR IS HONORED

Last week, members of LARC arranged a surprise party for a very special person. Their group advisor, Ms. Waltamath, was honored by appreciative young people who have developed and maintained a strong, vital YOUTH — ARC group under her able direction. One of the highlights of the party involved the members presenting Ms. Waltamath with a photo album spanning the years of her involvement with them since 1971.

## LARC ACTIVITIES

Sue Hotaling, Public Relations officer for the Love Association for Retarded Children, keeps us posted as to their wide range of activities.

Recently, the Marty Kittell orchestra played for their adult friends. Over a recent weekend, LARC members, Sara Waltamath, Advisor, Mary Reardon, Mim Millar, Paul Unson, Donna Wade, Tevor Coleman, Michael Seider and Sue Hotaling, took five young adults to Albany to see Hansel and Gretel and afterward dined at a restaurant.

The group arranges swimming lessons for retarded children every Wednesday from 6-7 p.m. at the Hudson High School pool. Every Wednesday, at 7:30 p.m., at the BOCES Center, LARC also provides sitting services for Parents of the Handicapped. Throughout the month, bingo, hiking trips, a picnic for children and one with music for adults was scheduled.

## SMITHTOWN JUNIORS

Hi. Warm weather is finally here. We hope it's here to stay because, before you know it, our camping season will begin. We're all really looking forward to it.

We have had a lot of functions lately. We had a dance at Bohemia. It was a really good dance and everyone had fun. We also had a teen center at Kings Park High School in March. There were a lot of people and we all had a good time.

We spoke at Kings Park Junior High about our auxiliary and our friends. We know it really made an impression because, at our next general meeting, there were 15 new members from the Junior High.

We are also painting at the hospital. We started a while ago and we are almost finished. It really looks nice and the colors are bright and cheerful.

We also got some tickets to see Garry Lewis at Smithtown West High School. Everyone really liked it.

We went to see Kings Park Junior High's performance of Peter Pan. We took some of our young friends, who really enjoyed it.

We still have our weekly gym program at Kings Park Hospital every Tuesday, and it's great! Anyone can come down and join us.

On Wednesdays we all go ice skating. This is a really great program and we really hope to continue it.

We had a small speaking engagement at a religion class from St. Joseph's Church. We hope to gain some new members from it.

We had a Special Olympics orientation and a large group of people from our auxiliary plan to attend the olympics.

## NORTHPORT JUNIORS REORGANIZE

The Northport Junior Auxiliary is currently re-organizing. New officers include: Annie Murphy, president; Mareanne Dirr, vice president; Karen Walker, secretary; and Katherine Caderberg, treasurer. Past activities have included dances and bread baking classes for special friends.

Anyone interested in being placed on their mailing list may call Annie Murphy, 757-3197, (516).

The group also needs a permanent advisor.

Call Annie (516) 757-3197.

## BRENTWOOD JUNIORS

The Brentwood Juniors held a Spring dance in the AHRC Bohemia multi-purpose room. We invited our friends at the Bohemia AHRC workshop. There was a very good turn-out. We danced to the music of "Free Parking;" ate many goodies and had a terrific time. We invited the instructors from the AHRC day treatment program. They gave us their support and assistance by their attendance. In particular, our auxiliary would like to thank: Judy Gallagher, Bonnie Moran, Karen Gordon and JoAnne McEnroy. Our chairlady (and newest member), Donna Zattergren, is to be commended for a fine job.

Four of our members have been teaching Special Education Confraternity. We train our friends in Baptism, Communion and Confirmation. More teachers are constantly needed. Anyone interested can contact Tim Sweetie at (566) 273-8882. The classes are held at St. Luke's R.C. Church on Saturday mornings from 10-11 a.m.

Brentwood Junior Auxiliary would like to take this time to give our "Best Wishes" to two new groups, Smithtown West and Connetquot. We welcome the opportunity to work with them in the future and assist them in any way possible.

## West Seneca on N.Y.C. visit



On their recent visit to New York City, officers of the West Seneca YOUTH group stopped by State Office to tell Mr. Weingold how much they enjoy reading OCV. Left to right: Robinne Axelrod, Corresponding Secretary; Mr. Weingold, and Lisa Nachbar, President.

## SUFFOLK COUNTY YOUTH

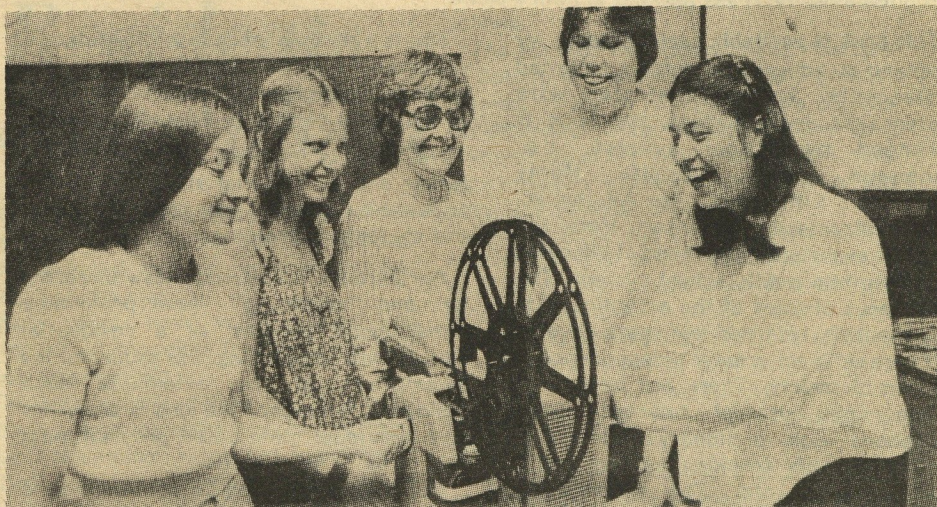
The Association's YOUTH council welcomes Smithtown West Junior Auxiliary. At a recent meeting of the new group, Jacquie Rice was elected President and Lauren Zambrelli Vice President.

Already in action, Smithtown West held two successful bake sales and have planned many activities for their special friends. Any of our readers who wish to have their son or daughter placed on

Smithtown West's mailing list, please call Jacquie Rice at 979-7010 (516).

The council also welcomes (belatedly) two new advisors, Lorraine Guadagno and Charles Weidig. Lorraine, Brentwood advisor, is a guidance counselor from St. John the Baptist High School. Charles, co-advisor for Smithtown juniors, is a teacher at Kings Park Junior High.

Thank you for giving your time and energy to these two outstanding groups.



## Hudson Falls Y.O.U.T.H.

Members of the YOUTH Association for Retarded Children of the Hudson Falls Senior High School check over a new movie projector purchased through fund raising activities by the group for the use by Warren-Washington Counties Chapter of the A.R.C. Pictures left to right are: Sheri Jones, Mary Livingston, Marion Doyle, Beth Stanton and Robin Waite.



## Schenectady complimented

Dear Ms. Sherwood:

Kathy Anderson and Laurie Allgaier gave a presentation on mental retardation to my health classes. Their knowledge, poise and insight created an immediate rapport with the students.

The presentation was well planned. A slide presentation was used in conjunction with lecture, discussion and class involvement.

I have been a teacher for ten years and have never seen a lesson taught better. Our heartfelt thanks to Kathy and Laurie for being the warm, caring individuals they are.

Sincerely,  
Mr. Peter Nardiello,  
Health Teacher  
Mohonasen Central Schools —  
High School  
2072 Curry Road  
Schenectady, N.Y. 12303

## Letter

LETTER TO Y.O.U.T.H.  
(an excerpt)

... It is my feeling that you young people enrich and bless so many lives now and will continue to do so in the future.

You have inspired me when I have needed it most, when I have needed to know others do care — and care deeply.

My heartfelt thanks to each and every one of Y.O.U.T.H. — ARC's members and to their advisors.

Love and best wishes always.

Ruth J. Brewer  
(parent and former  
advisor of Chemung Co.  
YOUTH ARC)



Pictured from left to right: David Hazer, Wendy Belter, Bill Hogg and Mr. G. Schroeder.

## Lynn Schroeder finds rewards in helping the retarded

Last Fall, one of the original founders of West Seneca Developmental Center YOUTH — ARC Group, Lynn Schroeder, volunteered to teach crafts to mentally retarded adults throughout the Kenmore, Town of Tonawanda School District Adult Education Program.

This project now seems to have blossomed into a career commitment: Ms. Schroeder is employed as a full-time aide at the United Cerebral Palsy Center; she has embarked on a one-person campaign to upgrade recreational activities for the retarded; and has managed to spark community awareness and acceptance of the retarded.

Her evening course, which enrolls 11 students ranging in age from 15 to 71, has its roots in her belief that handicapped adults need not be left to depend on the television tube for their recreation.

The highlight of one session was a recent trip to the Sheridan Drive-Eggert bakery operated by her well-known bakery family.

Her father, Rudy Schroeder, lent a helping hand as the students, who have a range of disabilities, tried their hand at decorating cakes and making bread.

## Zoning bill in

Continued from Page 1

to the municipality to fool around with the matter.

As reported elsewhere in this issue of the newspaper, 11 other states have either eliminated or limited the zoning ordinance, but none has so restricted the time element for decision by the municipality.

The feedback we get from the Legislature is that the tactics of the Department of Mental Hygiene in "dumping" mentally ill persons has so aroused communities that it has spilled over to the field of mental retardation and we are the victims of these actions. The excuse for this kind of legislation, as given by the administration, is that we must involve the communities in developing these group homes. It is the opinion of this Association, however, that all zoning is an infringement on the absolute rights of the mentally retarded and the Fourteenth Amendment for equal protection under the law, and a violation of the anti-discrimination laws of this state itself in legislation passed by Senator Flynn in 1976.

Nevertheless, we must live with this and we will try to do so.

For most of them the special field trip was their first visit to a bakery operation and a chance to be out in the public eye.

Becky Wasinsky, who at 15 is the youngest member of the class, typified the group's excitement when she whispered to her teacher how happy she was and how she hoped she would do well.

Each student worked on the designs for the cakes they took home and jointly decorated two half sheet cakes which were displayed Friday at the Very Special Arts Festival at the Learning Lab of Buffalo State College.

The flowers and patterns on the cakes may not be perfect. The lines may be crooked. But, that doesn't bother the teacher who has developed her own knack for cake decorating, having worked in her family's bakery since she was 14.

"One thing I stress," Ms. Schroeder said, "is individuality. If it doesn't turn out the way its supposed to, I don't care."

Ms. Schroeder, who plans the crafts and gets them started before each class, credits her family, friends and Traverse' Blvd. neighbors for their support with fund raising, as well as collecting empty jars, cans, bottle caps and scrap materials for the crafts.

One of her biggest worries has been to fund the activities since the students only pay for part of the actual cost. The Master Mason Clown Association and other area community groups have come through with donations to keep the class going for two semesters.

Whether it continues in the future will depend on how successful Ms. Schroeder is with fund raising projects planned for this summer.

Most of the minimal pay she received for teaching the class (the state requires she be paid) goes back into it.

Ms. Schroeder's sensitivity to the world of the handicapped stems from her growing up with a younger brother who was mildly afflicted with cerebral palsy.

"The therapists used to come to the house and I was so amazed at what they could do. When I got to Herbert Hoover Junior High School, I became involved in the special education program and started to get a feel for it."

What followed were summers of volunteer work and a realization that her gift was to work with the handicapped.

YOUTH — ARC State Board salutes Lynn for her efforts on behalf of the retarded and takes pride in her accomplishments as one of our outstanding YOUTH — ARC members.

## North Country Y.O.U.T.H. formed



Mildred Giroux, Chairman, Committee for Volunteers, is shown with Geraldine Sherwood, Program Coordinator, of the New York State A.R.C., during her visit to discuss formation of a YOUTH-ARC in St. Lawrence County.

## W. Seneca D.C. Choral Group at press conference



Pictured left to right, Mayor Griffin presents awards for participation in Very Special Arts Festival to Roger LaBarbera, Joe Byron, Ann Trillizio. Chorus Director Mrs. Deborah McElwain looks on.

## Hyman Forstenzer dies

The Association noted with regret the recent passing of our long time friend, Hyman Forstenzer. Hy began his career

with the Department of Mental Hygiene in 1950 as education director of the State Mental Health Commission and advanced to assistant director of the commission in 1952. Two years later he was named assistant director of the department's division of community services and in 1958 was named its director.

In 1961 he was appointed coordinator of the mental health programs and later became assistant commissioner for mental health resources and policy planning, a post he held until his appointment as second deputy commissioner in 1966.

After his retirement from the department in 1973, he served as an assistant professor of psychiatry at New York Medical College.

In 1969 he received the Charles Evans Hughes Award from the American Society for Public Administration in Albany for outstanding public achievement.

Executive Director Joseph T. Weingold stated, "We will long remember Hy for his courage, and for the many hours we spent working for the mentally retarded of New York State."

## YOUTH at regional meet



Schenectady Chapter hosted Northeast Regional Meeting. Standing: Suzanne Crane, Sue Hotaling, Marie Hotaling, Mim Millar, Mary Reardon, Dave Lewis, Chapter Board Member. Seated: Laurie Allgaier, Liz Valachovic, Kathy Anderson.

# Ulster, Columbia lose execs to OMR - DD

The ranks of our local Executive Directors in the State were swiftly thinned when Joe Ryan, Executive Director of our Ulster County Chapter and Jan Wheeler, Executive Director of Columbia County Chapter both announced their resignations to join the staff of the Office of Mental, Retardation and Developmental Disabilities (OMR-DD).

Jan assumed a position as Community Residence and Placement Specialist with OMR-DD in the Central Region of the State effective May 11th. A new Jersey native, Jan had taught English at Hudson High School for a year before joining the ARC as a teacher at a pre-school program. She became executive Director of Columbia in June 1974 and served in that capacity during a tremendous period of expansion of the Chapter. Under her leadership, the number of clients in her program increased from 70-200, and 3 hostels and a supportive living apartment were also started under her direction. Very active in the Executive Directors Association, Jan had been the Vice President for her region at the time of her resignation.

Those who have known her in the ARC, know that her abilities will be thoroughly missed throughout the Association. Some indication of this was the Testimonial Dinner given for her by the Chapter attended by more than 100 persons.

We wish Jan well in her new position, and must say that we have already found her presence most helpful in working with Chapters in her new area. Mr. David Van Denburgh is Acting Executive Director during the Chapter's search for a replacement.

## JOE RYAN LEAVES ULSTER

Joe Ryan Executive Director of Ulster County Chapter for just about 6 years w

Joe Ryan was Executive Director of Ulster County Chapter for just about 6 years, having become the Exec in July, 1972. He will be leaving Ulster County Chapter to assume the position of Deputy Director of the Western County Services Groups of the New York State OMR-DD. Working under Richard Mercus, former Director of Wassaia Developmental Center, Joe will be reunited with an individual with whom we worked very closely in the past.

In his new position, Joe will be responsible for licensing, certification and improvement of services for 17 Western-most counties in New York State.

Also seen as one of the very active and capable Executive Directors, Joe pointed out upon his leaving, that among the things which have happened during this time at Ulster County Chapter, was the increase of clients in the sheltered workshop from 20 to 200 people. What had previously been only a Kingston Agency now has programs operating in Kingston, Ellenville and Saugerties.

Although his resignation came on rather short-notice, his staff, showing their good training under his leadership, was able to stage a surprise luncheon in his honor on Friday, April 21st and a dinner was held in his honor by the Chapter even after his new employment had begun on May 21st. Finally, a Staff Recognition Day was held for him on June 17th. Peter Pierri, Director of Special Services, will be Acting Executive Director for Ulster County Chapter.

Perhaps, Joe said it as well as one can in his final "Open Letter to the ARC." A few excerpts are reported here.

"It has been just a little under six years since the day in July, 1972 when I reported for work as a brand new employee of the Ulster ARC. On that day, some of you were already 'veterans' and others were still to join the ranks. Today we are all veterans,

and together have built one of the finest Agencies in New York State. We have managed to dramatically expand services to meet the need while not compromising on quality. We have improved the quality of life for everyone in Ulster County

By the time you read this letter, I will be working in Albany. By then, a new Executive Director may be anticipating his first day as an employee of the Ulster ARC. His experience of that day will be different from mine because the Agency is different. It will also be the same. He will join with the competent, seasoned veterans. He will receive the support, ideas and vitality which make this Agency one of the finest. He will feel the pride, as I do, which comes from being associated with outstanding people who are part of something good."

## Ed. Comm. brochure

### featured by HEW

HEW's publication, Programs for the Handicapped, features Your Right to Your Rights in Education in the June issue.

Betty Pendler is the Chairperson of New York State Association for Retarded Children's Education Committee, which prepared and published Your Right to Your Rights in Education, a handbook for parents of handicapped children.

## Vocational Rehabilitation bills - continued from page 1

Governor's office, which came down at 7:00 p.m. and reached the desk of the Senate at midnight, sped the passage of the bill at 3:00 a.m. the following morning.

### SELLING TO GOVERNMENT EXPANDED

Another bill that may affect the contracts of the rehabilitation agencies in the state is the bill adding services to products manufactured by the blind and other severely handicapped offered for sale to state governmental agencies, political subdivision of public benefit corporations, by charitable, non-profit making agencies.

This is a counterpart to the Javits-Wagner O'Day Act in the Congress, passed through the efforts of this Association with Senator Javits. It opens up the possibility of selling products or services to governmental agencies by handicapped other than the blind, who were the most favored group at one time. In this bill, the General Services Commissioner is mandated to determine the price of products and services offered to the government. The program is administered through the New

## Statewide permits for parking

A new New York State law has established universal parking permits for handicapped persons. They are to be issued by the Commissioner of Motor Vehicles and distributed by the local governments of the town or city where the individual applying for them lives. They are valid any place in New York State which has reserved public parking places designated for the handicapped.

The permits are in the form of cards that can be placed in the windshield or on the sunvisor.

As we understand the law, the handicapped person applying for the permit does not necessarily have to be the driver — the permit can be for a car that transports the handicapped person, even if driven by someone else.



Legislative Messenger Service: Standing (left to right) Lous Russo, director, Joseph O'Connor, Ben Lawson, Bob Pollick, Rick McDonald, Senator Conklin, Peers Beardsley, Frank Rotundo, William Gerard, Barbara Zelker. Seated (left to right) Gerald Gravelle, David Jenkins, Marie Vitelli, Anne Berry, Kathryn Gregorie.

## Handicapped messengers in Legislature

One of the first to demonstrate that the retarded can be helped to work was the Legislature of the State of New York which instituted a program of employing the mentally retarded and other handicapped to the Legislature Messenger Service Program.

Last year, the Legislature adopted a resolution saluting these young men and women and honoring the ten messengers who are regular employees of the Legislature.

"These young people," said Senator Conklin, "who instituted this program with Lou Russo, head of the Senate Printing Service, are among the most dedicated

employees of the state. Their attendance is the highest and we, in the Senate, benefit everyday from their loyalty, competence and cheerfulness. They provide a much needed service to all of us, and they do so with efficiency and enthusiasm."

Mr. Louis Russo, the director of the program, added that the messenger staff has more than tripled in size from its original group of three in 1974 and the number of jobs completed has jumped from 1700 since 1974 to 18,000 in 1977.

We, too, salute the Legislature and the handicapped employees that prove that they are not handicapped in any real sense of the word.

York State Industries for the Severely Handicapped and its benefits are open to all workshops. The bill was introduced by Senator William T. Conklin and Assemblyman Mega. The bill passed was A. 8356A — Mega.

Since the Legislature is in recess, it may well be these are 10 day bills and we anticipate, by the time this is seen by our readers, the Governor will have signed them as he promised to do at a breakfast of the United Cerebral Palsy Association held in Albany earlier this year.

### OTHER BILLS

Other bills are still in the pipeline with some hope of passage. These are:

— bill to relieve parents who incurred liability to the Department of Mental Hygiene before August 5, 1977, when Governor Carey relieved parents of future liability from obligation to pay (A. 9988A Kremer). The Senate bill introduced by Senator Padavan has passed and the Kremer bill is on third reading as of this date.

— bill to make interest on mortgages and money borrowed to finance the state while it delays its payment as a reim-

bursable item (S. 8123 Marino; A. 10531 Kremer). Both are in the Finance and Ways and Means Committees waiting until the supplemental budget is passed. This is a bill that was vetoed twice by the Governor, but which he certainly promised to sign if passed this year.

— bill to create a demonstration project for in-home care for mentally retarded persons living at home who have not been institutionalized (A. 12309 Connelly) which is in Ways and Means. This is a compromise with the Conklin bill, making the families of mentally retarded persons, not institutionalized, eligible for family care reimbursement as are families who take their children out of the institution.

— 3 bills dealing with education. These are a bill to repeal that part of the Education Law which prohibits transportation by public schools to public school classes of children residing in institutions operated by the state. This prohibition slipped into Chapter 853 of the Laws of 1976 and should be eliminated so this transportation can be provided for these children no matter where they reside. It is S. 8171 LaValle, which passed the Senate, and A. 10610 Virgilio, which is in Ways and Means.

The second bill is the bill to increase the number of parents on Committees on the Handicapped and to make the impartial hearing officer really impartial by giving the parent a voice in choosing such an officer. This is A. 12982 Virgilio, and introduced in the Senate by Senator Nolan. It has not come out of the Education Committees.

Finally, a bill to permit the school district to transport those over 21 to rehabilitation facilities, S. 452 LaValle, which is still in the Education Committee, and A. 6900 Eve, Ways and Means.

There is little doubt, at this time, reading Budget and the Governor's intentions, that the bill to increase state aid for community services for the mentally retarded from 50 percent to 75 percent will fail.

## Onondaga Coughlin heads awards dinner

Members and friends of the Onondaga ARC put a hard year behind them and gathered together for an evening of fun and celebration to honor several community leaders and organizations for their extraordinary support of the Chapter.

Commissioner Thomas A. Coughlin III, head of the State Office of Mental Retardation and Developmental Disabilities, was the principal award recipient and guest speaker at the Chapter's Recognition Dinner held June 16th at the Syracuse Marriott Inn Ballroom.

Dr. Herbert Schneiderman, President, presented the Commissioner with a handsome walnut plaque in the shape of New York State, with a brass inscription citing his "outstanding achievements and inspiring leadership." "I Love New York!" said Coughlin with a grin as he held the plaque aloft.

Sharing in the limelight with the Commissioner were ten others:

- John F. X. Mannion, President of Unity Mutual Life Insurance Company, honored for generosity and leadership in spearheading the Company's efforts sponsoring three benefit tennis tournaments. The trio of popular sports events raised \$12,000.
- The Center on Human Policy at Syracuse University was recognized for exceptional leadership in advocacy and public education. Dr. Douglas Biklen, Director, was applauded for his strong commitment and guidance.
- Mario Rossi, Night Editor of the Syracuse Herald-Journal and widely read columnist, won a plaque for his support of the Chapter's community education program.
- Mary Carol Fisher, the new President of Friends of Retarded, accepted an award for this hard-working organization. The "Friends" are noted for their benefit fund raisers and have raised tens of thousands of dollars since 1970.
- Louis J. Latore was singled out for outstanding design work. Lou, Vice President of Crawford Advertising in

Syracuse, donated his services to create the newsletter banner, "Patterns" and the Monarch Industry logo and letterhead.

- Russell S. Andrews, immediate Past President, was thanked for his services and extraordinary efforts. Russ acted as Master of Ceremonies at the dinner.
- On behalf of the Bingo Committee, Judy and Gordon Eyer accepted an award for hours and hours of time and superb organizational skills in raising funds for the agency's programs. Bingo, the biggest moneymaker of all, has brought in well over \$100,000 in recent years.
- David Mealy, Director of Educational Services, was saluted for his ability and dedication when he served as Acting Director of the agency from September 1977 to March 1978.
- Staff members who achieved the hallmark of ten years or more of service with Onondaga ARC were honored. They were: teachers Nancy Naramore, Dottie Gotham, Beryl Johnson and Gee Gee Drysdale, Gwen Gary, social worker; nurse Carol Gridley and Susan Morse, public relations director.

A special 1977-78 President's Award was given to Dr. Herbert Schneiderman by Russell Andrews.

## One to One aids ARC for HUD project

Once again One-To-One has come to the aid of the State Association by helping to fund part of the expenses for implementing the HUD grant.

We received notification that One-To-One is making a grant of \$5000 to help meet interim expenses for the implementation of the grant. Such expenses will cover some of the costs of travel and rent.

The Association is deeply grateful to One-To-One for its understanding and help.

## State Parks Commission employs mentally retarded

Under the Reorganization Law effective April 1, 1978 each community services board will have "separate subcommittees for mental health, mental retardation and developmental disabilities. . ."

It further states that each separate subcommittee shall be composed of persons who have demonstrated an interest in the field of services for the particular class of mentally disabled and shall include former patients, parents or relatives of such mentally disabled persons and community agencies serving the particular class of mentally disabled."

This mandate has been widely distributed to all the chapters of the ARC some of whom are having difficulty in making their community service board and/or the Legislatures understand this mandate.

All chapters are urged immediately to bring to the attention of their Legislator and to their community service boards (formerly community mental health boards) this mandate.

If there is any trouble concerning this, please communicate with the New York State Office of the ARC.

## ARC reps mandated on community service subcommittees

The New York State Parks and Recreation Commission, which produced the "Employer of the Year" in 1976 via the Genesee State Park Commission, is once again making preparation to hire mentally retarded persons. Training sessions are being held for their supervisory personnel in Rockland County, and the State Association was pleased to be able to assist in this effort.

A long-time State Board Member, Jim Maroon, of Rockland County, who has worked in the parks over many summers, called the State Office to tell us that these sessions were taking place. The State

Office quickly sent out brochures entitled "So You're Going to Supervise a Mentally Retarded Employee" and "So You're Going to Hire a Mentally Retarded Employee" and the film, "Selling One Guy Named Larry".

Jim called to tell us that the response was most enthusiastic, that he had been invited to speak to three separate groups of supervisors on the mentally retarded, and that the material was most helpful.

We hope this effort will in some way help provide more jobs for the mentally retarded in the community, and we thank Jim for calling this to our attention.

## Lexington D.C.

## Blowing ones' own horn

"The main drive of the Town Developmental Center is to get mentally retarded people back into the community," David Cummings, a social worker for the center, told Lion Club members recently at the YMCA.

Cummings, a former Gloversville resident, said that mental retardation is often something that is misinterpreted and feared. He pointed out that, many times, families will allow a family member to be put into a facility and then "forget" them. This can be a traumatic experience, he added.

Much has been done to bring these mentally retarded persons, who are determined as being such because of subaverage intelligence and impaired adaptive behavior, back into the community, Cummings said.

"Lexington Center offers the finest day program in the state for these people," he added.

Cummings stated that many local physicians are also dealing with the problems of the mentally retarded in different ways.

The ultimate goal at Wilton is to increase family and parental involvement and to provide residential settings for the retarded.

The center is constantly in the process of trying to find family care homes for its clients, Cummings said. These homes can be any private residence, and a person taking a client need not be married. Those taking a client are interviewed, and the home is inspected for such things as potential fire hazards.

If adjustment is successful at a private home, then the client is moved to a larger group home, three of which exist in Fulton County. Eight to twelve persons are generally housed in each group home.

Cummings pointed out, that in 1971, there were 2,300 clients living in 700 family care homes state-wide. Since that time, the number of retarded persons living in private homes has increased to 5,000 and the homes themselves now total 1,700.

He noted that the former Bishop Burke School is the site of a Day Training Program. Sponsored by the State Department of Mental Hygiene and operated by Lexington Center, the Day Training Program will serve 60 retarded persons, including 40 from Wilton and another 20 who will eventually live in a community residence.

Cummings said that Wilton Center serves Warren, Washington, Montgomery and Saratoga Counties as well as Fulton County. He added that it offers 24-hour service.

Cummings noted that the center works towards a partnership with community resources in order to develop a comprehensive community-wide response to the needs of the mentally retarded, provide each retarded person with needed specialized services in the least restrictive setting that can meet his current needs and provide care and rehabilitation when needed throughout the life span of each retarded individual. The center also supports efforts for prevention, early identification and therapeutic intervention of developmental disabilities.

## Handicapped in Head Start

Thirteen percent of the children enrolled in full-year Head Start programs during the 1976-77 school term were handicapped, said a recently released HEW report.

It was the third consecutive school year in which enrollment of the handicapped exceeded a 1972 Congressional mandate that 10 percent of Head Start's national enrollment consist of handicapped children. Handicapped children accounted for 10.2 percent of the enrollment in 1975, and 12.2 percent in 1976.

Compiled by the Administration for Children, Youth and Families of HEW's Office of Human Development Services, the report was submitted to Congress by HEW Secretary Joseph A. Califano, Jr. The report was based on responses to questionnaires covering 89 percent of Head Start programs and on telephone interviews with selected program officials.

The report also shows that all states except California and the District of Columbia are now meeting the 10 percent enrollment requirement which Congress imposed on individual states in 1974.

The survey found that handicapped children were enrolled in 91 percent of all Head Start programs and in 84 percent of Head Start classrooms.

The Placement of handicapped children in regular Head Start classrooms has required special training of Head Start staff and extensive work with outside

agencies and associations serving handicapped children. The effort has also included funding — in cooperation with the Bureau of Education for the Handicapped in the Office of Education — 14 technical assistance centers which help Head Start programs meet the special needs of handicapped children.

The distribution of children by handicap was approximately: 50 percent speech impaired; 14 percent health impaired; 7 percent physically handicapped; 7 percent seriously emotionally disturbed; 6 percent mentally retarded; 5 percent specific learning disability; 4 percent hearing impaired; 4 percent visually impaired; .4 percent deaf; and .4 percent blind. The report noted that the percentage of speech-impaired children was consistent with national estimates of all children with that condition.

The report also said that a recent study of 269 children with representative handicapping conditions from 59 Head Start programs found that 92 percent of the children spent nearly all their time in groups with their non-handicapped peers.

"Both groups benefit most from being together on a regular basis during the years when their attitudes and perceptions of themselves are most pliable," the report noted.

According to the report, there are an estimated 190,000 handicapped children aged 3-5 from low-income families who are potentially eligible for Head Start.



Do it!  
Register  
TODAY.

# CONVENTION

## Register Here

## PROGRAM

TO: Monroe County Chapter, A.R.C.

Al Sigi Center

100 Elmwood Avenue

Rochester, N.Y. 14620

ATTN: Mrs. Evelyn Anderson, Registration Chairperson

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

Registration \$8

Tour (please indicate:) \$2

A. Al Sigi Center

B. Monroe Dev. Ctr.

Luncheon \$8

Dinner \$12\*

Total \$

\*Dinner will be \$14, if not pre-registered.

Name

Address

Phone

TO: Holiday Inn

120 Main Street East

Rochester, N.Y. 14604

Gentlemen:

Please reserve the following accommodations for me for the Convention of the New York State A.R.C., October, 1978.

Single at \$27

Twin at \$33

Date of arrival Departure

Name

Address

### STATE CONVENTION

OCTOBER 26-29, 1978

### LINKED TOGETHER IN A COMMON CAUSE

#### Thursday, October 26th

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

#### Friday, October 27th

9 a.m. all day — Registration — Convention and YOUTH  
9 a.m. - 1 p.m. — Meeting of Board of Governors continues  
10:30 a.m. — YOUTH Conference begins  
11:30-12:30 p.m. — YOUTH Luncheon  
12:30-4:30 p.m. — YOUTH Conference continues  
1:00-2:00 p.m. — Lunch (open)  
1:30 p.m. — Tours (\$2.00)  
A. Al Sigi Center  
B. Monroe Developmental Center  
2:30-5:30 p.m. — Meeting of Chapter Officers and Executive Directors  
5:00-6:30 p.m. — YOUTH Dinner  
6:30-10:30 p.m. — YOUTH Meetings continue  
6:00 p.m. — Dinner (open)  
8:00 p.m. — Convention convenes

#### Saturday, October 28th

7:30-8:30 a.m. — YOUTH Breakfast  
8:30-11:30 a.m. — YOUTH meetings continue  
9:00 a.m. - 5:00 p.m. — Registration  
9:00 a.m. - 12:30 p.m. — Business Session Continues  
12:30 p.m. - 2:00 p.m. — Luncheon — Everyone  
Hosted by YOUTH (\$8.00)  
2:00-5:00 p.m. — Workshops — These workshops will be run twice. 2-3:30 and 3:30-5:00.  
1. Community Residences — Anne Kraus, Chairperson  
2. Institutions — Karin Burgess, Chairperson  
3. Human Sexuality and the Retarded — Becky Marks, Chairperson.  
These workshops will be done once only, from 2-4 p.m.  
4. Education — Betty Pendler, Chairperson  
5. Subchapter C and Medicaid — Michael Goldfarb, Chairperson.  
2:00-5:30 p.m. — YOUTH Workshops  
6-7:00 p.m. — Reception  
7:00 p.m. — Banquet (\$12.00)  
10:00 p.m. — Dancing

#### Sunday, October 29th

9:00 p.m. - 12 noon — Meeting of the Newly Elected Board  
9-11:00 a.m. — Meeting of YOUTH BOARD.

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

175 Fifth Avenue

New York, New York 10010

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Retarded Children Can Be Helped

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