

# Our Children's Voice

Retarded Children Can Be Helped

Vol. XXIX No. 1

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

January 1977



## Retarded children CAN be helped

More than 600,000 mentally retarded persons in NY State are getting help from us:

- research
- diagnosis
- clinics
- treatment
- early intervention
- schools for severely retarded
- vocational rehabilitation
- community residences
- camps and recreation
- guardianship
- legal advocacy

Now we need your help in directing bequests and trusts to:

New York State Association for Retarded Children, Inc.

And, for your clients who must provide for the welfare of their own retarded children, please write for our valuable booklet, "Wills and Trusts for Parents of Retarded Children."

The more you know about retarded children, the more you know what your help can mean.

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN  
175 FIFTH AVE. • NEW YORK, N.Y. 10010

## ARC launches lawyer appeal

In a series of ads appearing in the New York Law Journal, The Association appeals to lawyers throughout the state for consideration of the Association when they plan estates for their clients.

The ad will appear in 14 issues of the New York Law Journal (it has already appeared twice) and will reach 40,000 lawyers each time.

## 1977 Legislative Program

### Separate office, zoning, priorities

#### SEPARATE OFFICE FOR M.R. AND D.D. HIGHEST PRIORITY

Reaffirming the position of the State Association on legislation, a part of its program for a number of years and adding some new facets, the State Association adopted a new Legislative Program ranging from the establishment of an Office of Mental Retardation and Developmental Disabilities in the Executive Department (first priority) to provision for public hearings by Community Mental Health Boards on proposed programs before submission to the Commissioner of Mental Hygiene... to mandatory education for the handicapped from 3 to 21 and a total revision of the Social Services Law with regard to reimbursement for fees in the private institutions serving retarded adults.

The full program includes:

#### A. State Institutions and Services

1. Establishment of an Office of Mental Retardation in the Executive Department.
2. Elimination of parental liability for fees for children under 21 years of age in the institutions operated by the Department of Mental Hygiene.

#### B. Community Mental Health Services

1. Reimbursement to communities by

the state at the rate of 75 per cent for mental retardation services provided locally.

2. Provision that interest on any mortgage for the acquisition, construction or remodelling of a facility to serve the mentally retarded be a reimbursable expense under contracts with Mental Health Boards.

3. Provision that net, rather than gross, income realized in the operation of specific programs be deducted from operating costs under Mental Health Board contracts.

4. Provision that Community Mental Health Boards must hold public hearings on their proposed programs at least 30 days before submitting them to the Commissioner of Mental Hygiene.

#### C. Education

1. Provision that education of the handicapped by mandatory from age 3 to age 21.

2. Provision that school districts be permitted to transport persons over 21 years of age to and from rehabilitation facilities without state aid.

#### D. Social Services

Under the Social Services Law, the state pays for mentally retarded adults in

retarded persons of New York State, and that this Association strongly urges Craig Developmental Center, the Finger Lakes Regional Office and the Department of Mental Hygiene to commit without reserve, its resources to the immediate development of Community Residences, so that there will be no need for the expansion of the Department's institutional efforts to accomplish repatriation.

Whereas, the Department of Mental Hygiene has developed a plan to transfer King's Park Mental Retardation Unit Willowbrook Decree residents to the Suffolk Developmental Center (Suffolk State School) and from Wassaic Developmental Center to Harlem Valley Psychiatric Center, it is therefore

Resolved, that the New York State Association for Retarded Children urgently condemn and oppose any and all arbitrary, capricious and frequent shunting about of residents from institutions in total disregard of their human needs and dignity, and in further dislocation and deprivation of their lives and it is further

Resolved, that NYSARC re-affirm its opposition to these practices wherever they may occur throughout the State.

The next Convention, 1977, will be held at the famous Grossinger Hotel in Sullivan County.



Elliot Aronin swearing in George Hirsch, President, at the Convention Banquet.

### Inside

Sermon In Seville	2
Convention pictures	3
ARC and Advocacy	4
Education Law Summary	5
Chapter News	16
Special Feature	
The Retarded in Fiction	12-13-14
YOUTH News	19
Foster Grandparents	20
ARC Christmas Winners	21
Education Committee	23
THE HEIMLICH MANEUVER	24

(Continued on Page 21)

# ~~ Sermon In Seville ~~

## EIGHTH INTERNATIONAL SYMPOSIUM ON MENTAL RETARDATION SEVILLE, SPAIN, MARCH 1975

By Joseph T. Weingold

When asked to speak on the topic "The Adult Mentally Retarded Consumer", my first reaction was how limiting this topic is. After reviewing the whole program I have the feeling that we are fragmentizing the mentally retarded person into bits and pieces, concentrating now and again on one part of him, neglecting the whole person, as a human being, an integral part of society.

Furthermore, I am wondering to whom we are speaking. Are we indeed listening to the sound of one hand clapping? Are we marching to the music of an individual drum for each of us? Are my eyes your eyes?

And if such are my difficulties with you, a knowledgeable and sympathetic audience, what of society? In what light are we presenting the mentally retarded individual, child or adult, to society? Are we stressing his disabilities rather than his abilities? I have the feeling over and over again that we have not come very far from 1950 when I was the speaker at the first banquet of the National Association for Retarded Children, as it was then called, when I ended my talk with the statement "Although there is some doubt as to how much we can change the retarded for the world's sake, there is no doubt how much we must change the world for the retarded's sake."

How far, indeed, have we come? Have we fought our way out of the dark secret place, cradling this different human being in our arms, holding him close to us year after year, gradually exposing him to a world whose values are so inimical to him?

All our efforts seem to be along the road of changing him for the world's sake, making him a consumer, integrating him into the community, talking to each other, listening to the echoes of our own voices.

But who has delivered the world from its secret dark place that we stand here today and speak of legal rights — social barriers — professional attitudes — for whom, towards whom?

We are all falling into the terrible trap of the procrustean bed. All of us seem to be engaged, as I have viewed this whole movement over the years, in the process of cutting off the mentally retarded person's legs to make him fit into the bed of society.

To speak of the mentally retarded adult as a consumer is to misunderstand his place in society. It perpetuates a stereotype of the mentally retarded as a dependent perpetual taker. It would be more appropriate for us to speak of the mentally retarded adult as a contributor and user, rather, as most of them are, than consumer which may have a pejorative interpretation when spoken of the mentally retarded.

In the United States alone there are some 6 million mentally retarded persons. Of these more than half are adults. And of these 3 million, only about 100,000 adults are in institutions. The rest are in the community.

If we discount the contributions the mentally retarded adult makes to the institutional community, which is very considerable, perhaps we could describe him or her as a consumer on a very limited basis in the sense he or she is receiving services not ordinarily supplied to the general population.

But, what of those in the community? What of those who are working, married, hold jobs, are in sheltered workshops or other daily activities? These we must treat as contributors and users and not as consumers. And what of the severely retarded adult? Do we need to fit him also into this procrustean bed that he must be a

consumer in the ordinary sense of the word? Or does he have rights on our society to supply him with his needs. Are the words "We measure society by what it does for those who need the most" merely empty rhetoric? If not, then we must stop looking at stereotypes and concentrate on the world in relation to the mentally retarded as well as the mentally retarded in relation to the world.

Is it not a puzzle, a curious dilemma, that although most of this large population, whom we call mentally retarded, is integrated in some way into our economy and yet is not generally accepted as part of it.

This is an enigma that we must try to solve. The enigma is: when are persons not persons? The enigma is: how can a person be a part of society, an integral part of society, and yet be considered something less?

The answers must be found in the shibboleths that have been built up around mental retardation over hundreds of years and in the tremendous pendulum swings that society has gone through in its attitude towards the retarded, from Plato's admonition that we should take them into some secret dark place, to the great hope of Itard and the wild boy of Aveyron, to the pity of the religious orders, to Seguin's belief that education would take care of everything, to the nightmarish genetic alarm of the early 20th century, coming round finally to today with our theories of integration, "normalization" and all the other catch phrases which gloss over differences and the outstanding fact there must be a manipulation of society as great as that of the mentally retarded.

Perhaps some of the blame for this must go to the parents themselves who, although in a fabulous operation bootstrap made their adult retarded stand up before society and society count him in some way, still want to "normalize" this retarded person. The fact is that we are denigrating the retarded by speaking of normalization. We must beware of later day ideologies and catch phrases. Normalization implies that they are now something less than normal, whatever that is, and we must "normalize" them in some way, whatever that means.

The fact is that we must talk of humanizing, of treating them as human beings, in fact, of humanizing society. We must talk of the mentally retarded as human beings with all the rights, privileges, needs, demands that all human beings have in our world, in fact, with more, because their needs are greater. So we must humanize, not normalize, but the humanization must be of society as well as the retarded.

In this concept, perhaps, we can view him as a contributing member of society, as someone who is worthwhile and for whom the investment of time and effort will repay us a thousand fold.

I need not quote to you here statistics of how well the mentally retarded do on various jobs. This is patronizing. I need not quote to you that the mentally retarded have the right to vote in our country. This is patronizing. You are too familiar with facts, figures, statistics, studies — all around, but not of the human being.

We must avoid this pitfall. We must recognize the sound of one hand clapping. It is the sound of communities of people still fearful and superstitious about mental retardation, refusing to afford them a place in their community.

It is the sound of small groups of concerned parents struggling through morass of interagency areas of jurisdiction, interagency levels of responsibility, arbitrary and conflicting regulations, zoning ordinances, special building and program

standards, inaccessible sources of funding and community resistance, trying against these odds to develop viable community programs.

It is the sound of social scientists arguing that the mentally retarded principally present a problem in deviancy and only when their problems are viewed in this manner will we be able to resolve the problems they present and develop more appropriate community programs.

It is the sound of families who have a retarded member desperately wanting to keep their loved one as an integral part of the family but who lack the fiscal resources, supportive services, respite care, and community acceptance and so must settle for something less.

Above all, it is the agonizing unheard cry, hundreds of thousands, millions, of retarded people living out their lives in a society that gives them lip service, something short of total acceptance.

I call upon you, you the paracletes of the retarded, their champions, their voices, to make sure that those whom you have helped carry from the secret dark place to the sun do not dwell in a partial eclipse. I call upon you to wipe the slate clean and to start with fresh concepts of a human being with special needs, living in a society with other human beings, with all that flows from it.

No, my friends, this is not easy, it may not even be accomplished in our lifetime. But if the effort is not made, society will remain comfortable and warm in its cocoon, snug and full of patronizing phrases, small pats on the head, and we shall burst with pride at our non-accomplishments to the thunderous voice of one hand clapping.

I welcome this opportunity to speak to an international community. My voice, by constant repetition has become too strident, too familiar, perhaps, and therefore, ignored, perhaps, in my own country. Perhaps the older world shall become the newer world. The newer world for the mentally retarded. Perhaps the older world will recognize what is the sound of one hand clapping and supply the resounding other hand.



Janice Mehlman

## Wassaic teacher

### scholarship winner

Mrs. Janice Mehlman, a teacher at Wassaic Developmental Center, has been awarded the Arthur W. Pense Memorial Scholarship given yearly in memory of Dr. Arthur Pense, a former deputy commissioner at the Department of Mental Hygiene, by the New York State Association for Retarded Children.

Mrs. Mehlman started her career in mental retardation in November 1971 as a teacher assistant. She was promoted to teacher in January 1972, working with a class of educable boys and girls. In 1973, Mrs. Mehlman volunteered to work with the severely and profoundly retarded and multiple handicapped students in residential buildings at Wassaic. She assisted in the development of an experimental feeding program in 1973 with the most extremely handicapped and retarded children in the hospital, working closely with Mrs. Renee Wallace of Houston, Texas, who developed the program.

The Arthur Pense Scholarship will help towards attaining her master's degree in special education. Her academic work also focuses upon the severely handicapped and mentally retarded persons.

# Our Children's Voice

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NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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## Ten years.... what has changed?



Leslie Collins, director, Public Education, SOAR, preparing the great stuff.



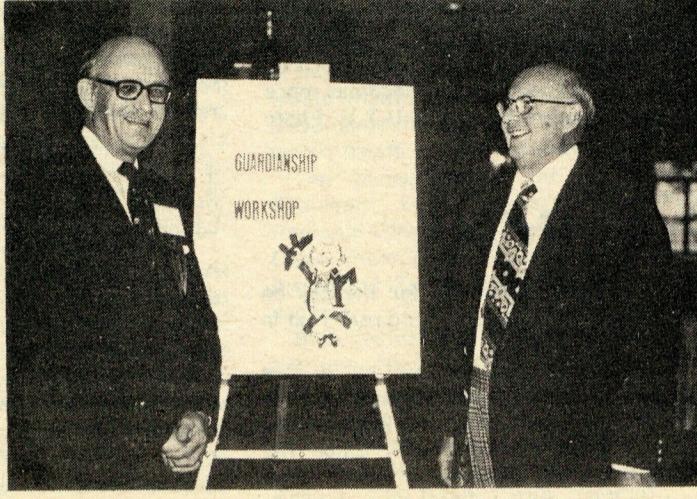
The great man himself, Robert Meltzer, who pulled it all together.



Just the old time gang. Left to right Augustus M. Jacobs, Chairman, Legal and Legislative Committee, George G. Hirsch, President, and Seymour Rubin, Board member, New York City Chapter.



George Heymann of SOAR and Betty Pendler, Chairman, Education Committee, selling education at their booth.



Bob Hodgson, Chairman, Guardianship Committee, and Gene Laughery, trying to pull them into workshop.

## Scene at the '76 Convention



Pictured are, left to right, Ms. Marion Slemowitz, registration chairman, pinning badge on George G. Hirsch, president of New York State Association for Retarded Children. Also standing, Robert L. Meltzer of Port Chester, convention chairman, and Joseph T. Weingold, executive director of NYS ARC. Seated, Ms. Cynthia Ferguson of N. Tarrytown.



Kathy Baker, President Y.O.U.T.H. ARC, with Robert Maurer accepting Advocacy Award from Hilarie Seifert, on behalf of Senator Conklin.



Elliot Aronin, former president, giving words of wisdom.

Looking through material on a conference in March of 1966 on Services for the Mentally Retarded through Community Mental Health Boards, a conference sponsored by the Department of Mental Hygiene, Joseph Weingold, one of the speakers, posed the following hypotheses to explain the lag in services to the retarded through Community Mental Health Boards:

1. Mental health boards do not provide services in depth for the mentally retarded because

A. They have no money for these programs

B. They do not want to spend the money available on the mentally retarded.

2. Mental health boards do not provide services for the mentally retarded because their directors

A. Do not want to

B. The Boards will not permit it

3. Mental Health boards do not provide services because

A. They do not know what to do

B. They haven't the time to learn

C. Their interest is in mental illness only

D. They are irritated by parents' groups

E. They are afraid of the scope of the problem

4. When mental health boards do provide services, most of the time no county or city money is provided because

A. The Boards do not ask for money

B. The contracting agency does not ask for it.

C. The county or city does not understand and is not informed by the Board.

5. Projects for the mentally ill are financed mostly by state and counties, only 8 per cent coming from community agencies. Is it significant that for projects for the mentally retarded, more than 90 per cent of the matching funds come from ARC and other community agencies?

6. Mental health boards do not accept the ARC statement of needs as controlling, even when the services are being rendered by ARC Chapters and even when no municipal money is asked for.

Is this because

A. ARC is not trusted?

B. No one on the mental health board is competent to judge the needs?

C. The Boards are too busy with other projects?

We welcome comments about what changes, if any, have taken place in the last ten years, to affect this presentation.

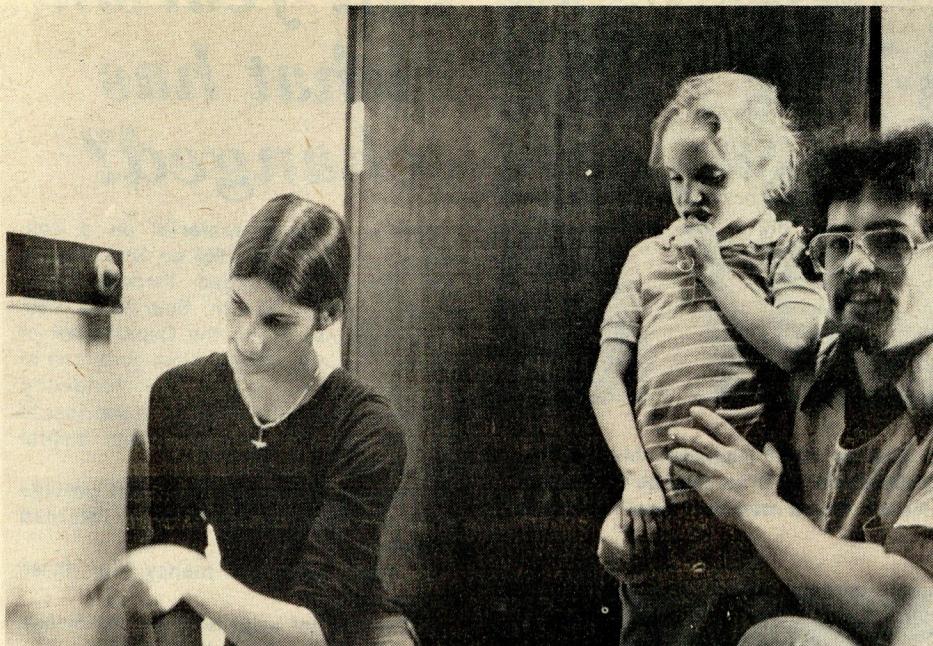
## Outreach with DDC grant

A program to reach, evaluate and teach developmentally disabled infants and children under age three has been given a go-ahead by Developmental Disabilities Council, with a grant towards a \$40,000 project cost.

The \$27,916 seed money will start an outreach program for infants and children under age three, when the children are "at a more advantageous age", according to Donald Geist, Executive Director of the Clinton County Chapter. It will also allow the Chapter to "work with the family when they need assistance the most".

The children being sought out by the ARC are those with mental retardation, cerebral palsy or other permanent disabilities according to Developmental Disabilities Services Act. The children who have completed the ARC's program will be taken into the BOCES pre-school program and then admitted to the Lakeside School program of the ARC at age six.

The Federal Grant is being matched by \$12,000 from the United Way.



A young resident of Syracuse Developmental Center watches as her world becomes more colorful, thanks to the efforts of Youth Organized and United to Help, Y.O.U.T.H. Photo by Joe Sheedy

## Color My World

"Color My World," a major undertaking of the state YOUTH ARC Projects Committee, had a splashy beginning at the Syracuse Developmental Center December 10, 11, and 12. YOUTHers from around the state arrived en masse Friday evening, prepared to paint as many rooms as possible on the Children's Unit. They camped out in the facility in sleeping bags, enjoying baked goods and big breakfasts supplied by donors and the SDC chapter of ARC.

"It was truly a labor of love," commented Gerry Sherwood, state YOUTH Coordinator. "The kids got right down to work after they arrived, organizing painting crews, taping moldings, priming newly patched areas. Twenty six rooms were completely re-painted in bright, fresh colors, and Sunday the rooms were thoroughly cleaned before the youngsters departed."

Gerry extends heartfelt appreciation and the lion's share of the credit to Hilarie Seifert, chairperson of the Projects Committee. Hilarie, who abounds with enthusiasm, is a superb organizer who is a student at Syracuse University and serves as YOUTH secretary.

Gerry, Hilarie and the YOUTH group have singled out several special persons to be thanked for their efforts and splendid cooperation: Bill Morgan and Keith Patrick, Team Leaders on the Children's Unit; Dr. Vito Giola, Director of Children's Services; Art Knight of the maintenance staff, the entire SDC kitchen crew and Susan Morse of the Onondaga ARC, who arranged coverage of the event.

Also deserving of recognition were the many volunteers and Foster Grandparents

### Puleo resigns as Exec.

In a letter dated October 19, 1976, to Mr. Jerry Weingold, Matthew J. Puleo advised he has tendered his resignation as Executive Director of Schenectady County Chapter.

"I have done so to accept another position in keeping with my career development," writes Matt.

"During my tenure as Executive Director, we have made numerous program improvements and expanded the services rendered to the retarded in Schenectady County. This has been made possible only through the cooperation offered by you and your Agency."

"I wish to thank you for your assistance during my tenure as Executive Director, and look forward to seeing you in the future."

who took the children out for the day on Saturday so the painters could really go to town.

The SDC project serves as a fine example of many groups working together with one common desire — to brighten the lives of retarded children. "Color My World" will be repeated in other state settings. Further information may be obtained by contacting Gerry Sherwood at the state ARC office.

### Private schools raise rates

Apparently though a concerted move by the private schools in the State of New York, parents of mentally retarded adults in such schools have been asked to contribute anywhere from one hundred to three hundred dollars a month over and above the six hundred plus dollars a month being paid by the Department of Social Service for retarded adults in such institutions under Social Service Law.

Many of these have been deinstitutionalized into such private schools.

The situation has become extremely acute with dozens of complaints in the office of the Association from parents who cannot afford these payments.

Many of the parents have said the Department of Mental Hygiene will just have to take the children back into the institutions.

Joseph Weingold, Executive Director, protested this situation to Kevin M. Cahill, M.D. Advisor to the Governor on Health Affairs. This was backed up by a letter from George G. Hirsch, who pointed out that the provisions of the Social Services Law were dated.

"The cost of living has been increasing every year," wrote Hirsch, "but the fees have remained stationary. The schools, therefore, probably have a point if their operating statements reflect a hardship because of this."

Hirsch is a member of the Governors Advisory Committee for the Committee on the Handicapped.

According to Weingold, Dr. Cahill wrote that specific information and data from the schools as to their costs has been requested by Walter Schofield, Assistant Commissioner, and that a three month moratorium with the schools would be negotiated ending November, 1976.

"When this, (the date) is received," wrote Dr. Cahill, "the department will analyze this material and make recommendations to my office and other state offices."

# ARC ineligible for Advocacy

## Guidelines cite conflict of interest

Recent draft guidelines for Protection and Advocacy under the Developmental Disabilities Services Act, issued by HEW, have eliminated the ARC as a possible recipient of the extended advocacy grant because of "possible conflict of interest". Although the law itself states that no State agency delivering services may be the advocate, the guidelines interpret this to mean no state agency or any other agency. This would definitely include NYS ARC.

The State ARC Convention passed a resolution unanimously condemning this and this was followed by letters from Association President George Hirsch to the Secretary of HEW in which he cited the record of SOAR in this field.

Calling the conflict of interest problem "a straw man", Hirsch stressed the meaning of voluntarism and the role of a voluntary agency in this area.

He furthermore suggested that, if there is such a feeling, it should be treated on a case-by-case basis. The ARC, who has demonstrated its ability to carry on a statewide advocacy program, should be eligible to receive the expanded grant. In answer to Mr. Hirsch's letter, Francis X. Lynch, Director of the Developmental Disabilities Office cited the Senate report which he says "indicates the absolute intent to assure protection and that personal advocacy agencies be independent of any service providing agency. HE PLACES HIS POSITION SPECIFICALLY ON THAT OF THE NARC WHO HAVE DEFINITELY STATED MEMBERS OF NARC WHO ARE IN THIS CATEGORY SHOULD NOT RECEIVE ADVOCACY GRANTS. The position paper is written by Peter Marshand, an employee of NARC.

Mr. Hirsch replied this answer was not responsive, the law was being rewritten, and if the Congress wished to adopt the Senate report it would have stated no state or other agency funded by governmental grants would be eligible for an advocacy grant.

Commenting on this, Joseph Weingold, Executive Director of the State Association and organizer of SOAR, said, "As it now stands, when there is more money available and with no matching funds, the ARC is being booted out. We feel secure that we have shown the way and the path to be followed. We shall remain as advocates for the mentally retarded no matter what agency is designated".

## K of C grants for handicapped

We have received reports that the Diocese of Ogdensburg has awarded grants totaling \$12,500 to organizations serving the retarded and handicapped. In the 1976 grants from the Diocese of Ogdensburg (totaling \$12,500), St. Lawrence County Association for Retarded received \$1,000.

At the same time, the Schoharie County Chapter announced receipt of a \$500 gift from Bishop Edwin B. Broderick of the Albany Catholic Diocese, again made available by the Knights of Columbus.

It is interesting to note the Knights of Columbus campaign to raise funds is on the basis that these funds will go to help the mentally retarded, but the bulk of the funds seem to be going, certainly in the Ogdensburg diocese, to other handicapped.

## Convention blasts Advocacy elimination

In a resolution unanimously adopted by the Convention at the Rye Hilton Hotel in Westchester, the delegates voted to condemn the policy of HEW declaring voluntary associations delivering services to the developmentally disabled, ineligible for advocacy grants because of conflict of interest. In a strongly worded letter to Secretary of HEW, Mathews, both Joseph Weingold and George Hirsch stated that section 113 of the Developmental Disabilities Services Act forbids such contracts to "State agencies delivering direct services" and the guidelines rewrite the law. In fact, the guidelines specify "no state or other agency" receiving funds for direct services from the state is eligible for such grant.

### Carnahan named DMH counsel

The appointment of William A. Carnahan of Buffalo, one of the State's top authorities on mental disability and the law, as Legal Counsel to the State Department of Mental Hygiene, has been announced by Dr. Lawrence C. Kolb, Commissioner.

Mr. Carnahan, a practicing attorney in Buffalo, is co-author of a two-volume legal treatise entitled "Mental Health: New York Law and Practice". A former Counsel to the Massachusetts Department of Mental Health, he is currently Chairman of the Committee on Health and Law of the State Health Advisory Council and Adjunct Professor of Legal Psychiatry at the New York school of Psychiatry.

The advocacy grant for the ARC (SOAR) expires January 7, 1977. The new agency must be in place by October 1977 and the question now is whether the ARC will continue until such time as a new agency is in place.

The ARC has made strong protestations to Developmental Disabilities Council, that it is now acting as an advocate for all developmentally disabled in the state, has done so for almost two years and should be eligible for a new grant. All to no avail.

At this writing, it seems the matter is virtually settled unless the new administration changes these guidelines. Then, however, it may be too late for the ARC.

In addition to serving as advisor to the Commissioner on important legal matters affecting the Department, Mr. Carnahan, in his new post, will assist in policy formulation, decision making and program expansion where legal and legal administrative problems are involved. He also will formulate the Department's legislative program and direct the legal staff in drafting proposed legislation.

A practicing attorney in Buffalo since 1969, Mr. Carnahan is a member of the New York and Massachusetts bars and is admitted to practice before the United States Supreme Court and the United States Court of Military Appeals.

# Education Law summary

## The formula for Federal help

PL94-142 establishes a formula by which the Federal government makes a commitment to pay a gradually escalating percentage of the national average expenditure per public school child times the number of handicapped children being served in the school district in each State of the nation. That percentage will escalate on the yearly basis until 1982 when it will become a permanent 40 per cent for that year and all subsequent years.

Formula Scale: Fiscal 78 - 5 per cent, Fiscal 79 - 10 per cent, Fiscal 80 - 20 per cent, Fiscal 81 - 30 per cent, Fiscal 82 - 40 per cent.

Formula "Kick In" — The new formula will not go into operation until Fiscal 1978.

The previously existing law was already moving toward the permanent significant increase in the Federal commitment. Public Law 93-380, the education amendment of 1974 signed August 21, 1974, created the first entitlement for handicapped children based upon factors of the number of all children aged 3 - 21 within each state times \$8.75. This formula (called the Methias Formula after its originator) amounted to a total annual authorization of \$680,000,000. It was authorized for Fiscal 1975 only, with a view towards permitting an emergency infusion of money into the states while, at the same time, deferring to final determination of a permanent new formula as now contained in PL94-142. The Methias Formula is retained in both bills until kick in of the new formula.

## Nassau's painful hostel fight

The Village of Freeport in Long Island is intense in blocking the plans of our Nassau County Chapter ARC to use an unoccupied house on Cedar Street, a block of well-kept middle-class homes, as a hostel for eight mentally retarded women.

The Village has gone so far as to bring an action against the Association to enjoin them from using this house. The latest development occurred in September when Justice Albert Oppido, sitting in Mineola, denied a motion by the Village for a preliminary injunction barring the hostel.

In denying this motion, he said, "It is doubtful the plaintiff (the village) will be able to prevent defendant from using its property in the manner intended". Furthering this opinion, he quoted the Ferrarolo case in Westchester and the Worc case in Queens, both of which were successful in the aims of the Associations involved to establish group homes.

At the same time, the Judge refused to grant a motion to dismiss the complaint ruling that a trial is necessary.

The village residents opposing this are divided in their reasons. Some say it will bring property value down. Others say that the residents will be a menace to their children. Still, others feel they are being unduly burdened with taxes to support non-taxable properties used by voluntary agencies.

The vote of the neighbors to decide whether or not they wish to oppose the hostel was a secret one.

Mayor William H. White, Mayor of Freeport, said although he was sympathetic toward the aims of the AHRC Nassau County Chapter, to place the retarded in the "mainstream of an environment", he felt it was unfair to the Freeport residents.

It was the old feeling of "Yes, but not on my block."

Helen Kaplan, Executive Director of the Association, said Mayor White's

PL94-142 prohibits counting more than 12 per cent as handicaps served within the total school-age population, say between the ages of 5 and 17.

First priority is given to children "unserved"; second priority to children inadequately served when they are severely handicapped (within each disability). During the first year of the new formula, 50 per cent of the monies will be allocated to the State Education Department and 50 per cent to the local educational agencies. In Fiscal 1979, the local educational agency entitlement will be enlarged to 75 per cent.

The law requires every state and its localities to provide a free public education for all handicapped children age 3-18 by the beginning of the school year September 1, 1978. It further orders the availability of such education to all children age 3 - 21 by September 1, 1980. However, the mandate would apply only when such a requirement is not "inconsistent" with State law or practice, or any court decree. We have been unable to ascertain what this means exactly.

The law requires a state educational agency to be responsible for insuring all requirements of the act to be carried out. All educational programs within the state for handicap children, including all such programs administered by any other state or local agency, must meet state educational agency standards and be under the general supervision of persons responsible for the education of all handicapped children. This, of course, is of

great significance to education of the mentally retarded in institutions. The State of New York has initiated "child find" activity in a statewide effort to find and evaluate all handicapped children in the state. It is using its work of associate special education instructional material centers (ASEIMC's) for this purpose.

The question might probably be asked what will happen to the children when they find them.

## DMH scraps merger

The Department of Mental Hygiene has scrapped its plans for a complete merger of the Gowanda Psychiatric Center which treats mental illness and the J. N. Adam Developmental Center in Perrysburgh which treats mental retardation.

The announcement by Dr. Stanley Platman, then Western New York Regional Director for the Mental Hygiene Department, came last summer at a joint meeting of the Boards of Visitors of the two centers.

Both centers will continue, however, to explore possibilities of sharing supplementary service such as clinical lab, pharmacy supplies, vocational rehabilitation services, and professional staff education services, said Theodore A. Bravos, J.N. Adam Center director.

The Department received word of the decision from Dr. Lawrence Kolb, Commissioner, and his first deputy, Dr. Robert McKinley.

Originally the Department of Mental Hygiene decided to phase out J. N. Adam by transferring the residents of J.N. Adam to the Gowanda Psychiatric Center. This was protested vigorously by Joseph T. Weingold, of the New York State Association for Retarded Children, in a letter to Governor Hugh Carey in May and letters also to the members of the legislators from that area.

"All the statements of the legislature, the federal government and professionals to the effect that mental retardation and mental illness are two separate and distinct entities are being disregarded," wrote Weingold to the Governor.

"I am sure you and your staff are aware of our very strong opposition to the utilization of psychiatric centers for services for the mentally retarded," continued Weingold. "We feel this is a throw back to conditions over 100 years ago when 'insane' and 'idiots' were lumped together in institutions."

It is not at all sure the Department is finally abandoning this idea, although Weingold suggested to Dr. Kolb that it would make more sense to combine Gowanda Psychiatric Center with Buffalo Psychiatric Center, thus saving huge sums of money, rather than putting the mentally retarded in the same facilities as mentally ill.

statements somehow don't hold water because it isn't that he doesn't want a hostel in Freeport, but he does not want the hostel in that neighborhood. "As a matter of fact," said Mrs. Kaplan, "he has offered us houses in run down, terrible and horrible neighborhoods."

My Hyman Clurfeld, president of the chapter, in spite of the setbacks, is still optimistic. "I am optimistic," he said, "that everything will work out in the end. The neighbors are afraid right now. They fear what they don't know, but they will adjust."

Helen Kaplan joined with Jerry Weingold, Executive Director of the State Association, in pointing out that a number of states have laws preventing zoning ordinances such as those which exist in Freeport. "It is interesting to note," said Mrs. Kaplan, "that the Association proposed legislation to the same effect in New York State which was introduced to the Senate by Mr. William B. Conklin, but no one in the assembly was brave enough to put it in.

The Association will continue its efforts to place a hostel in the community where it belongs, fighting a legal battle when necessary and urging the legislation which may prevent this kind of unsensible fight.

Weingold also urged the Department of Mental Hygiene to launch a saturation campaign by the radio, television and newspapers to prepare the community for the acceptance of these hostels.

"Without such a campaign of education," said Weingold, "we will have the greatest difficulty in establishing the homes necessary for the thousands of mentally retarded that the State Plan says will be placed in the community within the next few years. This, of course, is an addition to the many other thousands in the community, who need such homes as the parents grow too old or die."

## ARC prophet

## in Willowbrook

Elsewhere in this issue is an article on the motion to punish for contempt in the Willowbrook case.

It is interesting to note the Association predicted exactly what was going to happen upon the signing of the Decree on April 21, 1975.

At that time, Governor Hugh Carey called a press conference, and the Association issued a release in the form of a statement by Mr. Elliot L. Aronin, then president of the New York State Association, in connection with the signing of this Consent Agreement.

"Although we, as the major plaintiff, in this action, are signing this Consent, we are doing so with reservation. Although there are considerable advances in this Consent promising a better life for the residents of Willowbrook State School, significant portions dealing with the means to develop community facilities as alternatives to Willowbrook were vetoed by the defendants."

"Furthermore," continued Mr. Aronin, "the success or failure of the objectives of this Consent hinge almost entirely on the bureaucracy charged with implementing it. This implementation rests in the same bureaucracy which created and perpetuated Willowbrook and failed to carry out to any great degree the interim order of Judge Judd."

This statement was made at the time when the bills for a separate office of Mental Retardation and Developmental Disabilities were on Governor Carey's desk. He had not yet indicated whether he would sign or veto it. Subsequently, he vetoed it.

The following statement, therefore, is in connection with the situation:

"We are hopeful however, this Consent will become more than a lengthy scrap of paper because there is now the possibility of a creation of a different vehicle for its implementation. This vehicle is the creation of an Office of Mental Retardation in the Executive Department as enacted by the Senate and Assembly in the Conklin - Steingut bill which passed both houses overwhelmingly. This separation of powers would take mental retardation out of the Department of Mental Hygiene into its own office directly responsible to Governor Carey and the Legislature."

It is noteworthy that the review panel appointed by Judge Judd to oversee the implementation of the Decree has urged that implementation be taken out of the Department of Mental Hygiene with the appointment of a special person appointed by the Governor, answerable to the Governor only and not to the department.

"We must repeat," concluded Mr. Aronin, "we have little, if any, faith in the will or power of the present bureaucracy to implement this Agreement."

We suppose that this certainly demonstrates that a prophet is without honor in his own country.

## Carey quotes ARC opposition

In vetoing a bill introduced by Assemblyman Pazananti, Governor Hugh L. Carey cited the opposition of the New York State Association for Retarded Children.

The bill amends a municipal law requiring the State, its agencies and authorities, to give notice to the local community boards established by the City of New York before entering into any agreements or approving any applications by private parties relating to the purchase, rental or change of use of real property within the city.

In his veto, which the ARC strongly urged, the Governor stated that the purpose of the bill was to provide a greater

level of community participation, through local community boards, in proposals for the use of real property. It would mean, if we wish to get a piece of property for a hostel, we would be required to give notice to the local community boards, as well as Heaven knows how many other agencies, and nothing could be done until the community board acted.

"As a result," said the Governor, "this bill would subject the State to lengthy and inhibiting delays and, in some instances, prevent implementation of programs."

Well, the Governor doesn't sign all the bills we approve. But, at least sometimes, he does veto a bill of which we disapprove!

# White House Conference ignores mentally retarded

## WEINGOLD URGES STATE COUNCIL FOR THE HANDICAP TO ADDRESS INDIVIDUAL PROBLEMS

In the 25 Awareness Papers prepared for the White House Conference on Handicapped Individuals, there is no evidence whatsoever of any concern for the mentally retarded. These papers are to be used by the States in their Conferences preliminary to the National Conference.

In a statement before the Council on the Handicapped held November 17, 1976 in New York City, Joseph T. Weingold urged the Council to distinguish between handicaps and pay attention to the individual needs and differences between them.

"On the broad level," he testified, "I should like to suggest to the Council that the word 'handicap' encompasses so many disabilities as to be almost meaningless with regard to programs that would suit everyone. For example, when New York City began to cut down the curb stones to remove a barrier for the physically handicapped, objections were voiced afterwards by the blind who found this a deterrent to their locomotion. So too, it is with programs advanced for the handicapped whom the public identify with physical handicap. What, then of the others?"

In the testimony, Weingold urged:

**That the community be enabled to help to change their attitudes by the passing of a bill advanced by the Association to**

## Hospital loses accreditation

The St. Lawrence Psychiatric Center, the largest single employer in Ogdensburg, has lost its accreditation, mainly because of turn-of-the-century buildings which house 750 patients.

The hospital, one of 28 state-operated psychiatric facilities in New York, learned of the finding in a report from the Joint Commission on Accreditation of Hospitals, a Chicago-based firm.

Dr. Lee Hanes, administrator of the Center, said the accreditation loss would jeopardize some \$4.8 million third-party payments, such as Medicare and Medicaid, which are received each year.

The Governor suggested a \$15 million appropriation to build a new facility for 300 patients at the St. Lawrence Psychiatric

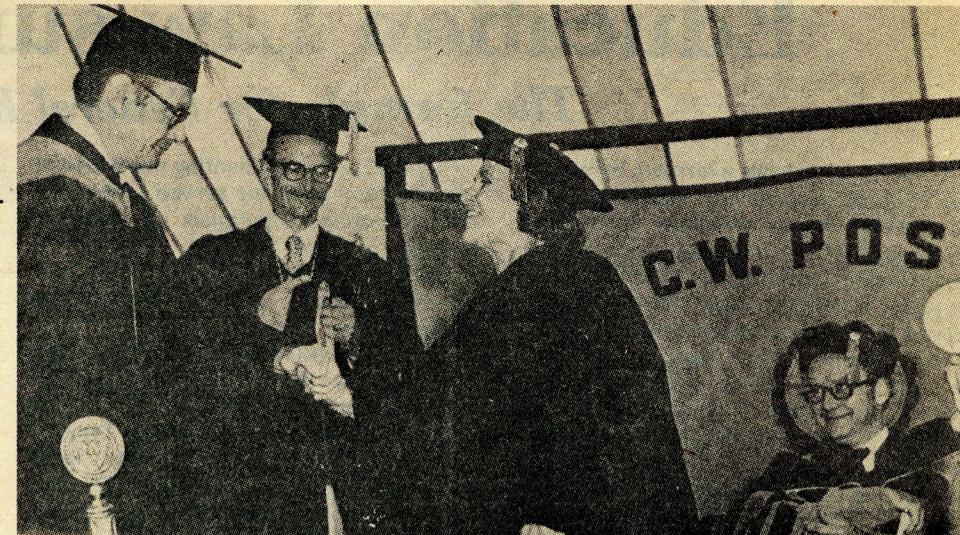
prevent restrictive zoning ordinances with regard to housing.

That an Office for the Ombudsman dealing with all the handicapped will be almost meaningless in the light of the fact that the handicaps have so much difference and there is no legal component in the Ombudsman plan. Furthermore, he pointed out, that under the Developmental Disabilities Services Act of October 1977 a System of Advocacy for the Developmentally Disabled on a statewide basis must be in place.

He also made suggestions concerning mass transportation, funding of education, support of schools services, vocational rehabilitation and transportation.

Throughout his talk, he insisted the positive should be emphasized in all we are doing. As an example, he pointed to the bad program that has been highlighted at Willowbrook. Although the problems of Willowbrook are being attacked as vigorously as possible through court action, the fact remains that the general public seems to think now that the mentally retarded consist only of the worst cases as shown on television in Willowbrook. "This is a disservice," said Mr. Weingold, "to over 85 per cent of the mentally retarded."

He closed by urging the Council again to distinguish between the needs of the various types of handicap and that the mentally retarded not be lost in the consideration of "handicap" as a total word.



Edward J. Cook, President, C.W. Post Center, Professor Newton Meiselman and Helen Kaplan at commencement exercises.

## Helen Kaplan receives Honorary LLD from L.I.U.

AHRC Executive Director Helen Kaplan was awarded the honorary degree of Doctor of Laws at commencement exercises of C.W. Post Center, Long Island University, this spring.

Mrs. Kaplan was singled out for her extensive activities for the welfare of the retarded since 1949 when she became a charter member of what was then the

Long Island Chapter of AHRC. When that chapter separated into two, she became the first president of the Nassau Chapter before reaching her present position of Executive Director. The citation said in part that her ". . . dedication and commitment to the cause of retarded children has convinced us that improvement is possible for those with a severely limited intellect; her perseverance has influenced public policy at the state and national levels."

The citation concludes, ". . . In appreciation of your contribution to the formation of our conscience, and in recognition of your achievement and unselfish spirit in aiding the cause of retarded children, we are proud to present you for the Degree of Doctor of Laws."

All of us are proud of her.

## N.Y.S. plan criticized

Federal Law 94-142 requires the State to have a plan in place for the education of all the handicapped.

In reviewing this plan, the Education Committee of the State Association, under the chairmanship of Betty Pendler, voiced these chief concerns:

- 1) Too general
- 2) Nothing is mandated (speech, P.T., O.T. etc.)
- 3) Interagency cooperation is not a directive — it cannot always be enforced at local level and must come from State level.
- 4) Nothing on strict implementation of vocational evaluation and programs.
- 5) Still no curriculum guide for TMR.
- 6) Nothing to stop drop-outs or to discourage local districts from encouraging it.
- 7) No plan for what to do with:
  - a) already found children
  - b) children found under "child find"
  - 8) Neurologically impaired classes are often dropped by end of J.H.S.
  - 9) No definitions of:
    - a) least restrictive setting.
    - b) meeting needs — does education for special needs of the child encompass anything else besides reading and writing (speech, O.T., P.T., etc.)
  - 10) Regional associates areas for the most part too large to be effectively monitored (Regions, I, II, III).
  - 11) Nothing on parent liability for parent who is on the committee on the handicapped. (This has been changed by law).
  - 12) Pre-school was a chief thrust of plan — yet it is not mandated and the \$300 per child is not sufficient for most local school districts to set up pre-school programs.
  - 13) Definite plan for referral of student records from local school to agency if necessary after graduation (in many cases there is a 5 yr. lag in referrals).

## Sexual abuse charges reduced

Charges against five men accused of sexually abusing retarded boys at the Monroe Developmental Center (Rochester, N.Y.) were reduced from felonies to misdemeanors early last summer.

The men, former or suspended workers at the center, originally were charged with felonies ranging from first degree sodomy to sexual abuse.

The grand jury reduced some of the felony charges against the five men because evidence showed the boys may have consented to the alleged sexual acts.

"I cannot comment about the legal aspects of the case," said Dr. Albert PScheiner, the then center director. "This

is one of the few times mentally retarded people have presented a charge against people of normal ability," Scheiner said. "In terms of dealing with retarded people, I think the word 'consensual' is hard to define."

"They were frightened," said Scheiner, "(by the grand jury process). They were afraid of retaliation by authority figures. In these situations, I think they have the same mental processes as normal people," Scheiner said.

These charges are brought against persons in a small institution where there is supposed to be complete supervision and understanding.

## Willowbrook conditions "not good"

In her message when inducted as President of the Willowbrook Chapter, Benevolent Society for Retarded Children, Genevieve K. Camen, stated "implementation of the year old Consent Decree mandate remains nothing more than a promissory note. Very little has

been done for our retarded. It is no secret that the quality of life among the retarded at WDC is less than wholesome, humane, civilized, or salubrious.

In anticipation of dismantling WDC, the attitude of the Department of Mental

Hygiene appears to be one of cleaning out, and not of cleaning up, WDC.

Where the retarded reside, additional staff has been added to hasten the mass exodus of these poor unfortunates; but no additional staff has been added, placed, or trained for the buildings to give our loved ones quality care, as mandated by all standards included in the Consent Decree.

We urge the parents and relatives of the children at Willowbrook to dedicate themselves once more to demand the immediate change in the present living conditions and the working conditions of our "dedicated employees".

# N.Y. counties counter Carey

## Mental help cuts proposed

### CUTS PROPOSED IN MENTAL HELP

Financially troubled counties throughout the State are planning sharp cutbacks in spending for community treatment programs for the mentally ill and retarded. This development reverses a trend of the past several years and threatens to undermine a cornerstone of the Carey administration's mental hygiene policy.

The budget cuts are especially alarming, because under the various formulas by which state aid is channeled to the counties, a \$1 cut on the local level automatically triggers a \$1 cut in state aid.

This may not affect many of the chapters of the Association as much as the so-called county money comes from the voluntary agency chapter of the Association. In other words, the Association puts up most of the money that is matched by the State for local services.

Where, however, the county puts up its own money, this may cut deeply into programs.

### CEILING PLACED ON FUNDS

Since county fiscal years do not begin until Jan. 1, the figures are far from final. But in planning their own state budget request, mental hygiene officials here have begun to review the proposed mental health budgets of some of the larger urban counties and are alarmed at what they are finding.

For example, in Onondaga County, which includes Syracuse, the County Executive placed a \$1.1 million ceiling on the money to be raised from county taxes that could be spent on mental health in 1977. This represents a 27 per cent reduction from the 1976 level of \$1.5 million, and would trigger an additional cut of \$400,000 in state matching funds.

Erie County, which includes Buffalo, is discussing a 20 per cent reduction of \$700,000 in its mental health budget.

### New M.H. officer appointed

Dr. Henryk M. Wisniewski has been appointed director of the New York State Department of Mental Hygiene's Institute for Basic Research in Mental Retardation.

The appointment was announced by Dr. Lawrence C. Kolb, Commissioner of Mental Hygiene, and Dr. Leonard Lester, dean of the College of Medicine at Downstate Medical Center where Dr. Wisniewski is a professor of pathology.

The faculty appointment is in line with a new affiliation agreement developed between the research institute and the medical college. That affiliation establishes a cooperative effort in interdisciplinary research into the nature, causes, care, prevention and treatment of disabilities associated with mental retardation between the college and the department of the type that has been successfully used in the past elsewhere in New York State to enhance research efforts related to mental hygiene.

Dr. Wisniewski, a noted neuropathologist, has been director of the British Medical Research Council's Demyelinating Diseases Unit at Newcastle General Hospital and a visiting professor of pathology at New York City's Albert Einstein College of Medicine since 1975.

### N.Y.C. CHAPTER AFFECTED LITTLE

For the fiscal year that began in July 1976, New York City cut \$9.1 million or 20 per cent, from its mental hygiene budget, with the cut supposedly to be made up in services provided by voluntary agencies. New York City Chapter is not too affected by this because, out of a budget of almost \$4 million, it receives only \$180,000 from the City of New York.

The problem is that upstate counties have been hit with surging welfare costs that they can do little to control, and so are trying to balance their budgets by cutting the services that, however traditional, are not required by law. The alternative is to raise county property taxes.

### D-INSTITUTIONALIZATION IN JEOPARDY

According to Mr. Edward Skloot, Deputy Commissioner for Internal Management of the Department of Mental Hygiene, the administration's plan calling for reducing state's inpatient population of the mentally retarded from 20,000 to 10,500 in the next five years is very much in doubt because of this development.

He said it is important to decide whether the state should continue to release patients when there are no local programs to care for them.

Another response would be to make strenuous efforts to change the current laws that link state spending to local spending, something that has been proposed by the Association for years.

## On deductions from SSI

The Department of Mental Hygiene has requested a speedy decision of the U.S. Department of Health, Education and Welfare, as to whether or not the federal agency would deduct newly provided state payments to patients living in family care homes from those patients with Federal Supplemented Security Income.

In a letter to HEW Secretary David Mathews, Dr. Lawrence C. Kolb, Commissioner of Mental Hygiene, said an adverse HEW interpretation of the SSI regulations would deprive the patients of the up to \$290 a year provided for them by the Legislature in Chapter 805 of the Laws of 1975. "The money," Dr. Kolb wrote, "is meant to help the patients purchase clothing, meet small incidental expenses and pay for recreation or cultural activities."

Dr. Kolb said an informal opinion from HEW's regional office indicated the incidental expense money would be considered personal income for the patients. This would mean it would be deducted from their SSI payments. Of 7500 New York State family care clients, 6500 receive SSI payments for their support. "If those deductions are made," he told Secretary Mathews, "it would negate the intention of the legislation and deprive patients of the benefits."

Dr. Kolb requested Secretary Mathews' assistance in assuring a "speedy review" of the potential effect of the interpretation of the SSI regulations on the State's program. "I believe you will find the modest stipend proposed by the state for its mentally disabled is in no way the type of individual income envisioned by the creators of the Supplemental Security Income regulations".

# Basic rights in education

The Council for Exceptional Children has provided these guidelines for the rights of children and their parents in education, resulting from state and federal court decisions, as well as laws recently passed:

### BASIC RIGHTS OF CHILDREN AND THEIR PARENTS

1. All children are entitled to an appropriate education and an education in the least restrictive environment possible.
2. Parents have the right to appeal a decision made to alter their child's educational program.
3. Parents have the right to review and use in their appeal all information used by the school to make the decision.
4. Parents have the right to have a neutral party decide on the most appropriate program for their child.
5. Parents have the right to have the benefits of a special program specified and evaluated.

### IMPLICATIONS FOR EDUCATORS

1. Educational services must be

available to all children regardless of severity of handicap.

2. A variety of special education services must be available if children are to receive an education that is appropriate and as close to a program of normalization as possible.

3. To promote understanding, parents should be informed early of difficulties experienced by their children. They should be involved in the planning and evaluation of the special services provided.

4. Educational decision making must be based on the efforts of an educational team that collects and uses all appropriate information, not on a single test.

5. Measurable objectives must be set for children receiving special services. The progress of these children must be reported to their parents.

The demands of courts and school laws should not frighten us. They are only saying that every child has the right to "fair play" and an appropriate education in the schools. This is no more than what we would wish for our children."

A further right would be the right to education without cost to the parent.

## SSI amendments benefit retarded

local standards. The amendment also eliminates a ban on SSI payments to persons in public institutions serving no more than 16 persons.

### PROTECTION OF MEDICAID ELIGIBILITY

This amendment protects those who are entitled to Medicaid because they receive SSI payments or state supplemental payments from losing Medicaid coverage when there is a Social Security cost-of-living adjustment.

### CHILDHOOD DISABILITY

Although SSI has been in operation for almost three years, HEW has yet to publish criteria for determining whether children under age 18 are disabled. This amendment mandates HEW to develop child related SSI criteria within four months. Additionally, the amendment requires that disabled children under 16 be referred to the state agency administering crippled children's services under Title V of the Social Security Act or an equivalent state agency. These agencies must prepare individual service plans for each child and refer each child to appropriate medical, educational and social services.

For further information, send for:

S.S.I. Advocates Handbook, \$3.50 from the Center on Social Welfare Policy and Law, 95 Madison Avenue, New York, N.Y. 10016.

### District transports

### ARC pre-schoolers

The Carthage Central School District will transport as many as 10 pre-school handicapped children to the ARC center in Watertown in the coming school year.

At the recommendation of Dr. Lawson A. Rutherford, district superintendent, the Board of Education agreed to absorb the transportation cost, estimated at about \$6,000 for the year, or \$32.50 per day. The cost is not reimbursable.

The program and facilities of the Jefferson County Center for Aid to Retarded Children offers participating pre-school children a "better chance to achieve," Dr. Rutherford told the Board of Education. The children identified as eligible for the ARC program range in age from 1 to 4.

# Double standard riles parents of retarded

When Judy Scarcello was born with brain damage, doctors warned that "she would never walk or talk or hold a cookie" said her mother Carolyn, who also has three normal children.

But Mrs. Scarcello opted against sending her daughter to an institution, and fourteen brain operations later, Judy, now 11, walks and talks. "Not very well, but she does", said her mother — and she is toilet trained.

Judy stays at home in Scarsdale. "She lives on a drug schedule. If she had been placed in an institution, I doubt she would have lived, because I don't know that they would have given her the proper medication," said her mother. "I've always wanted her at home. She smiles, and she's a real blessing to the family."

But Mrs. Scarcello's decision to keep Judy at home is costing the family money. Not only must the family pay Judy's medical bills, pharmacist bills, and tuition at Saint Jude's Habilitation Center in Valhalla, the family cannot collect a State subsidy available to parents who have brought children home from one state institution.

## MONTHLY SUBSIDY FOR SOME FAMILIES

A monthly subsidy — \$292 in New York City and \$237 in the rest of the state — is funded by the State Department of Mental Hygiene (CMH) to "family caretakers" who have brought home children from the Willowbrook institution on Staten Island.

Nobody else — not families who have kept their mentally retarded children at home, nor parents who fetch their children from other state institutions — get the "family caretaker" allowance. Why not?

"Because those children were not residents of Willowbrook on March 17, 1972," said a DMH spokesman, Thomas Coughlin, DMH deputy commissioner for mental retardation. "Our aim is equity and we're not there yet. I'm the first to admit it."

## CARETAKER PROGRAM

"The 'Family Caretaker Program' was set up as part of the Willowbrook consent decree, the result of a 1972 class action suit brought by the American Civil Liberties Union, the state Association for Retarded Children (ARC) and the parents of Willowbrook residents. It offers a subsidy to parents who bring home members of the 'Willowbrook class', that is, children who were Willowbrook residents on March 17, 1972.

The department has pledged to run down the population in the institutions, and to put the mentally retarded children in community-run programs in their home communities. The payment, said DMH spokesman, "enables these people to move home faster, years before they would have."

Coughlin added, "We've been using the Willowbrook consent decree to try out projects, and if they work we can expand them statewide." Coughlin noted that response to the program "had not been great." At last count, two months ago, 20

Arcy Degni of Utica has been reappointed by Governor Hugh L. Carey to the Job Development Authority, which helps business and industry to build and expand and provide employment.

Mr. Degni is a member of the Oneida County Chapter and a member of the Board of Governors of the New York State Association.

He is president of New York State Building and Construction Trades Council and Mohawk Valley Building and Construction Trades Council.

families had taken advantage of the allowance available.

## DOUBLE STANDARDS DISCRIMINATE

However, parents rearing institution-eligible children at home are up in arms. "The state is forcing parents to place their children in institutions," said Mrs. Scarcello. "Something has to be done to help these families keep their children at home. We can't live by double standards. We would like our children to be on the same level with children who are in institutions."

Mary Doyle of White Plains said, "The parents with mentally retarded children at home are being discriminated against. Why should we not get an allowance also?" Mrs. Doyle, a widow with six children, is rearing at home a severely mentally retarded daughter, Nora-Ellen, who at age 20 cannot walk or talk and isn't toilet trained. Nora-Ellen has learned to hold a cup and spoon.

Caring for Nora-Ellen is "physically hard and very expensive," said Mrs. Doyle. "But I've never considered institutionalizing her," she said. "I read about the conditions in those institutions. Who could put their child in there, who could do it?"

## Rome dumping protested

Upset with the state's policy of increased community care of the mentally retarded and mentally ill, Oneida County executive William Bryant has urged U.S. Secretary of HEW, David Mathews to reject the state's five-year plan to serve the mentally retarded.

Bryant said he was asking HEW to reject the plan because the State Department of Mental Hygiene is dumping patients into the community from Utica and Marcy Psychiatric Centers as well as Rome Developmental Center.

The State's plan of compliance calls for deinstitutionalization of 1201 additional Rome Developmental Center residents. That would be a reduction from 1890 in 1975-76 down to 689 by 1981.

By releasing the patients without providing what he called "human community facilities" Bryant said the state is creating "a mental health ghetto" in Utica.

Bryant said the county already has more than 3000 mentally disabled individuals being served in government sponsored mental health programs. Of these, the Association for Retarded Children serves about 350.

**To release these patients, who are after all ill, prematurely and massively, as the state is doing now, is merely to commit them to a different form of institutionalization where they are now confined by the hostilities and fears and anxieties of those who are not yet equipped**



## Welfare League opens new offices on Letchworth grounds

Dorothy W. Gasman, right, President of the Welfare League, receives, from Dr. Oleh M. Wolansky, director of Letchworth Village Developmental Center, Thiells, the keys to the new offices of the League, the local chapter of the New York State Association for Retarded Children, which were recently dedicated at Letchworth. It is the first time that a chapter of the ARC has established a headquarters on the grounds of the institution it serves.

## Parents harassed for state fees

### THREATENING LETTERS SENT FOR FEES FOR INSTITUTIONAL CARE

The State Office has received many complaints from parents of children in our State Developmental Centers indicating the office of Patient Resources has reinstated its policy of harassment of parents who are not paying for their children's care. The most recent letters demand payment within two weeks, or "we will be forced to refer this matter to the New York State Department of Law".

Some letters request payment on the grounds of the recent "Levy" decision.

The question of reimbursement for residents of State Developmental Centers is being litigated in the Civil Court of the City of New York in the case of State of New York vs. Robert Dolan.

The case of Levy involved private, out-of-state schools, not facilities of the Department of Mental Hygiene.

Furthermore, the laws under which the Levy case was considered, have been changed, effective 7-1-76. In addition, regulations dealing with the Vocational Rehabilitation Act of 1973, section 504, clearly indicates there is some question about the ability of the Department of Mental Hygiene to charge for special services for the mentally retarded. Under that regulation, the tuition for such educational services would include food, clothing and usual medical care.

Of course, this does not affect the possible liability of parents for fees before July 1, 1976 or before 1973, date of the Vocational Rehabilitation Act. But that is the very question now being litigated in the case of New York State vs. Robert Dolan.

In spite of the repeated requests of New York State Association for Retarded Children to the State of New York DMH that this harassment cease pending final decision of these cases, expensive efforts to collect funds continue.

## ARC Director named to post

Arcy Degni of Utica has been reappointed by Governor Hugh L. Carey to the Job Development Authority, which helps business and industry to build and expand and provide employment.

Mr. Degni is a member of the Oneida County Chapter and a member of the Board of Governors of the New York State Association.

He is president of New York State Building and Construction Trades Council and Mohawk Valley Building and Construction Trades Council.

## Late filing loses city \$1.8 million

The City of New York incurred interest costs of 1.8M dollars it should have avoided if its Department of Mental Health and Mental Retardation Services had promptly claimed \$111.6 million in state aid for which it was eligible, a state audit disclosed recently.

The audit cited sloppy administration by the department as the principal reason for long delays in claiming state reimbursement on department contracts.

Among the major reasons for the delay in claiming state aid, the audit listed the following:

Submitting the department's annual local services plan three months after the state deadline in fiscal 1973 and two months after the cutoff on fiscal 1974.

Rejection by the state of major elements of the plans after they were submitted because the information they contained did not meet state requirements.

Delay of two weeks to over 11 months in the department's review and approval of its own contracts for mental health services with voluntary agencies.

# MH plan to meet Federal standards

## Carey's release plan scored

### CAREY'S RELEASE PLAN

Details of New York's proposal for meeting new federal regulations governing intermediate care facilities for the mentally retarded were announced last August by Governor Hugh L. Carey.

The major thrust of the five-year compliance plan is to develop a comprehensive system of community-based services.

"We will not perpetuate the mistakes of the past in this important area," Governor Carey said.

### PLAN OUTLINED

"This plan outlines our commitment to develop the framework which will allow every mentally retarded citizen to realize his or her maximum potential and to live in the most comfortable, independent and normalized setting possible. . ." The Governor also related his compliance proposals directly to the commitment he made when signing the Willowbrook Consent Decree (see the article on motion for contempt). He said the plan will assure the benefits of the Willowbrook judgment to every person who must remain in residence in a state developmental center. (see action against Wassaic). The highlights of the plan which result in the saving of over \$30 million originally requested to renovate older state facilities include:

— Five year placement goals to return nearly 9,000 mentally retarded people to their own communities and reduce capacity of state developmental centers from the present 23,000 to 10,500.

— The hiring of 1300 new employees.

— Correction of some \$2.7 million in equipment deficiency to bring state centers in line with new regulations.

— Increase in the number of available hostel placements in the state from the present 1100 to more than 7000. 60 new hostels, each designed to serve about 15 people, are planned during the current fiscal year.

— Increase in generic services such as intermediate care facilities and nursing homes with 1500 placements required over the five-year period.

— Use of purchase of service agreements to provide start-up costs of reimbursement to public and private agencies offering community-based residential and habilitation programs to former developmental center residents.

Reactions to the plan have been almost unanimously critical with descriptions that is is "a hoax", "cruel and inhuman", etc.

### 2 ARC members

#### appointed

Governor Carey has appointed members of the Association for Retarded Children to Boards of Visitors of the Developmental Centers of the State.

Jerome W. Isaacs of Staten Island, a research analyst for Philip Morris, Inc. and a director of the Willowbrook Chapter, succeeds Lee L. Landes of Staten Island on the board of the Willowbrook Developmental Center.

On November 4th, 1976 Governor Carey also appointed Evald Gassstrom, First Vice President of the State Association, to the board of visitors of the Westchester Developmental Center.

It is interesting to note there is yet no residential facility in Westchester.

Congratulations to our two board members on these appointments.

### RELEASE LABELED CRUEL

For example, Governor Carey's plan to release half of the mentally retarded residents in state institutions into local communities was labeled "cruel and inhuman" by Nassau County Executive Ralph G. Caso. He noted Carey is providing no state funds for the Association for the Help of Retarded Children or other agencies which may have to assist the former patients after they are released.

He also observed that neither the AHRC nor any other groups, which may be responsible for the future welfare of discharged retarded persons were consulted when the Governor was developing the plan.

He said Carey has overlooked the fact that "97 per cent of the retarded already live in their home communities."

### HELEN KAPLAN JOINS CRITICS

Mr. Caso was joined in his criticism of Mr. Carey's plan by Helen Kaplan, executive director of the Nassau County Chapter of ARC and many others.

The Governor was charged with doing nothing to aid construction of new facilities and recently vetoed a bill which would have permitted community agencies, who have constructed such facilities, to compute interest on mortgages for new facilities as a reimbursable expense from the state.

Joseph T. Weingold, executive director of the New York State Association for Retarded Children, said, "This is a plan that deals without the most important elements. . . the creation of community facilities to serve these institutionalized persons who are placed in residences. There is no plan for this, no funds available for capital construction for this, and apparently no interest in this except to put the burden on the voluntary agency which is staggering already under the burdens of benign neglect by the state."

## Simches resigns

In a letter dated October 20, 1976, Raphael F. Simches, Director of Division of Development Support Services, Education of Handicapped Children, State Department of Education, indicated he would resign effective November 1 to take a position with Nero Associates in Virginia.

In his letter to Jerry Weingold, he wrote, "I don't know if this is presumptuous on my part, but I would appreciate if you would express my gratitude to the members of your Association with whom, over the years, I have had the pleasure of working and planning with in bringing about the many changes in the field of special education. The past 23 years in New York State have been exciting ones and despite the stress and the controversy, out of it, gratifying things have happened. It seems like such a long time ago that we used to sit and talk in Dick Hungerford's apartment. The past has had good years and I anticipate the future will have as much to offer."

Acknowledging this letter, Jerry Weingold wrote to Ray Simches, "I need not tell you how disturbed I personally was by your call to me that you were leaving and why you are leaving the State Education Department. I can only say that it is their loss. But, this is not entirely true; it is also the loss of the mentally retarded and other developmentally disabled in this State."



Left to Right, William Walker, President New York State Hotel, Restaurant and Liquor Dealers Association, Elmer Heckman, President Saratoga County Chapter, Jeanne Walczak, Joseph Cassella, President Saratoga County Hotel, Restaurant and Liquor Dealers Association.

## Restaurant Dealers help

At the recent annual Dinner Dance of the Restaurant Dealers Association, a check for \$4,500.00 was presented to Elmer Heckman to support the work of the Association for Retarded Children in Saratoga County. The check included the proceeds of the second annual Charity Ball sponsored by the Hotel, Restaurant and Liquor Dealers Association, held at the Casino in Congress Park on September 17. Al Kaye's Orchestra played for dancing until 2 a.m. All the food and liquid refreshments were donated by the Hotel, Restaurant and Liquor Dealers Association.

Much credit for the success of the Ball is due to Sid McIntosh, Ball Chairman and his hard working committee. Recognition was given to Mrs. Walczak, wife of Edward Walczak, Chairman of the Restaurant Dealers Board of Directors, for the tremendous job she did on ticket

## ARC loses Wassaic first round

The New York State Association for Retarded Children has lost the first round in a legal battle to prevent the transfer of 200 Westchester residents from Wassaic State School to Harlem Valley Psychiatric Center.

At a hearing this summer, the United States District in Manhattan, Judge Milton Pollack, lifted a temporary restraining order won earlier by the Association for Retarded which had halted the transfer of the first group of 25 patients from the crowded facility.

Jack Bernstein, director of the System of the Advocacy for the Retarded (SOAR), which has filed a class action suit on behalf of all Wassaic residents to improve their care, said "The move will not raise the standards of care for the retarded. The facility at Harlem Valley is close to a railroad track and a road that presents a hazard for the retarded".

Furthermore, according to Joseph T. Weingold, Executive Director, transfer from Wassaic to Harlem Valley is not to the least restrictive alternative.

The Association is opposed to the "warehousing of retarded from one institution to another rather than integrating them into the community, a philosophy that had been agreed upon by the state mental hygiene department".

The Association is continuing with its action, the major thrust of which is to extend benefits of the Willowbrook decree to the other institutions for the mentally retarded, in this instance, Wassaic.

sales. She personally sold \$1,600.00 worth of tickets.

The Saratoga County Restaurant and Liquor Dealers Association is sponsoring the Charity Ball for the Association for Retarded Children as their major annual charitable contribution.

## Handicapped count for HEW

According to a release from HEW, all states must report the number of handicapped children receiving special education and related services.

Under the requirements of the new Education for All Handicapped Children Act (P.L. 94-142), the count is essential to determine the allocation to the States of Fiscal Year 1978 funds. The new formula in the law bases the allocation on the number of handicapped children aged 3 through 21 served in each state.

P.L. 94-142 contains extensive amendments to the Education for the Handicapped Act, Part B., which provides aid to states and outlying areas to initiate and improve programs for the education of handicapped children. Most of the amendments are not effective until Oct. 1977, but the new funding formula requires the states report to the Commissioner of Education the number of children served on October 1 and February 1 of 1976. The allocation is then based on an average of the number counted on those two dates.

Although the Commissioner of Education shares the concern about labeling children, it has been determined reporting should be done on the basis of handicapping conditions to assure an accurate count and to eliminate duplication. Information would not be in a personally identifiable form and would be subject to protection under existing confidentiality requirements.

Thanks!



©HVAS

## Society fails to develop potential of retarded

This story by Saul Kapel, M.D. appeared in the Daily News and was sent to us by H. Steven Fineson, son of the late Bernie Fineson, former president of the State Association, our dear friend and colleague. Steven is a resident of Finesone House, hostel run by the New York City Chapter, and is employed by the Postal Department in New York City.

Two contrasting stories involving the mentally retarded appeared recently. The first concerned a middle-aged mentally retarded man who had become lost while visiting his sister in an unfamiliar part of New York City.

A TV news show asked the public to keep an eye out for him and described the missing man as 54 years old with the mentality of a 6-year old.

About the same time, a newspaper ran a long piece about 28-year old Tommy Trussell of Lubbock, Texas. He had suffered brain damage as a child and on the basis of IQ tests on which he scored from 50 to 70 he was classified as mentally retarded.

The contrasting items demonstrate the common, destructive, and inaccurate way in which many people regard the mentally retarded. Dr. Willard Gaylin, president of the Institute of Society, Ethics and the Life Sciences and a professor of psychiatry and law at the Columbia University Law School says: ". . . we now recognize the mentally retarded as a broad spectrum of individuals who, while limited in their capacity for certain functions of the healthy mature adult, are not limited in all.

Gaylin rejects the notion of a retarded adult as having the "Mentality of a 6-year old." He says: "A 36-year old with severe retardation to the point where he can neither read, write, count, tell time, nor follow street directions can still be a mature adult in a host of ways beyond the capacity of the 6-year old.

The price we make the retarded pay for their incapacity in one area is the sacrifice of capacity in certain other areas which could be compensatory if allowed to develop."

## Kolb on consumer conflict of interest

In a memorandum sent to the Mental Health Boards of the State of New York, the Commissioner of Mental Hygiene, Lawrence Kolb, stated that members of the mental health boards that are connected with service providing agencies such as the ARC, may have a conflict of interest and should be (a) excluded from all deliberations involving grants to their own associations and (b) removed from the room when discussions of budgets are going on.

The New York State Association for Retarded Children, through its Executive Director, protested this is obvious discrimination against representatives of the consumers of these services participating on community mental health, mental retardation and alcoholism boards.

"They were duly appointed by the proper authority," said Mr. Weingold. "They have every right to participate in every way."

In a letter to Mrs. Karin Burgess, member of the New York State Board of Governors and on the mental health board of Cortlandt County, he said, "the conflict is the ambivalence of the Department of Mental Hygiene with regard to consumers. It is a love-hate relationship, that requires psychiatric intervention."

Gaylin blames society's failure to develop the potential of the retarded upon too heavy a reliance upon IQ scores. These tests, as I have often pointed out, measure only limited aspects of learning power.

The public should recognize that the label of "Mentally retarded" covers a wide range of youngsters who are intellectually deficient. Many of these retarded individuals with special training and counseling, can learn to handle simple jobs and some can live by themselves, as Tommy Trussell does, rather than in institutions.

Actually, as the newspaper points out, Trussell is representative of a growing number of retarded adults who have entered the labor force.

"We find our mentally retarded employees to be patient, persistent and dependable," says an official of the Marriott Corporation which employs the retarded in its hotel operations. American Motors Corp. claims more than 100 of its regular work force are mentally retarded and Emerson Electric has a dozen earning \$3.55 an hour assembling chain saw engines.

Based on this evidence, parents of a child diagnosed as mentally retarded ought not to resign themselves to thinking of him as a child all of his life. As Tommy Trussell says: "Nobody has to baby me anymore."

## MH planning chairman named

Governor Hugh L. Carey announced the appointment of Mrs. Jean Kennedy Smith as chairperson of the newly created Council for Mental Hygiene Planning.

The new 15-member council will formulate statewide goals and objectives for the State Department of Mental Hygiene and will review comprehensive master plans for the delivery of services to the state's mentally disabled. It was established under a bill passed in the 1976 session of the legislature.

The council will be composed of the Commissioner of Mental Hygiene and 14 others appointed by the Governor; two of whom will be chosen through recommendation by the Senate Majority Leader, two from recommendations by the Speaker of the Assembly, and two directors of community services from recommendations by the New York State Conference of Local Mental Health Directors.

Members are required to have demonstrated an active interest in, or professional knowledge of, mental disabilities and are to be chosen from among consumers, former patients, consumer groups, parents or relatives of patients, or former patients, providers and voluntary agencies.

Active in a number of civic efforts including the Kennedy Child Study Center in New York City, Mrs. Smith is also a trustee of the Joseph P. Kennedy, Jr. Foundation, the John F. Kennedy Center for the Performing Arts in Washington and other family philanthropic endeavors.

Mrs. Smith, a graduate of Manhattanville College in Purchase, resides in New York City with her husband, Stephen E. and their four children, Stephen, Jr., William, Amanda, and Kym.

Her appointment is subject to Senate confirmation.

## Willowbrook

## Parents protest



Relatives of patients protest conditions at Willowbrook Developmental Center on Staten Island, contending the state broke a series of promises to upgrade the facility for the retarded. Members of the Staten Island C.B. Radio Club joined protesters from the Willowbrook Chapter of the New York State Association for Retarded Children.

With the battle cry that retarded children cannot wait, members of the Benevolent Society for Retarded Children, Willowbrook Chapter of the State Association for Retarded Children, went to the protest lines to demonstrate against a number of conditions at the developmental center on Staten Island.

Mrs. Genevieve Camen, president of Benevolent Society, blamed the Department of Mental Hygiene for not working with compassion for the residents.

Mrs. Camen, with Anthony Pinto, second vice president of Benevolent Society, cited "poor supervision, lack of proper planning, mismanagement, understaffing, lack of progress in compliance with the Consent judgement, marginal medical care and a host of other grievances not properly considered by the Department of Mental Hygiene."

### DMH NOT IN COMPLIANCE

At this point, the Department of Mental Hygiene is clearly not in compliance with the Consent Decree in the Willowbrook Case, an action brought by the New York State Association for Retarded Children and the parents against Governor Carey and the Commissioner of Mental Hygiene.

The situation was exacerbated with the appointment of Dr. Lee Cannon as director of Willowbrook without any consultation with the Society or the parents who were promised that they would be so consulted before a selection was made.

She added, "We feel that the director of Willowbrook should not in any way be connected with the Department of Mental Hygiene because he brings with him the Department's locked in philosophy about the place."

### CAREY INSULATED FROM PARENTS

Meanwhile, a month after these demonstrations, Governor Hugh Carey returned for a quick tour of the institution and left with a generally favorable impression over what he called "a substantial improvement" in conditions.

Carey's first stop on the tour, escorted by the Willowbrook director, Dr. Cannon, was the vocational workshop program, building 61. Carey noted that one child he met in the workshop was a visible example of changes in the institution. "The last time I was there this boy was lying on his back, in a restraining situation, now he is up and about and obviously making progress".

He also visited building No. 12 used for younger multi-handicapped children where a federally assisted program is

helping children to be trained to feed themselves.

Afterwards at the Institute for Basic Research, which has been about 80 per cent underutilized since it was opened in 1968, Carey reiterated his hope that the Institute will eventually lead to the prevention of many cases of mental retardation.

### CAREY TOUR NOT REPRESENTATIVE

Mrs. Genevieve Camen, President of the Parents' Association, later said that Carey was shown the two best buildings at the institution, both of which were unrepresentative of conditions there.

"We have been trying to see the Governor for months," Mrs. Camen said. "Why didn't they show him the buildings where children have no programs at all, no decent food, and inadequate medical treatment?" Mrs. Camen also said she had been prevented from seeing Carey during his tour at the institution.

## Oswego parents

### help parents

When a couple finds out that a newborn infant is handicapped, they want to know how they could help their child to grow to his or her potential. Their baby has special needs.

In Oswego County, parents in this situation have a place to turn. The ARC chapter teaches parents how to help their handicapped children develop.

And it all begins right in the home, where the child and parents are most comfortable.

Although ARC focuses on programs for mentally retarded people, the Association offers similar services for children and adults with other handicaps as well.

According to the Executive Director, Elizabeth Vaught, the ARC believes in the simple truth that the sooner a handicap is detected, the sooner services can begin, the better off that person will be later on in life. Early intervention may make the difference in a child's ability to walk and speak as an adult.

Other chapters of the Association, such as Suffolk, Onondaga, and many others have similar programs of early childhood intervention which was the theme of in-service training for teachers and teacher aides in private schools for mentally retarded and other developmentally disabled persons.

# Plaintiffs accuse three of contempt

Dr. Lawrence C. Kolb, New York State Commissioner of Mental Hygiene, and two other state officials have been accused of civil contempt for their failure to carry out a court order to improve living conditions for the mentally retarded at the Willowbrook Developmental Center on Staten Island.

In addition to Dr. Kolb, those named in the papers filed by lawyers for the plaintiffs are Thomas A. Coughlin, III, a deputy commissioner for mental retardation, and Dr. Alvin M. Mesnikoff, a regional commissioner for the Department of Mental Hygiene. The contempt motion asks that the state officials be required to pay "a substantial fine" for not putting into effect a consent decree signed last year and that the officials be confined on weekends either in a federal house of detention or in a typical residential ward at Willowbrook until they purge themselves of contempt.

The major area of noncompliance, according to the motion papers and the review panel, has been the failure to place Willowbrook residents in small community facilities.

## TRANSFERS NOT MADE

A spokesman for the Review Panel said 200 were to have been removed into such facilities the first year, but only 135 were transferred. Moreover, 600 were to have been transferred this year but, in the first six months, only 81 were moved.

Other major areas of noncompliance were said to be the failure of the state to provide adequate staffing for Willowbrook and the failure to comply with the requirement that each resident get six hours of individually tailored program.

Barbara Blum, the assistant commissioner of the Department of Mental

## Teacher firings

### menace retarded

The head of the school system in New York City, Special Education Program for Retarded Children, charges that mentally handicapped students will face severe safety hazards in the coming year because of teacher layoffs ordered by the Board of Education.

Maeline Dalton, director of the system's Bureau for Children with Retarded Mental Development, warned that the elimination of 233 of the Bureau's 1,076 teachers would force an increase in class size, "that would not only exceed state maximums, but will make it impossible for teachers to adequately protect these severely handicapped children."

Ms. Dalton, responsible for the education of 13,000 retarded students, said the Board of Education has been advised the layoffs would force class sizes that "violate state law".

She said many children involved are afflicted with multiple handicaps "and many have serious emotional problems which make them very difficult to control."

The classes last year varied, depending on age, from 8 to 18 students. These same classes now will go from 13 to 23 students.

School Chancellor Irving Anker, when asked about the possible safety hazards, said he felt the director's fear was exaggerated.

Anker felt the board had given special consideration to the special education program and had actually increased that budget by \$15 million more than the amount specified by the city.

Hygiene in charge of placing Willowbrook residents into the community, said, "Given the realities of the situation, the deadlines are too short." She added that one major factor holding back the placement of disabled in community facilities was community resistance.

**Editor's note:** The State Association for Retarded Children offered a bill last year restricting the power of local communities to pass or enforce the zoning ordinances which would prevent the establishment and operation of group homes for the mentally retarded and other developmentally disabled.

## INADEQUATE STAFF

As for having adequate staffing at Willowbrook itself, Mrs. Blum said, "The place is so large, it can never be staffed adequately."

At a hearing on November 19 before Judge John R. Bartels, who replaced Judge Judd, deceased, he considered a motion by the Willowbrook Review Panel, the group designated by the court to monitor the state's compliance with the federal guidelines to have responsibility from Dr. Kolb shifted to an expeditor to be named by Governor Carey.

An affidavit submitted with the contempt motions said that the areas of noncompliance were so broad as to "seriously jeopardize the lives, health and welfare" of the mentally retarded residents.

Audits by the Department of Audit and Control under Controller Levit have been consistently critical of the internal operations of Willowbrook.

## Federal contract

### for Oneida

A Federal government contract, estimated at a cost of \$400,000, to produce tent pins for the General Services Administration, has been awarded to Progress Industries of the Oneida County Chapter sheltered workshop, according to Gerald Matthews, Executive Director of the chapter.

The center was chosen, with 40 others in the nation, to produce commodities and services through the Javits - Wagner O'Day Program. Under the program, workshops for the severely handicapped are authorized as the sole producers and sellers of selected commodities and services normally purchased by the government.

The Wagner O'Day Act was amended by Senator Javits at the suggestion of Jerry Weingold in 1971.

On June 13, 1971, President Nixon wrote to Senator Javits "Recently I signed S. 557 revising provisions of the Wagner - O'Day Act. I understand this bill, of which you were the principal sponsor, originated from an idea presented to you by Joseph T. Weingold, executive director, New York State Association for Retarded Children. I am enclosing a pen which I thought you might want to give to Mr. Weingold as a memento."

## 9 hostels

### for Jefferson

Jefferson County Chapter of the Association has purchased the Wendell E. Holland residence at Evans Mills for \$40,000 for use as a hostel. This hostel is the ninth for the ARC. It is hoped, by the time this issue of OCV is in your hands, the hostel will be occupied.

# Welfare League position on de-institutionalization

## Letchworth population depletion opposed

In a recently issued statement, Dorothy Gasman, President of the Welfare League, Letchworth Village Chapter, stated a position on deinstitutionalization which, we think, requires careful consideration by all the members of the Association and should be the basis of some policy decisions by the Board:

"A few years ago, the Federal Government began to recognize the rights of the retarded and, among other actions, embarked upon an ambitious program to improve conditions for the retarded in institutions. We are in complete agreement with the goals of this program which are embodied in the regulations regarding Intermediate Care Facilities for the Mentally Retarded. But the implementation of this program, at the present time, will require the resettlement of approximately 1,000 people from Letchworth Village within two to five years.

We are opposed to such a rapid depletion of the population of Letchworth Village for the following reasons:

1. The stated goal of the Department of Mental Hygiene is to place these people in the metropolitan area of New York City. Can such an area be found other than at Letchworth or its environs? One must keep in mind that 80 per cent of the residents of Letchworth Village come from New York City. To place them farther away would be to deprive them of visits from home and family.

2. A sufficient number of sites cannot be obtained, nor hostels built in time to accommodate such numbers.

3. Large numbers will have to be placed in Family Care units which are being too rapidly recruited — a fact which contributes to their instability.

4. A sufficient number of programs and facilities cannot be made available to accommodate such numbers, even if the money is readily available to these communities.

5. Accountability will be diffused. Improper care and feeding and mistreatment cannot easily be discovered by a social worker whose clients cannot use a telephone and who see her perhaps once a month.

## Allen named

### NYS E. & G. head

Wells P. Allen Jr. of Binghamton was recently named President of the New York State Electric and Gas Corporation.

Wells Allen is known to us as a devoted worker in the field of mental retardation and former president of the Broome County Chapter.

Allen was elected president of the utility during a board of directors meeting held in Ithaca. Allen who was executive vice president of the utility, replaces Lloyd L. Kelly, who resigned as president and director on Sept. 2nd. Allen joined the utility in 1949 and was elected to the board of directors in 1974.

He is a director of the Empire State Electric Energy Research Corp., Columbia Mutual Life Insurance and the Broome - Tioga County Chapter of the ARC. He also serves on the Board of Governors of the New York State Association and is a member of the Foundation for the State University of New York in Binghamton.

We are sure that all the members of the Association join in congratulating Wells and wishing him the greatest success in his new job.

Furthermore, we oppose the entire concept of deinstitutionalization as presently conceived because it does not take into consideration the needs of those residents in the community as well as those in the institution who will need care for the rest of their lives. These people should remain the responsibility of the Department of Mental Hygiene. Deinstitutionalization will result in:

1. The diffusion of responsibility through various agencies and communities. The result will make the enforcement of accountability impossible.

2. It will disperse the professionalism and expertise so recently developed in the care of this special part of our population.

3. It will make the delivery of services more costly, but the costs will be hidden. Figures would make it appear to be cheaper to house someone in a hostel, but who will ultimately be paying for the programs and services that the retarded need? Who will pay for the transportation to these services located all over the countryside? Who will pay for the social workers to travel all over to visit their clients and their services? Deinstitutionalization will be inefficient.

4. Supervision over a widespread area and diffuse network cannot assure the quality of care.

5. The policy will engender hostility in communities slow to accept the retarded in their midst.

6. It will disperse a labor force, in most cases, trained and devoted to the care of our children.

7. It will weaken the parent organizations designed to safeguard the most severely handicapped.

We believe the needs of our retarded children can be served by the strengthening of community - based services. As the quality and quantity of these services is improved so that the communities are in a position to take care of their own retarded populations, they will be better able to absorb those coming from institutions who might profit from a community setting.

## Cayuga preferred

### supplier for N.Y.S.

After several months of negotiation, the Cayuga County Chapter was officially designated the preferred supplier for the State of New York for the production of hardwood pallets.

Currently dealing with the New York State Department of Mental Hygiene, Bureau of Supply Support, the Chapter has been supplying pallets since September. The overall volume to date is approaching 1,000 per month and is expected to exceed 1,500 within the next few months.

Cayuga Chapter, as a member agency of New York State Industries for the Handicapped, is authorized to deal with all State Divisions which purchase hardwood pallets on an exclusive basis.

In addition to the increased revenues generated by this manufacturing process, the training value for the Chapter clients is extremely valuable.

## The Enormous Room

## My Heart and My Flesh

## Raintree County

## Strange Fruit

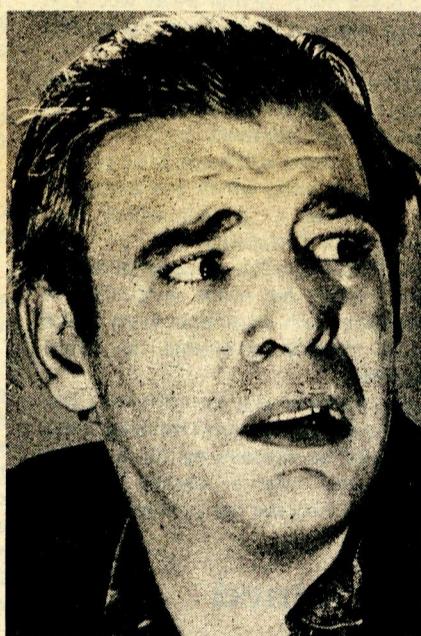
# The retarded in fiction After many generations, they 'g

Dr. Frances King, a professor of literature at American University and the parent of a retarded child, has published an annotated bibliography of the fictional treatment of the mentally retarded. Dr. King

This bibliography covers a period of about 70 years (American fiction 1900-1970) which mark a significant alteration in public attitude toward retarded persons. It was undertaken to discover whether fiction does or does not reflect public attitude. The answer, as far as this bibliography is concerned, is that some does and some does not and some anticipates. The earliest entry, 1903, reflects the general public misapprehension of the distinction between mental illness and mental retardation. *Their Child* by Robert Herrick describes what apparently is an inherited homicidal mania about which modern psychologists would be very skeptical. Earlier novels also frequently introduce two kinds of stereotypes: "the wages of sin" theme (*Shepherd of the Hills* by Harold Bell Wright) and the vicious monster (*My Heart and My Flesh* by Elizabeth Maddox Roberts). By the 1960's the retarded character had graduated into the human race in fiction as well as in life. On the other hand, Faulkner's retardates appeared in the 1930's well ahead of public understanding and acceptance, a fact which accounts for some hostile criticism of him. His characterization was both accurate and sympathetic.

The retardate plays a variety of roles. Artistically he may fall into categories something like this: The scapegoat, or the sacrificial victim; the touchstone character, the treatment of whom establishes the quality of other characters; the wise fool, who says better than he knows; the innocent eye, who establishes an original perspective; the parody of caricature, which heightens by exaggeration ordinary human failings; and some others. Psychologically he falls into levels of competence called in the old vocabulary (now variously translated by the discipline): the idiot, the lowest level, unable to care for himself, somewhere below

two or three years of age (like in Faulkner's *The Hamlet*); imbecile, ranging up to an intellectual level of about six (Billy, possibly, in McMurtry's *The Last Picture Show*); the moron, now called the "educable" because he



Lon Chaney Jr. portrays "Lennie" in "Of Mice and Men"

is, in a very limited way (Charly in the first part of Keyes' "Flowers for Algernon"); and the dull-normal, who can cope acceptably if the life situation is not too complicated (Ruby Fisher in Welty's "A Piece of News" or Private Williams in McCullers' *Reflection in a Golden Eye*). These levels are not rigid of course. The psychologists do not agree. Furthermore, some authors obviously are more perceptive than others. The insight of those cited immediately above, however, is remarkably sharp.

In earlier fiction, the character was often sentimentalized unrealistically (*The Shepherd of the Hills*). The earlier instances

are included, but there are a number of examples of not dissimilar treatment in more recent years in magazines and collections of amateur stories. These are not included in the

published her research of American fiction between 1900 and 1970 in the *Bulletin of Bibliography*. Copies are available from the Montgomery County (Md.) ARC,

11212 Norris Drive, Silver Spring, Md. 20902.

bibliography, though their relatively more frequent appearance in such literature is significant. Strong cinematic versions of retarded characters have appeared recently ("Deliverance" by Dickey and "The Last Picture Show" by McMurtry). The retarded individual is now almost a fashionable inclusion in modern novels (*Play It As It Lays* by Joan Didion).

It is possible that William Faulkner's *The Sound and the Fury* is the great 20th century American novel. If it is, and if Benjamin Compson is its chief protagonist, then the hero of the great American novel of the 20th century is a 33-year-old idiot. A curious anomaly.

The division into novels and short stories is pragmatic and somewhat arbitrary. "Studs," the short story, according to Farrell, is the nucleus of the *Studs Lonigan* series. The short initial version of "Flowers for Algernon" is the one cited here because it is a prizewinner and superior to the later, novelized version, Faulkner's short sketch, "The Kingdom of God," presages Benjamin Compson in *The Sound and the Fury*. Faulkner used to assert that "The Bear" was part of a long novel, *Go Down Moses*. It has nevertheless been listed here as a separate novel. The determining factors in the two lists are length and independent unity.

A supplement to this list is planned. Information on omissions and additions will be most happily received.

Here is a sampling of Dr. King's remarkable bibliography:

Algren, Nelson. *The Man with the Golden Arm*. New York: Doubleday, 1949.

Sparrow is the nickname for "the punk," Solly Saltzman. He diagnoses his own level of competence in the courtroom when he is threatened with jail. "You're not allowed to do that

because I just ain't responsible...I got too many marbles to get put away...if a guy got twenty-one he's all there, so you can give him time. 'N if a guy got only eleven you can put him in the booby house. But I'm right in between, I got nineteen, it's not enough to give time 'n too many for the loony roost."

Peter Schwabatski, the son of the landlord, speech negligible, probably imbecile, plants paper flowers on the stairway and cannot learn to mend a stairstep in spite of his father's infinite patience. At the end of the novel, Sparrow says: "His dim-wit is goin to a school for tardy children, somethin like that."

Umbrellas, an incidental character, qualifies as well. Bellamann, Henry. *King's Row*. New York: Simon and Schuster, 1942.

Benny Singer is the moron in this case book of psychiatric studies, persecuted eventually

into defending neighborhood hanged by the o Didactic attempt possibility of people at this lev Bellow, Saul. *Augie March*. Dom House, 1960

Augie's yo George is in midway through undergoing ha stitutional meth described. Geor realized, a proper mother, who is s moron herself.

Bromfield, Le Country. New Row, 1948.

Emma Kleinfe faced sixteen poisons her foste to pursue Red, t trainer. She is viciousness but inaccurate. Prob



Billy, center, in a scene from Larry McMurtry's "The Last Picture Show" released by Columbia Pictures in 1971

All  
the  
King's  
Men

Of Mice  
and  
Men

The Shepherd  
of the Hills

Their  
Child

By Love  
Possessed

The  
Last  
Picture  
Show

Reprinted from CARC News — April, 1976.

# graduated into the human race'

his home against roughnecks, and obtuse community. Apt to show the habilitation for level of competence. The Adventures of New York: Random House, 1932.

—. A House Divided. New York: John Day, 1935.

The "poor fool," operating at a very low level, is a concern to her mother as long as she lives. After the mother's death, the father assumes this concern. The situation is a well drawn, realistic representation of the Chinese care of the mentally retarded.

—. The Mother. New York: John Day, 1934.

The blind daughter, since she is blind and useless, is married into a strange distant family. When the mother finally goes to see her, she is dead among the savage, hostile family. "The mother wished to see the husband. There he stood, a gangling, staring lad, and the mother saw he was nearly witless."

Caldwell, Erskine. *Tobacco Road*. New York: Random House, 1940.

Ellie May is the repulsive low-level idiot girl who contrives whenever and wherever possible to engage any male companion. She appears almost at once in *Tobacco Road* and sets the tone of the novel. Dude Lester, her brother, is also defective, probably because of cultural deprivation. Caldwell has a great many such characters, a favorite sociological cliche. Whatever its source, cultural retardation is a measurable phenomenon. Caldwell's treatment is accurate, hilarious, and tractarian; a combination of comedy and violence.

Capote, Truman. *A Christmas Memory*. New York: Random House, 1966.

"My friend" (possibly Miss Sook Faulk of Capote's own early life) is a well-oriented middle grade retarded female sixty years old whose affectionate contribution to a very simple household situation is a success story. Wry, contemporary posture: the dumber, the wiser. *Breakfast at Tiffany's*, New York: Random House, 1958.

a character who appears in Bromfield's autobiographical work, *Pleasant Valley*.

Buck, Pearl. *The Good Earth*. New York: John Day, 1931.

—. Sons. New York: John Day, 1932.

—. *A House Divided*. New York: John Day, 1935.

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Holly Golightly's brother Fred, whom she continues steadfastly to love, and, in her fashion, to protect, is a huge slow boy who loves peanut butter. He is accepted into the army and eventually killed. Army policy accepts a certain level of retardation for which Fred illustratively does qualify.

Carpenter, Don. *A Blade of Light*. New York: Harcourt, Brace & World, 1968.

The story follows the slow and painful rehabilitation of institutionalized retarded boy. Committed for criminal misbehavior and released a decade later, Irwin Semple is repulsively ugly and his real behavior patterns are altogether unacceptable. Nevertheless, he is a sympathetic hero. His adjustment and the ironic recompense to the villain constitute the story line. Excellent delineation of slow definite mental growth.

Cather, Willa. *My Antonia*. Boston: Houghton Mifflin, 1918.

Marek, one of Antonia's older brothers, is a retarded young man with webbed fingers (occasional syndrome). He works hard under his older brother's direction, but is eventually institutionalized. Cozzens, J.G. *By Love Possessed*. New York: Harcourt, Brace & World, 1957.

This novel involves a number of people "by love possessed." Caroline Dummer operates at the lowest level in the story. She is described by the institutional psychologist as a low-grade moron with a mental age of eight and is technically an accurate fictional representation. Her parents, who are nearly as stupid as she is, cannot induce her loving obedience.

Castaway, New York: Random House, 1934.

The doppelganger, who ranges destructively through the department store, may be retarded but may be only psychotic.

Cummings, E.E. *The Enormous Room*. New York: Boni and Liveright, 1922.

Jean le Negre, "of all the fine people in La Ferte, M. Jean le Negre ('le Noir . . .') swaggers in my memory as finest." "Jean le



John Steinbeck, Nobel Prize winner and author of "Cannery Row" and "Of Mice and Men."

Noir," "Jean le Geant" is the lighthearted man-mountain with the mind of a child, the huge and powerful Negro in jail with the narrator and thirty other men. Fairly lyrical, but the delineation of the pattern of Jean's behavior is sound.

DeVries, Peter. *The Cat's Pajamas* in *The Cat's Pajamas* and *Witches' Milk*. Boston: Little Brown, 1968, 3-189.

Raymond Yutch, "the backward boy," is the son of DeVries' protagonist's landlady, Mrs. Yutch, who shortly dies, leaving Tattersall the house and the boy. They live together in happy filth and chaos. They deal with the social worker who comes to inspect in this dialogue:

"Do you think this a good environment for the idiot?"

"Why don't you ask him?"

Raymond is the perfect audience for Tattersall's conversational gymnastics. Idiocy is an ideal foil for the verbal and intellectual DeVries high jinks. Raymond is a well-drawn mongoloid boy. His loving mother, before her death, has tried him both inside and outside the institution so that he will go happily back at Tattersall's demise. Tenderhearted comic DeVries tragedy.

Dickey, James. *Deliverance*. Boston: Houghton Mifflin, 1970.

The decorative retardate appears momentarily in Dickey's best-selling novel. An albino bajo player who had never gone to school, he cannot speak but can certainly play the banjo. The treatment is accurate and sensitive without being sentimental. In the book the mentally retarded character seems fairly extraneous but in Dickey's cinema version he becomes a powerful metaphor for the wall of incomprehension between the two subcultures.

Edmonds, Walter, Chad Hanna. Boston: Little, Brown, 1940.

(Posted Advertisement)

Claude Cronk, the

## DOGTOOTHED BOY

### HE EATS RAW MEAT!

Huguene's Great and Only International Circus will Exhibit the said Lusus Naturae, at each and every performance, inside the main tent.

This is the same situation Eudora Welty treats in "Keela, the Outcast Indian Maiden" from a different point of view. It lacks the humane overtones but is not sadistic. It is also lively, suspenseful, and hilarious. Claude is fully and fairly realized.

Farrell, James T. *Invisible Swords*, New York: Doubleday, 1971.

Recital of an uninspired average young American family's reaction to the birth and diagnosis of a retarded child. The baby Billy is very slightly sketched for an otherwise so minutely detailed treatment.

Studs Lonigan, New York: Vanguard Press, 1935.

"Curly, the corner imbecile," appears several times. He is not really imbecile — more nearly high-grade moron, but he is always the innocent clown.

Faulkner, William. *Absalom, Absalom*, New York: Random House, 1951.

At the end of the novel, Jim Bond, a mulatto imbecile, is the only living male descendant of Thomas Sutpen, the ambitious white adventurer. He lives for many years with old Clytem-

Continued on next page

# The retarded in fiction . . . continued

Continued from preceding page  
nestra in the abandoned slave quarters and disappears at the time of the burning of Sutpen mansion.

**Sanctuary.** New York: Cape and Smith, 1931.

Tawmy is the ugly, dirty imbecile with "rapt, empty gaze" who lives with the bootlegger Goodwin in the old de Spain house at Frenchmen's Bend. He cannot talk but attempts to protect Temple Drake by sitting outside the corncrib. He is shot for his pains and becomes the occasion for the trial.

**The Sound and the Fury.** New York: Random House, 1946.

It is conceivable that Benjamin Compson is the hero of *The Sound and the Fury*, in which case an idiot may be the hero of "The Great American Novel." The first section of *The Sound and the Fury* is an attempt to reproduce in words the thoughts of an almost wholly inarticulate human being. Granted that this is just a variant of what occurs in all literary art, the result is a profoundly skillful approximation. The technical means — synesthesia, a collapsed time sense, eidetic imagery, very elementary color perception, sentence structure which eliminates subordination, reduction of metaphor to direct apprehension — are all delicate and exact, but the whole effect transcends the means. This must be the most powerful literary representation of the idiot mind.

**Fox, John Jr.** *The Little Shepherd of Kingdom Come.* New York: Scribner's, 1931.

Jack Dillon, the slow one of the giant twins who confront each other on the two sides of the Civil War, motivated, sharpens up a bit by the time they are reunited at the end of the war.

**Glasgow, Ellen.** *Vein of Iron.* New York: Harcourt, Brace, 1935.

An idiot boy appears in the first chapter, persecuted by the neighborhood children, a situation which disturbs the heroine and manifests her humanity. Realistic.

**Herrick, Robert.** *Their Child.* New York: Macmillan, 1903.

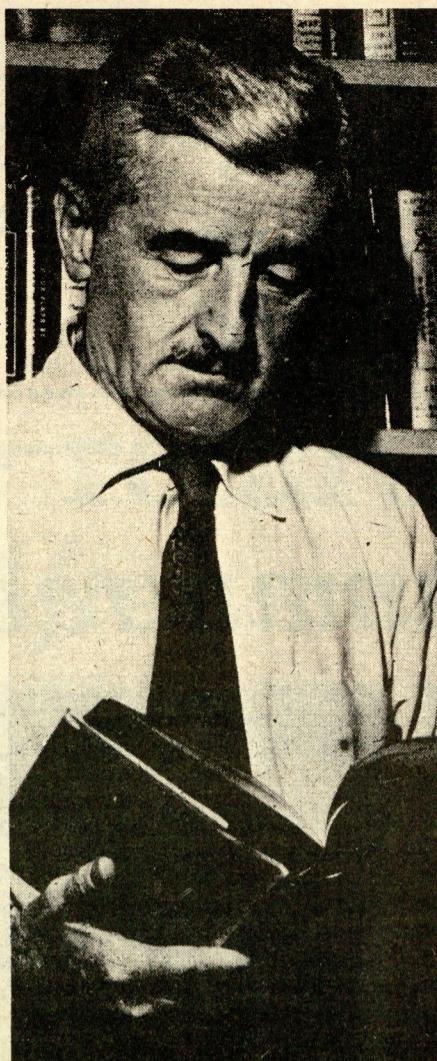
Inaccurate picture of an inherited homicidal mania in a small boy, considered mentally retarded but not. Notion of inherited family guilt sociologically acceptable in 1903.

**Hough, Emerson.** *The Broken Gate.* New York: D. Appleton, 1917.

"The Eejit," John Adamson, "has a low scowl like that of some angered anthropoid." Stereotype of viciousness. He kills a man whose death is attributed to the innocent hero. All is discovered and the Eejit is, happily, accidentally shot at the end. Saccharine and false.

**Lockridge, Ross.** *Raintree County.* Boston: Houghton Mifflin, 1948.

The beautiful woman who says



Nobel Prize winner William Faulkner, author of three books with retarded characters.

practically nothing throughout (played by Elizabeth Taylor in the movie) is a high grade moron, possibly dull-normal.

**McCullers, Carson.** *The Heart is a Lonely Hunter.* New York: Bantam, 1967.

The Greek mute, Antonopoulos, good friend of the intelligent deaf mute Singer who is the listener in the story, is an institutionalized cipher during most of story. His deterioration and eventual death destroy Singer.

**McMurtry, Larry.** *The Last Picture Show.* New York: Dial Press, 1966.

Billy, the deaf and dumb retardate, is the protege of Sam the Lion and, eventually, Sonny. He is the occasion for the resolution of the story when he is killed at the end by a truck as he is peacefully sweeping his way down the street early one morning. The sheriff says to the mildly perturbed truck driver, "He was just an ol' simple-minded kid, sort of retarded, never had no sense. Wasn't your fault. I can see that. He was just there. Wasn't doin' nothing." Touchstone character.

**Mannes, Marya.** *They.* New York: Doubleday, 1968.

Several genius couples are isolated on a distant shore by the future youth culture. One mother remembers sadly her retarded daughter Cora, who is no doubt discriminated by the new civilization, as are all the elderly except these isolated few.

**Roberts, Elizabeth Maddox.** *My Heart and My Flesh.* New York: Viking Pres, 1927.

Stiggins is Theodosia Bell's Negro half-brother, bastard son of her father and a half-witted Negress. His "response became a low monstrous laughter like the bleat of some great animal." Stereotype.

**Rawlings, Marjorie.** *South Moon Under.* New York: Scribner's, 1933.

Ramrod is an elderly religious fanatic. (Cf. the Misfit in O'Connor's *A Good Man is Hard to Find.*) Clearly retarded.

**Smith, Lillian E.** *The Journey.* Cleveland: World, 1954.

Largely autobiographical. Retarded characters appear more fully established in the fictional version, *Strange Fruit.*

**Strange Fruit.** New York: New American Library, 1954.

Crazy Carl, noisy cerebral palsy victim, is retarded but less so than he appears. Boysie Brown, the hydrocephalic child, is cared for by the young black heroine. Spencer, Elizabeth. *Light in the Piazza.* New York: McGraw Hill, 1960.

Beautiful young retarded girl is married, with her sophisticated mother's awareness, into a somewhat unaware but welcoming big Italian family.

**Steinbeck, John.** *Cannery Row.* New York: Viking Press, 1945.

Frankie is a mentally retarded 12-year-old who tries to steal a gift for Doc, the main character.

On a substantially higher level but still slow and somewhat incoherent is a young man named Hazel (cf. the young soldier in Carson McCullers' *Reflections in a Golden Eye*). "Casting about in Hazel's mind was like wandering alone in a deserted museum. Hazel's mind was choked with uncatalogued exhibits."

**Of Mice and Men.** New York: Random House, 1938.

Lennie, giant moron, loves soft things and almost inadvertently

kills a young woman. His friend George must rescue him from lynching by killing him. Sentimental but effective. Lennie is fairly realized.

**Styron, William.** *Lie Down in Darkness.* New York: Random House, 1964.

Maudie, the retarded sister of the heroine, is too greatly loved by the mother. This psychotic attachment sparks a story of disintegration and eventual suicide.

**Warren, Robert Penn.** *All the King's Men.* New York: Random House, 1953.

George, traumatic idiot, is the protege of Jack Burden's nominal father, the Scholarly Attorney. Jack, the narrator of the story, finds them in a drab upstairs room where George interminably chews up bread and makes small shapeless figures.

**Welty, Eudora.** *Delta Wedding.* New York: Harcourt, Brace, 1946.

Maureen Fairchild, beautiful retarded child, is rescued from an oncoming train just in time.

**The Ponder Heart.** New York: Harcourt, Brace & World, 1954.

Uncle Billy Ponder irresponsibly throws away handfuls of money in court, among other shenanigans.

**West, Jessamyn.** *Witch Diggers.* New York: Harcourt, Brace & World, 1951.

Of the population of the poor farm, four are listed as simple, one as crazy, one as bedfast, one as apathetic, two as diggers. Mild farce.

**West, Nathanael.** *The Dream of Life of Balso Snell.* Paris & New York: Contact Editions, 1931.

An idiot dishwasher is murdered by John Gilson according to his dream life journal.

**Miss Lonelyhearts.** New York: Liveright, 1933.

Letters to the Lonelyhearts column declare two problems: no nose and a mentally retarded sister.

Reprinted from Connecticut ARC News (CARC) April, 1976.

## How to be a killer

The following editorial from the publication whose name has not been given to us is sent by Evald Gasstrom, regional vice president of our Southeast Region.

All of us who feel that our duties as volunteers are too heavy, really should be reading this.

"We all belong to professional clubs and organizations and these groups are important contributions to the growth of an industry. Our industry, all industries. Yet, how many of us are killing them off with benign neglect — or worse?

There are nine sure ways to bury your organization. If you're guilty of any of the following, you've got your hand on the shovel:

1. Don't come to the meetings, or if you do attend, come late.
2. If you're wary of the weather, stay home. Or, use it as a good excuse to leave the meeting early.
3. If you do attend a meeting, criticize the work of the officers and committees.
4. Never, never accept an office. It's

easier to criticize than to head a committee.

5. On the other hand, get angry if you're not named to a committee. Then, if by some fluke you are appointed, do not attend committee meetings.

6. If you're asked for your ideas, always say you have nothing important to add. Then, after the meeting, complain bitterly about how things ought to be done.

7. Never do more than the least you can get away with. Then, when others work unselfishly and hard to get the job done, you can howl that the club is run by a clique.

8. Don't mail your dues until you've been dunned at least four times. Maybe you won't have to pay at all this year.

9. Don't try to get new members interested. After all, isn't that what the membership committee is supposed to do?

You can probably add a few ideas of your own to the basic list. But these nine — employed by enough of any club's membership — will surely demolish it in time.

## HUD funds ONONDAGA

A \$300,000 loan to establish 6 area group homes for retarded adults was announced recently by representative William F. Walsh, R-33rd district (representing Onondaga County). The loan is from the Federal Housing and Urban Development (HUD agency) to Onondaga County Chapter of the ARC.

According to Walsh, the loan will allow the local chapter to purchase 6 housing units in Onondaga County neighborhoods.

Dr. Nicholas Collis, Executive Director of the Chapter, explained that 8 retarded adults, plus a houseparent, will live in each unit. The adults are expected to be referred to group homes by the Syracuse Developmental Center and other area institutions as well as from the community.

All residents will be employed either at the center or in the community.

Included in the Federal grant is subsidy money that will make the difference between rent income and the cost of housing. This is the only grant of its kind made in New York State, although there were numerous applications, including the application for the Mid-Hudson Region for 10 hostels by the State Association.

## SSI recipients and benefits

On July 1, 1976, all aged, blind and disabled SSI recipients become eligible for participation in the food stamp program. All SSI recipients should have received correspondence outlining procedures which enable many to certify themselves for food stamp assistance by mail. Of particular note to many of our members is the category: SSI individual or couple living with others not on SSI. The New York State and New York City Department of Social Services clarified their positions. Each SSI recipient has to go through a means test and the entire household in which the SSI beneficiary lives will have to be declared eligible depending on household size. Household resources must be less than \$1500. Also, the household gross income should generally be less than the following:

1. \$3400; 2. \$5100; 3. \$6800; 4. \$8800; 5. \$10,600.

If the recipient uses form C., and states that he purchases and prepares his food separately, but lives with people who do not receive Public Assistance or food stamps, he will be eligible for food stamps.

If further information is needed, get in touch with the nearest Social Service office in your area.

It has also been brought to our attention that SSI recipients may be eligible for rent subsidies in group homes. To follow this up further, get in touch with your Housing and Urban Development Department in your area.

## ARC members serve on Advisory Panel

Two members of the State Association, Robert Hodgson, a reappointment, and Mrs. Rosalind Sagar of Onondaga County Chapter have been appointed by Commissioner Eward B. Nyquist (since the appointment, dismissed by the Board of Regents) to serve as members of the Commissioner's Advisory Panel for the Education of Children with Handicapping Conditions. Mrs. Sagar will also serve on a subcommittee charged with developing a guide for parents outlining educational services for handicapped children in New York State.

Congratulations from the Association.

## Win one, lose one Court decisions affecting handicapped

**The Little Neck Community Association, et al. v. the Working Organization for Retarded Children, et al. No. 7494 (Sup. Ct., App. Div., N.Y.)**

May 3, 1976, a New York appellate court affirmed a previous lower court decision that a group home for mentally retarded children constitutes a "family" and, therefore, complies with the legal requisites for single - family zoning.

The Little Neck Community Association, representing property owners of one-family residences in Queens, New York, filed suit September 23, 1975, to enjoin the Working Organization for Retarded Children (WORC) from using a single - family residence as a group home for mentally retarded children.

The New York trial court rejected their arguments and granted WORC's motion for summary judgment based upon the group's qualification, as a "family". A "Family" is defined by the New York City Zoning Resolution for purposes of residential zoning, as "not more than four unrelated persons occupying a dwelling, living together, and maintaining a common household."

WORC is authorized by the New York State Department of Social Welfare to operate a "group home," a facility for the care and maintenance of not less than seven, nor more than twelve mentally retarded children, who are at least five years of age. Significantly, the rules of the Department of Social Welfare also specify that the "group home shall be in an appropriate neighborhood and so located that it is readily accessible to religious, school, and recreational facilities, and other community resources".

As legal precedent, the appellate court cited *City of White Plains v. Ferraioli*. It stated "that group home is structured as a single housekeeping unit and is a relatively normal, stable and permanent family unit."

The appellants contended, however, that because of the children's mental disability they would not interact as a family and the home, would, therefore, resemble a mini - institution. Consequently, they argued that the proposed home should be located in a residential zone other than one restricted to single - family homes.

Judge J. Titone disagreed, stating that "institutionalization has been the traditional means of accommodating and caring for the mentally retarded. However, the recent trend has been toward the establishment of community residence programs for the mentally disabled, including mentally retarded children. . . Although WORC will provide services to children who would otherwise be subject to institutionalization, the services will be provided in a non - institutional environment."

Furthermore, the court noted, in the event the group home did not constitute a family, it would qualify as a health related facility which is also permitted in a single - family residential zone.

This is one for our side, but there is also one against us and that is as follows:

**United Handicapped Federation, et al. v. Andre, et al. 409 Supp. 1297 (D. Minn. 1976).**

On March 11, 1976, the United States district court in Minnesota held that no federal legal authority requires transit buses to be totally accessible to persons confined to wheelchairs. Therefore, the defendants' motions to dismiss the complaint were granted.

The defendants include officials of the Metropolitan Transit Commission (MTC), the Urban Mass Transportation Administration (UMTA), the U.S. Department of Transportation, and AM General Corporation.

The plaintiffs are the United Handicapped Federation, a Minnesota non-profit corporation, and the North Country, Minnesota Chapter of the National Paraplegia Foundation. They brought suit challenging the defendants' acquisition of transit buses, with financial assistance from UMTA, which were not specially equipped to transport the wheelchair handicapped.

As statutory authority for the right of every person to public transportation, the plaintiffs cited the Urban Mass Transportation (UMT) Act of 1964, and Section 504 of the Rehabilitation Act of 1973.

The UMT Act states handicapped persons have a right to mass transportation, special efforts be made in the planning and design of mass transportation to accommodate the handicapped, and programs receiving federal aid should comply with this policy.

The court ruled, however, that this Act does not require every standard - size transit bus to be specially equipped to transport the wheelchair handicapped.

### COURT CITES SNOWDEN

As authority for its ruling, the court cited *Snowden v. Birmingham - Jefferson County Transit Authority, et al.* (Reported in AMICUS, November 1975), which is presently on appeal. In that case, an Alabama district court found that disabled persons do not have a fundamental right to

public transportation, based upon the federal statutes also cited in *United Handicapped Federation v. Andre*.

In addition, the Andre court found it was unreasonable to interpret the Act as requiring total accessibility, because at that time no bus manufacturer in the U.S. manufactured a standard-size specially equipped to safely transport those confined to wheelchairs.

Similarly, the court held that the Federal-Aid Highway Amendments of 1974 do not require total accessibility for every standard - size transit bus.

### ALLEGED VIOLATION OF SECTION 504

The complaint also cited Section 504 of the Rehabilitation Act of 1973 which prohibits discrimination of the handicapped by any program receiving federal aid. The court ruled, as in the Snowden case, that the Act sets forth a statement of congressional policy and, therefore, does not require all standard-size regular route transit buses to be totally accessible to handicapped persons. As in Snowden, the transit authority does not exclude the wheelchair handicapped from riding the buses if they can arrange for assistance, the court commented.

Finally, the plaintiffs alleged a cause of action based upon a denial of equal protection and a denial of their right to travel. The court, however, ruled that no invidious discrimination existed, again affirming the Snowden case. "Defendants do not prohibit plaintiffs from riding mass transit buses, and the Constitution does not require defendants to provide special facilities for a special class of people," the court held.

## Krupsak and Weingold at NYS A. T. M. H. meeting



**Lieutenant Governor Mary Ann Krupsak and Joseph T. Weingold renewing friendship.**

Lieutenant Governor Mary Ann Krupsak delivered the keynote address at a banquet commemorating the New York State Association of Teachers of Mentally Handicapped Bi-Centennial Invitational Convocation in Special Education held recently at the Granit Hotel in Kerhonkson, New York.

The Convocation centered around the theme, "Rights, not Rhetoric". Lt.

Governor Krupsak focused on the importance of our meeting the needs of all special children. She especially stressed the urgency for continuing research as well as the necessity for early identification programs so actual or potential deficits in a child's cognitive, psychological or physical areas might be addressed in the most timely and effective manner. Such Early Intervention Programs spare children permanent impairment and diminished life opportunities. Mrs. Krupsak urged parents and educators to assume the responsibility of informing their legislators at local level and at state level, as well as to unmet needs in terms of programs and services for our special children.

She stressed the need for constituencies all over the State to become articulate in furnishing their legislation decision - makers with clear-cut rationales as to the basis for sought - after legislation. The audience was invited to keep actively involved in the legislative process by contacting her directly with concerns for the mentally retarded of New York State.

After the Lt. Governor spoke, President Ruth McCarthy honored our Executive Director, Mr. Joseph T. Weingold, for his continuing efforts on behalf of the retarded in New York State. A beautiful bronze plaque was presented to him in an expression of appreciation for his outstanding leadership and guidance in the field of mental retardation.

# CHAPTER NEWS

What our chapters are doing and saying for our children.

We begin with **PUTNAM COUNTY**, where 500 county residents walked 10 miles on October 17th to bring \$11,000 in pledges to **PUTNAM COUNTY CHAPTER**. Among the walkers, were Carmel Supervisor Thomas Bergin and Assemblyman Willis Stephens. Our thanks to all these people. . . **HERKIMER COUNTY** bidding farewell to Executive Director Randall Soffer who has moved over to work in Oneida County. . . Oneida and Herkimer are both chapters that have started recycling programs, including clothing and fabric. Have to ask them what that's all about. . . Talk about moving rapidly, **NIAGARA COUNTY CHAPTER**, in their September Newsletter, talked about the possibility of adding a second hostel for their clients. An October newspaper article talked about 5 new residences. We hope they get them all. . . We share **CHAUTAUQUA COUNTY'S** sorrow at the loss of long time active member, and State Board member, Gladys Delahoy. It's hard to believe. In the years we first met, the chapter's programs included about a dozen adults and children. Today, we read of an enrollment in their 3 workshops alone of over 300 persons. . . Hard to believe our **ONONDAGA COUNTY CHAPTER** is 25 years old. But, on October 15th, they had a silver anniversary celebration. Judge Morris Garber presented the brief retrospect of the agency. Happy 25th Onondaga! In addition to this activity the chapter hosted Dr. Marc Gold's "Try Another Way" conference September 29 and 30, and apparently, in honor of their 25th year, they were granted a 3-year \$93,000 grant from the New York State Council on Developmental Disabilities for early intervention programs. . . **FRANKLIN COUNTY CHAPTER** very happy to have opened a new day training program on August 17th and has signed a contract for their first hostel. Had their second annual dinner-dance November 13, 1976. . . **ST. LAWRENCE COUNTY CHAPTER** jammed as much activity as we've ever seen into 2 days with formal dedication ceremonies on October 18, 1976 at 10 a.m. at its new hostel in Potsdam, and dedication of its hostel and rehabilitation facility in Norwood that same afternoon at 2 p.m. and the Ogdensburg Rehabilitation facility at 10 a.m. on the 19th. . . **GREENE COUNTY CHAPTER** workshop going full force. Delighted to see one of their clients was recently placed in full-time work with Becker Electronics. This company was named our Employer of the Year in 1973. Still having a number of clients served in the Columbia County Workshop. . . **LIVINGSTON WYOMING CHAPTER**, nominators of the 1976 Employer of the Year write:

We just received our first R.W.S.P. Grant for a Vocational Evaluator (Psychologist).

We were awarded an Innovation and Expansion Grant (O.V.R.) to purchase an Evaluation System and Equipment — \$10,923.00.

Our D.D.A. Grant was approved for \$15,379.00 to provide 70 per cent of a position and equipment for Vocational Training in the printing industry.

Effective 7-26-76, we will be paid O.V.R. Fees in Category II.

We are planning our first hostel to be operative in 6-8 months.

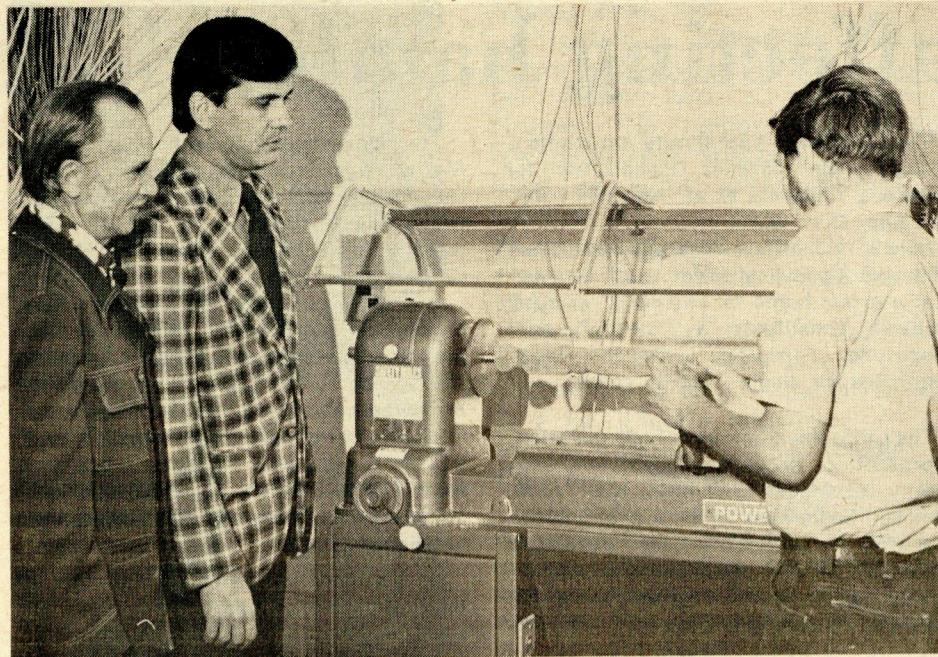
We are pursuing Direct Service Contracts with Craig Developmental Center.

We are looking for a larger building.

We have more work contracts than we can currently handle.

Competitive placements are increasing. M.H.B. relations are improving. . .

**MADISON COUNTY CHAPTER** joining the large number of chapters with more and more hostels as they open their



A client at the Clinton County Rehabilitation Center, shows use of Lathe donated to the ARC by the Plattsburgh Lions Club.

second. . . **CORTLAND COUNTY CHAPTER** facing one of the common problems of a chapter recently when, 5 days before their bowling program was due to open, they were told that there were no lanes available for them. As usual, a number of parents appeared with their bowlers only to be turned away. Thanks, however, to the understanding of the local proprietor, new arrangements have been made. However, we know the frustration which occurs in many places when we are the last ones in, first ones out. . . **ALLEGANY COUNTY** very excited about the move of their workshop to the Campus of Alfred University. Anticipate the new spot will give them much more opportunity for the expansion of services. . . **MONROE COUNTY CHAPTER** September, 1976 Newsletter, a very interesting issue entitled "The Anniversary Issue" and spending considerable time in reflection of the accomplishments of the agency since its birthday as a part of Sunshine League of Western New York in November 1950. . . **WELFARE LEAGUE - LETCHWORTH VILLAGE CHAPTER** had as always successful luncheon, their 37th, at the New York Hilton on November 20th. This followed, by about one month, dedication of their new offices, on the grounds of Letchworth Village. Dedication ceremonies were held on October 17th. . . Speaking of luncheons, **WILLOWBROOK CHAPTER** is working on their 1977 event which is already scheduled for May 14th, 1977. The chapter will be donating 20-ton hydraulic gated van costing \$12,000 to Willowbrook in memory of Judge Orrin Judd. A very interesting story in the October newsletter about Governor Carey's visit to Willowbrook, and what he did not see there.

**BROOME-TIoga CHAPTER** finally getting to the opening of that first hostel and we are all delighted to see, that in keeping with their copyrighted name, this is going to be called County Valley Hostel. . . **ORLEANS COUNTY CHAPTER**, overcoming great difficulties, managed to operate their summer camp again this past summer. With help from the State Association, they are hoping to be able to continue this activity in summers to come.

. . . **SUFFOLK COUNTY CHAPTER** has finally moved to their big new building in Bohemia. Everyone really excited about the new move and we are sure that considerable help for the funding will come from their active youth groups who are planning any number of walk-a-thons. . . From the north country comes word that Bishop Brzana of the Diocese of Ogden-

plemented a Forklift Operator Training Program for the mentally retarded. Using a number of audio-visual aids and tools for non-verbal applicants, the staff has designed a program which allows its potential enrollees a methodical step-by-step routinized approach to the training process. . . . Anthony J. Terranova, Jr., Executive Director, **CAYUGA COUNTY CHAPTER** has recently been elected to the Board of Directors of the New York Association of Rehabilitation Facilities. In addition to the above, Mr. Terranova has recently completed the first year of a three-year term on the Board of New York State Industries for the Handicapped. . . . **CLINTON COUNTY CHAPTER**, which sponsored the north half of the northeast regional meeting of the Association on December 11th also sends this news: "The Plattsburgh Lions Club has very generously given the Clinton County Chapter a gift of \$3,000 for the purchase of much-needed workshop equipment. We have been able to purchase a high-production wood lathe, accessories, and duplicator attachment; a ratio scale for counting large quantities of small parts; a shipping scale, and six steel-top work benches. The gift will allow us to become more self-sufficient by increasing our productivity and income levels." . . .

We close with news of **SARATOGA COUNTY CHAPTER**, working hard to get their workshop successfully off the ground. We will be bringing in Carl Klein from St. Lawrence County as their new Executive Director on December 13, 1976 and we know Carl will lead them forward from their present situation and that soon their 13 clients will be 130, and Saratoga will be up among the leading shops in the north country.

## Queens parents show the way

The parent members of ARC in the borough of Queens, N.Y. have formed a parents assistance committee which we are sure is duplicated in other parts of the state.

Although not unique, it has issued a flyer some of which bears repeating.

The PAC of Queens is a volunteer group of parents to retarded children who want to give personal individual help to other parents of retarded children.

When someone calls the PAC phone number, and the phone numbers are given (212-846-4864 and 846-8826) he or she talks to a mother who knows from her own experience what it is like to have a retarded child, who can make suggestions about the various problems, large or small, which may exist. They do not give professional advice, but talk as one parent to another, and, if necessary, suggest from their own experiences where a parent can find the professional help he or she needs. All confidentiality is respected.

Each year more than 30 families with retarded children are helped. They have talked about AHRC in general and PAC in particular and have visited professionals in the field of retardation and related fields including nurses, doctors, social workers, guidance counselors and others.

Their aim is to emphasize AHRC's slogan, "The Retarded Can Be Helped" and to offer that help personally.

It is through organizations such as this, that the ARC's around the state can maintain their "personal touch" through parent assistance committees emphasizing the importance of parent-to-parent communication.

**CAYUGA COUNTY CHAPTER**, within the past year, has successfully im-

# Governor's public works quest ignores Community Services

## M.H. package institutionally oriented

On October 26, 1976, Governor Carey, acting on the first applications, asked the Government to fund 123 public works projects worth 172 million dollars on the new public works employment program.

### DEVELOPMENT CORP.

**TOTALS \$28,188,750**

Only one vaguely resembles the development of community service... the alteration to the halfway house of the Manhattan Developmental Center in New York City for \$165,000.

Earlier in Sept. the Association requested Deputy Commissioner Thomas Coughlin, III, to prepare applications for sheltered workshops, the most pressing need of the Association and Coughlin, as backup serves for community residences. Twenty-one such applications were prepared, some of them down to schematic, and with ground available to be transferred to the State. Not one of these has appeared in the Governor's request.

On the other hand, requests contained \$24,518,000 for the construction of new research laboratory building at the N.Y. Psychiatric Institute, \$4,476,000. for alterations and improvements to existing buildings of the Alcoholism Research Institute in Buffalo and \$15,240,750 for the construction of a new 300-bed patient treatment center at the St. Lawrence Psychiatric Center. This, at a time when the emphasis is on de-institutionalization.

A number of the requests for the office of parks and recreation are for the construction of comfort stations at bus terminals and in park regions.

Twenty-one applications for separate workshops were delivered to Mr. Coughlin at the State Convention on October 8th. The first indication the Association had of what the Governor was going to ask for was the October 26 release.

The full number of requests for Mental Hygiene, and the amounts are listed here:

DEPARTMENT OF MENTAL HYGIENE—FACILITIES	Location (County)	Grant Request
<b>DEVELOPMENT CORPORATION</b>		
Alterations and Improvements to Existing Building Alcoholism Research Institute, Buffalo	Erie	4,476,000
Construction of New Research Laboratory Bldg. New York Psychiatric Institute	New York	24,518,000
Construction of New 300-Bed Patient Treatment Center St. Lawrence Psychiatric Ctr.	St. Lawrence	15,240,750
Alterations and Improvements to Sanitary Facilities Bldg. 2 Rome Developmental Ctr.	Oneida	316,000
Replacement of Glass, Main Building and 4 Resident Bldgs. Manhattan Children's Psychiatric Center	New York	132,000
Alterations to Halfway House Manhattan Developmental Center	Suffolk	238,000
Construction of New Laundry Service Building Suffolk Developmental Center	Erie	95,500
Alterations and Improvements to Elevator, Bldg. 13 Buffalo, Psychiatric Center	Bronx	595,000
Alterations and Improvements to Warehouses H and J Bronx Psychiatric Center	Kings	95,500
Alterations and Improvements to Elevator, Building 19 Kingsboro Psychiatric Center	Suffolk	2,317,000

It is noteworthy there is a \$5 million limitation for any one project and that most of the money that has been requested by the Governor for the Department of Mental Hygiene has already been appropriated by the Legislature.

## St. Lawrence printers, ARC dispute

A dispute has arisen between the printers of St. Lawrence County and the ARC workshops located in Hermon, Norwood and Ogdensburg. The printers claim the ARC workshops are in direct competition with them. They claim loss of business because the workshops can undersell them.

In fear of expansion of printing facilities in the sheltered workshops, the printers have protested, claiming their own tax dollars are being used to finance an industry in direct competition with them.

According to Richard Laurin, executive director of the county's rehabilitation centers, the ARC print shop in the Hermon sheltered workshop grossed \$9,375.03 last year in printing business and collating, or 18.5 per cent of their total gross contract sales of \$50,657.40.

### SOLUTION SUGGESTED

Ernest LaBaff, chairman of the county legislature's Economic Development Committee told both groups he believes

they were setting the groundwork for a solution after one of the printers made a proposal. His proposal was that they would give the ARC advice on any program that wouldn't be in direct competition with them. He suggested Christmas card, birthday card, greeting card business.

Mr. Laurin answered that such a solution might not be acceptable under federal and state guidelines of a sheltered workshop situation. He noted operating statutes direct a sheltered workshop to reflect an existing market, and that starting a new business where none had existed might be viewed as "speculating with government money."

"What if we print cards and can't sell them?" he asked.

### FUNCTION OF WORKSHOPS EXPLAINED

Mr. Laurin maintained, throughout the meeting, that the purpose of sheltered workshops was not to be in the printing

business, but to provide a function for the handicapped.

The printers claimed, however, the workshop was aggressively advertising to obtain jobs and possibly expand and produced a card containing the phrase, "Printed by the Print Shop, Box 235, Hermon, N.Y."

Laurin argued that the sheltered workshops "must charge competitive prices according to statutes of the labor department."

Some printers admitted they had sent work to the ARC they did not find profitable to handle, such as collating. This disclosure prompted Mr. LaBaff to ask that these two groups spend sometime deciding what they could live with and live without so an agreement could be reached.

Kate Klein, president of the board of St. Lawrence County Chapter, noted the county presently serves about 300 handicapped persons and may have the potential to serve 600.

## Medicaid disputes resolved

A hassle over Medicaid reimbursement, which threatened adult treatment programs for the mentally retarded in Orange and Sullivan counties, apparently has been resolved for the moment.

Peter Young, executive director of the Orange County AHRC, said he has been told by Social Services Commissioner, Henry G. Parry, Jr., that the county department will start processing \$92,000 in Medicaid claims from the AHRC.

Before this action, Young was preparing to close down AHRC programs for adults in Newburgh and Middletown and lay off 31 staff members.

Mark D. Brandt, executive director of the Sullivan County AHRC, also attended the Albany meeting with Mr. Young. The Sullivan County Chapter is owed \$250,000 in Medicaid reimbursement.

The reimbursement problem arose because the Department of Mental Hygiene licenses the programs but the Social Services and Health departments administer Medicaid payments for recipients.

Medicaid payments to the Orange and Sullivan organizations apparently were held up in the Health Department's regional office in White Plains. Young said he and Brandt were assured that staffers in the state government's regional offices won't be allowed to hinder state policy that the AHRC programs are eligible for Medicaid reimbursement.

Young said there's apparently "a bitter feud" between the Department of Mental Hygiene and the other two state agencies. Mental Hygiene has been trying to get state residents out of large institutions and back into their home communities. But Young said representatives of that department at the Albany meeting charged Social Services and Health with frustrating this policy by discriminating against former institution residents.

## Education for public

We have a very interesting communication from our Suffolk County Chapter concerning the North Fork Auxiliary on Long Island.

Is the average community dweller well informed about services to the mentally retarded? Do they understand what mental retardation really means?

The North Fork Auxiliary thinks not, and, as a result, they have induced the Suffolk Times, a local weekly newspaper, to feature a series of articles about the Riverhead Workshop and the people in it.

Written by a volunteer at the workshop, it is called "They March to a Different Drum". So far, this series has covered such subjects as how the workshop started, who goes to the workshop, a typical "rap session", causes of retardation, Christmas at the workshop, what it is like to live at the Riverhead AHRC hostel.

"Reaction to these explanatory articles from community, staff and parents has been gratifying", says Beth Poom, Publicity Chairman.

Let's see much more of this and anybody who wants copies of these articles, write to Beth. Her address, Box 82A, Route 1, Cutchogue, N.Y. 11935.

# Lafave blames Kolb

Dr. Hugh Lafave quit his job as director of the Oswald D. Heck Developmental Center in mounting frustration over what he considered to be backsliding and equivocation by the State Department of Mental Hygiene under the direction of Commissioner Lawrence Kolb.

In an exclusive interview with Knickerbocker News, via a telephone call from Saskatchewan, Canada, where Dr. Lafave has moved, he stated he was "extremely disappointed" in what he feels is a lack of real commitment by DMH to the concept of community-based services for the mentally retarded.

Lafave came to New York in 1966 as an associate commissioner of DMH and was assigned in 1969 to plan and direct the Oswald D. Heck Developmental Center and the related Eleanor Roosevelt Developmental Services (ERDS) Agency which serves the retarded in the six county local region.

## OPPOSED LARGE INSTITUTIONS

An outspoken opponent of large institutions for the retarded, Lafave pioneered, through ERDS, the so-called developmental community-based model, an alternative plan for keeping the retarded in their home communities.

Over the last five years, he supervised the creation of a network of hostels and group-care homes for the retarded in the capital district area providing support services through "teams" of specialists out in the community.

During that time from 1969, Oswald D. Heck facility was being built. When it was ready, Dr. Lafave was asked to implement its original purpose by accepting the residents from other overcrowded institutions in the capital district area. Most of these were severely or profoundly retarded.

Dr. Lafave resisted this because it would result in the shift of ERDS staff from out in the community to inside the Heck building. One of his major complaints was that the request he accept such residents into the institution was not accompanied by staff, other than those he already had on community services.

## LAFAVE ATTACKED

Last year, Dr. Lafave was attacked for underutilizing space available at the sprawling Heck complex in Niskayuna, a suburb of Schenectady, a charge he viewed as a veiled attempt to force him to conform to the institutionalized model by filling Heck with inpatients.

A special team of auditors called in by Kolb in response to newspaper charges of irregularities in ERDS operations recommended that Lafave be fired, citing alleged poor administration of ERDS.

Although Lafave was eventually retained by Kolb at the urging of parents and legislators, over the last year he was forced to begin accepting a large number of severely retarded patients from overpopulated institutions, such as the Rome Developmental Center.

"The standard in the department (DMH) has always been institutional service, rather than community-based service", Lafave said in the interview with Knickerbocker News. He described a billion dollar a year DMH operation as "huge and bureaucratic".

## Putnam receives service award

The Putnam County Chapter of the State Association for Retarded Children was awarded the Distinguished Service Award by the Putnam County Jaycees at its annual dinner in Brewster, N.Y.

According to Stuart Grief, executive director of PARC, the award "will be hung in a place of honor in our new reception area at our vocational center on Bowen Road in Ludingtonville."

## COMMUNITY AGENCIES PRAISED

He had praise for community agencies and parents of Heck clients who, he said, deserve a great deal of credit for their hard work in establishing Heck.

The controversy between Lafave, Kolb and the department could not be resolved on an either-or basis; that is, whether there should be any institutional services or there should be all community services.

The facts of life, according to a spokesman of the State Association, are that institutions will be necessary for as long as our scientific knowledge does not prevent mental retardation. The state must be equipped to give the twenty-four hour a day care and training to the severely and profoundly retarded whom the community cannot handle. This should not preclude the utmost development of community programs as alternatives to institutionalization and to get the people out of institutions. The developmental model is one of a number tending in this direction, but any total program must recognize the institution, perhaps not in the form that we know it, part of the total program.

## Mental Hygiene's tragic error

The following article by William Stevens appeared September 13 in the Sun Bulletin of Binghamton, New York. We think it is of such importance with regard to the attitude of the Department of Mental Hygiene we reprint it in full.

It's really quite early to begin handing out the yearly awards in state government. Ordinarily one would wait until at least Dec. 31.

But, when somebody is a clear-cut winner already, it only seems fair to present the prize right away. That way, other officials won't keep trying for a medal in that category this year.

In this case, the "Understatement of the Year" prize goes to Dr. Lawrence C. Kolb, commissioner of the Mental Hygiene Department.

Although Kolb had some competition from other department heads for the honor, he gets the gold award for his statement during a sanity hearing for a man who had killed his mother with a hatchet.

The department had recommended that the man, who had struck his mother nine times with the deadly instrument only 16 months before, be released from a mental hospital.

Upon learning that the panel of experts who examined the man and recommended that he be released had never seen the man's trial record, which spelled out the grisly details, Kolb said, "It would appear that perhaps the recommendation was hasty."

For an understatement, that ranks right up there with calling the Queen Mary 'a nice little boat' or terming a midair collision involving two jetliners a 'mishap'.

Kolb conceded that perhaps the department should 'sharpen our own instruments', and 'consider revisions' in the methods used to determine if a person should be released from a mental hospital.

Consider revisions? That also ranks high on the list of understatements.

It has been charged that the department, partly because of budgetary restrictions, has been practicing a form of 'shove 'em out the door' in its release policies.

That charge has been sharply denied by Kolb — and others. The department's official position is that efforts are being made to 'deinstitutionalize' treatment by returning more people to the community.

That is a noble aim.

But it is set back sharply by such performances as were involved in the sanity hearing.

## League honors Employee of Year



James Hanifer, President of Community League, presents Employee of the Year award to Gwendolyn G. Streeter.

## Parents' Bill of Rights

(Reprinted from Exceptional Parent Magazine)

**Freedom to:** Feel that you have done the best you can. Love and care for and enjoy your child. Be depressed or have hostile thoughts once in a while without feeling guilty. Be guilty occasionally, but only if it organizes you.

Enjoy life as intensely as possible, even though you have a child who is disabled. Have interesting causes to support and be busier than the average person, to a point where people say, "How does (s)he do it?" (If you want something done, ask a busy person.)

Let your disabled child have his or her own privacy.

Enjoy being alone at times. Get away for at least a two-week vacation every year without the children. Have dates, anniversaries, celebrations, weekends away, time together designed to enhance your marriage or "singlehood" — in other words, freedom for escapist moments. Have a sense of humor without feeling guilty.

Acknowledge you are spending lots of time with your child without having it mean you love the rest of the family less. Not devote your entire life to the "cause", but freedom to devote as much as you want or to get away for a while. Say at times you don't want to talk about your problems.

Say, "I'm tired of always talking about my disabled child."

Let people know at other times about the progress and achievements with a genuine sense of pride.

Lie every once in a while, to say everything is fine, not feeling compelled to tell the truth to everyone who asks, "How are you?"

Tell teachers, professionals and other educators what you really feel about the job they are doing and to demand they respect your opinions.

Tell your child that you don't like certain things he—she does, even though he—she has a disability.

Not praise your child gratuitously even though you've been told to offer a lot of praise.

Spend a little extra money on yourself whether or not you can afford it. Have your hobbies and interests without interference, whether Majong, Mahler or Macrame.

**Warning:** Parents who do not enjoy almost all these freedoms are in trouble. A person who has a disability can only feel guilty if they sense parents have sacrificed themselves for them. Martyred parents are seldom appreciated by anybody, least of all their disabled child. These freedoms must be embarked upon especially by parents whose child has been dependent, clinging, demanding and difficult.

## Park Commission "Employer of Year"

The Genesee State Park and Recreation Commission was named the 1976 "Employer of the Year" by the State Association. In an award ceremony at the Annual Convention Dinner, at the Ryetown Hilton, the award plaque was presented to Mr. Richard J. Adams, Assistant Regional Park Manager by Edward B. Licence, Chairman of the Scholarship and Awards Committee.

Ten nominations were submitted by Chapters of the Association, and in a very close vote, the Park and Recreation Commission was selected. The winners nomination was submitted by Thomas P. Rick, Executive Director of our Livingston - Wyoming Chapter.

In naming the Commission for the award, the Chapter said: "The Genesee State Park and Recreation Commission has been an active employer of the retarded for eight years. This nomination for Employer of the Year seems particularly appropriate because of the Commission's demonstration of their positive attitude and active commitment

to hiring the retarded. Mr. Richard Adams Assistant Regional Director, and Mr. Al Davis, Director of Letchworth State Park, have been particularly instrumental in developing the accepting and understanding attitude of Commission employees. It is this attitude that has allowed for the assimilation of the retarded into the work force as valuable Commission employees. It is with extreme pleasure that we submit the Genesee State Park and Recreation Commission for nomination for the Employer of the Year."

Other nominees, to whom Certificates of Appreciation were presented are: Dunn & McCarthy Inc., nominated by Cayuga Co. Chapter; Swiss Farms, Inc. — Columbia Co. Chapter; Al Soprano — Tops Grocery Store — Cortland Co. Chapter; Schaffell Tanning Co. — Fulton Co. Chapter; Acco International and Alcoa (Massena) — St. Lawrence Co. Chapter; Rua & Sons, Inc. — Schoharie Co. Chapter; George Ferris — Mike Hoffis, Warren - Washington Chapter; Alexanders, White Plains — Westchester Co. Chapter.

# YOUTH Group News

For and About our YOUTH  
ARC Chapters around the state



Hilarie Seifert, Secretary of Y.O.U.T.H. ARC, assumes a handicap for Community Day.

## Community Day

Kelly Anderson, Chairman of Community Day Project, reports on an activity held during convention in Albany.

The picture depicts Youth ARC members simulating handicapping conditions in an attempt to raise their level of awareness as to the actual implications of such disabilities. Venturing into the community in groups of twos, one disabled and one non-disabled, the participants were able to interact, face to face, with other non-disabled persons in various settings such as restaurants, parks, shopping centers, public buildings. After a specific period of time, the role of the disabled person was then assumed by the non-disabled partner.

The experience of simulating a disability is extremely valuable for non-disabled persons. In essence, it is a powerful emotional encounter and contributes to substantial awareness raising concerning many of the realities of everyday life for those who are disabled.

## YOUTH ARC Week

It may be a little late to announce, but we are pleased the Governor declared August 26-31, 1976 as Y.O.U.T.H. ARC week in New York State. In making the proclamation the Governor stated: "Service to children and young people who are mentally retarded is one of the most important areas of volunteer action. Y.O.U.T.H. (Youth Organized and United to Help) is a component of the New York State Association for Retarded Children. This statewide organization operates in most counties of the state and has over 1,000 members. (We assume he was speaking of youth rather than the ARC).

Y.O.U.T.H. members volunteer their time for direct service to retarded children in many activities such as tutoring, recreational activities, social events and in providing sitters for families with retarded children. They work in administration, fund raising and in trying to expand the circle of friends of the retarded."

## 'Kamp Katskill Kaper'

by Kathy Baker

The caper was planned months in advance. They knew the job would take a mob, a motley mob at that, to complete. So the big Exec. came to the right place. He asked the leaders of the mob to do the job.

When we settled on all the food we could eat and 72 hours to complete the job, the contract was signed. Then it was our turn to go to work. The professional "Family" members had to be called in from all over the state. All the easy work was soon done and the waiting began. We were starting to get itchy fingers.

Then the evening of Friday, May 27th the mob began riding into town. As we made the long climb up the hill, the townspeople came out to see what was invading their quiet, peaceful town. When asked a question from one of the mob, they shrugged their shoulders and disappeared with fright.

By Saturday all the mob was present. There was a sense of excitement and anticipation in the air. We were armed and ready to go. We were waiting for the word. Each one among us knew what had to be done. So we armed ourselves with scrapers, brushes and pails. We were PAINTIN' the TOWN RED, a camp to be more exact, and it was WHITE! A camp with 28 cabins. "An easy job," we said as we started out that morning. Different members even threatened changing their majors to house — cabin painting.

When evening invaded our camp we were given a chance to survey the job. Well, the cabins looked whiter, the grass speckled and the mob covered from head to toe. That brought everybody into the showers and out again when we discovered the water was cold!

A discussion of who had a better cabin and a better group almost caused a split in the "Family." Some quick thinking and rank pulling produced a duel. The weapon was chosen and ten paces marked off. The rest of the mob took sides while the best soccer match got under way. When it was all over the parties forgot what the discussion was about.

We're considered a strong, tough bunch. Able to bear up to most anything. So the cold water never dampened the spirit. Nor did the fog, the rain or the lack of sleep. Morning came and we staggered out of the cabins realizing time was slipping by. Forty-eight hours and many white buckets of paint later we were packing up camp. A quick survey proved we had done the job we set out to complete.

So the caravan of fifty some odd, not so wide awake, "professional" painters made the long trek down the hill to join the real world again.

## YOUTH honors

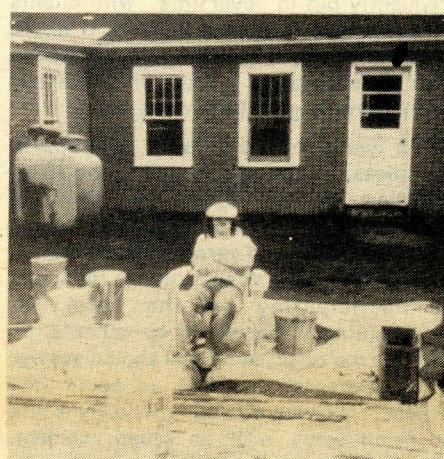
At its annual banquet, culminating a successful statewide convention in Albany, Y.O.U.T.H. ARC presented its first Advocacy Awards to two of New York State's most prominent advocates for the retarded.

Joseph Weingold and Senator William Conklin, long-time colleagues and pioneers in the field of legislation change for the retarded in New York State, were selected

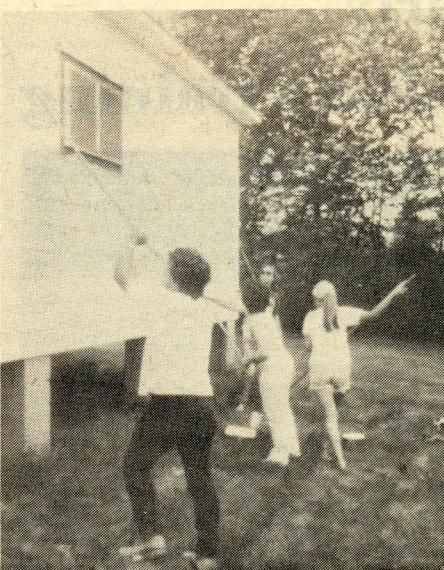
Space not permitting in the fall, we bring you this bit of sunshine in mid-winter . . . a project of YOUTH and fun that made a lot of our kids happy last summer!



The cabin before.



Resting after (before?) the labor.



The cabin after.

## Conklin, Weingold

as recipients of this award by YOUTH ARC's recently formed "Social Action and Legislative Change" Committee. Hilarie Seifert, Chairperson of the Committee, cited the many accomplishments of these outstanding men, who by their dedication and relentless efforts on behalf of those who are not always able to speak for themselves, are recognized as "models of advocacy for the retarded" by Y.O.U.T.H. ARC members throughout this State.

## Orientation

Michele Norgreen, senior Southeast Regional Vice President, of Y.O.U.T.H. ARC — State Board, has prepared an Orientation Program designed to aid new members.

Michele's suggestions for helping Y.O.U.T.H. ARC members become more effective in their service to the retarded include a three part program . . . an Initial Orientation, The Buddy System, and On-Going Orientation. It is for use before all first district - service activity with the mentally retarded. Those interested in obtaining a copy of this orientation guideline may contact Gerry Sherwood at New York State Association for Retarded Children, Inc., 175 Fifth Avenue, New York City 10010.

## Smithtown Junior Auxiliary Report

By Jeanne Groeneveld

I'd like to start this month's article off with congratulations to the Smithtown Junior Auxiliary. We received an award from the State Association for being the largest and most active junior auxiliary in New York State. We held over two-hundred various activities ranging from socials, dances, and teen centers to special occasion parties, swimming and field trips. The money to run all these functions is raised by youth through our two fashion shows, car washes, something we call "miles of pennies" and donations from people of the community. This month the Junior auxiliary is going to co-sponsor a square dance with the newly formed Senior Smithtown auxiliary.

Speaking of dancing, last month's dance had a band — yes, a real live band. In fact it was a real live, very talented band enjoyed by all. The dance was a success and the attendance was good. The band had a great influence on the atmosphere! They'll be playing for us again next month and we certainly appreciate it!

A camping clean-out was held last month at Pete Piggane's house. For some strange reason, I seem to remember seeing a lot more people on camping trips than those who showed to fix up and pack away the equipment. We had a busy camping season, and the tents were material evidence of it. Ripped corners and broken zippers were just some of the problems met by those who came to help. Now that it's all packed away, we have no permanent place to store it for the winter yet. Oh, well, you can't have everything!

Our first indoor teen center was held the third Friday of last month. Basketball was the dominating sport that night because it was not volleyball season and we didn't have the equipment for it. I didn't quite understand that because no one there actually cared if it was volleyball season or not — they just wanted to play.

A garage sale was held at Susan Klein's house. The Klein's donated their driveway for two days and all the money raised to the auxiliary. Thank you very much. This just happened to be another one of those functions few seemed to be able to make.

# Loving people: Doing what comes naturally

The Foster Grandparent Program at Broome Developmental Center, (BDC), Binghamton, New York, exhibits a rare sense of commitment and variety of service on the part of its members. Recruited from the local community, Broome's Foster Grandparents share a common interest in assisting in the habilitation of the developmentally disabled. This common interest is a natural outgrowth of the harmonious philosophies of both the Foster Grandparent Program and Broome Developmental Center.

The program has, at its core, the philosophy that our senior citizens possess many valuable skills and insights which can benefit culturally, emotionally, physically and mentally disadvantaged children. They have a life-long accumulation of experience and compassion which can make a big difference in the development of a child's life. This complements BDC's own treatment philosophy which emphasizes the human aspects of surrounding our children with normalizing experiences. What could be more normal than a "Grandparent's" love?

That is not meant to imply that Grandparents have walked into the facility and become immediately engrossed with the daily programs. On the contrary, the recruitment is done by the Volunteer Services Department subsequent to their initial screening by the local chapter of the Foster Grandparent Program (FGP). Potential grandparents are interviewed with careful attention being paid to their attitudes towards the developmentally disabled. Preconceived ideas, misconceptions, and general comfort with the prospect of working with our clientele is assessed, as well as their overall physical condition.

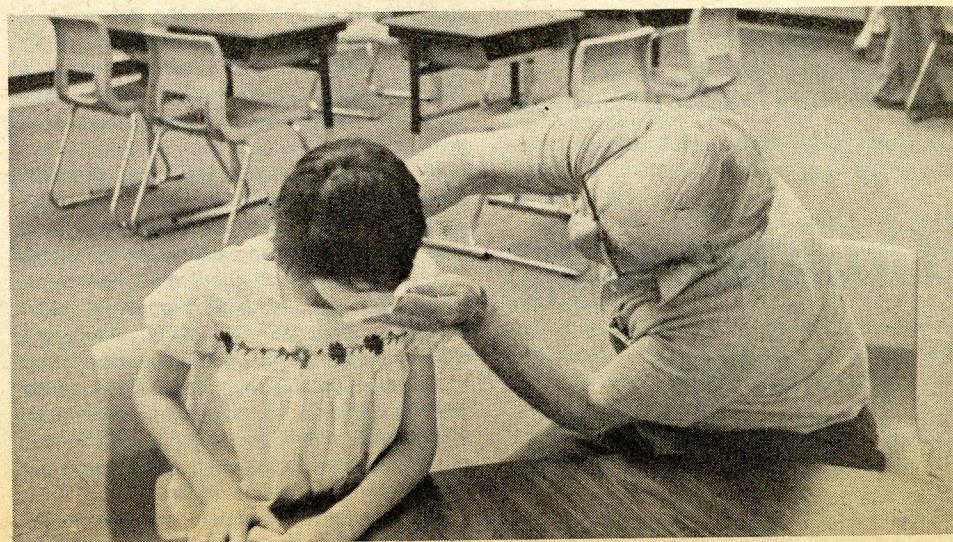
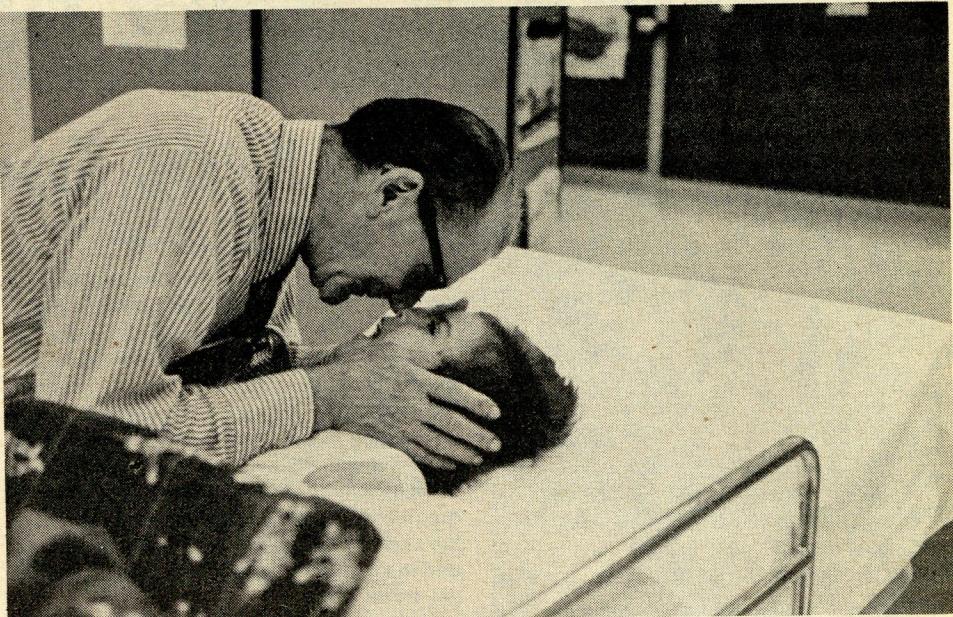
Candidates are then incorporated into a six-week orientation program which is identical to that provided to the permanent Civil Service staff, Broome Develop-

mental Center. At the end of this period, those grandparents who wish to remain are given a choice of assignments which will fulfill them personally together with program guidelines.

ACTION, the Federal Agency which sponsors the local Foster Grandparents Program, requires that each member spend twenty hours per week with two children assigned to them. That official statement does little to describe the deeply affectionate relationship which develops between "grandparent and child". Obviously, the love which characterizes the FGP Program at our facility, resulting from the opportunity of a child to regularly see a smiling face and hold a warm hand, is irrefutable.

It is the immeasurable quality which, fortunately, our fourteen Foster Grandparents find it impossible to contain. They cannot restrict their emotional commitment to the bounds of time and age suggested by ACTION. Their hearts lead them to share their love with residents above the twenty-one year old cut-off point. While they are careful to fulfill their ACTION guidelines, our Grandparents frequently put in "overtime" with clients not specifically assigned to them. It would be easier to empty the seas with a teaspoon than to attempt to confine the love our Grandparents give to our residents.

The forms that love takes is similarly boundless. In addition to daily time spent assisting in the Education, Physical Therapy, Recreation, Speech and Hearing and Occupational Therapy Departments, our Foster Grandparents realize the value of participating in the total interdisciplinary therapy of our clients. So don't be too surprised if you should see our "Grandparents" teaching an adult "the Hustle," showing a child how to fly a kite or reminiscing with an older resident. They're just doing what comes naturally — loving people!



Foster grandparents at work (love?)

## Library reverses

### exclusion of retarded

In a letter dated August 17, 1976 to the Assistant Commissioner for Libraries, State Education Department, Joseph E. Ryan, Executive Director of our Ulster County Chapter, expressed his dismay

over a ruling by the Kingston Area Library that retarded adults who are in the Ulster County Association's vocational rehabilitation program, are not allowed to obtain a library card and borrow books.

Apparently, the denial was based on the fact that handicapping conditions of the applicants excluded them.

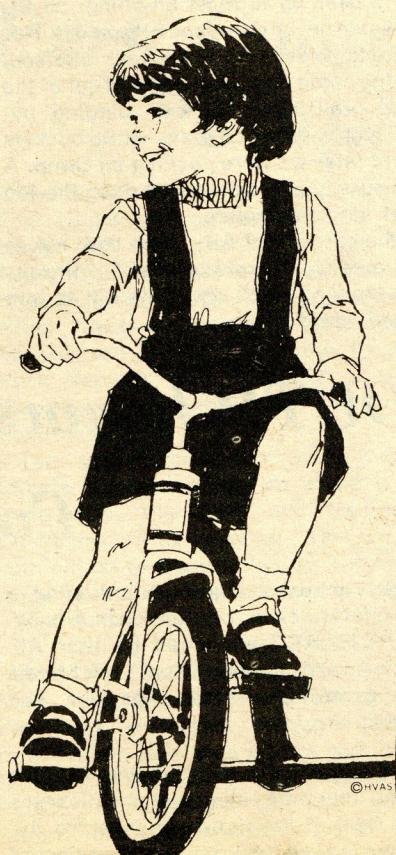
In a letter to Ryan on September 4th, Joseph T. Weingold, executive director of the State Association, pointed out that under the Education Law, Sections 262, 272, and 272, subd. 10a., although the library is authorized to exclude any person who willfully violates the rules of the library trustees, it is the opinion of counsel that having a handicap is not a violation of such rules.

Further, Section 10a. states "consideration shall be given to a. the prevention of unreasonable discrimination among the persons served by such library systems."

Also, under the Federal Vocational Rehabilitation Act of 1973, Section 504, there can be no such discrimination against mentally handicapped by any state agency receiving Federal funds.

"In brief," wrote Weingold, to Ryan, "this discrimination must stop immediately."

On September 9th, Ryan informed Weingold the problem at the Kingston Library has been resolved and he has been assured in writing that the clients of the Ulster County Association would be allowed to have full and unrestricted use of all library facilities.



The Trike Trac in operation

Although it is the policy of the Association not to promote proprietary items, we are making an exception with the TRIKE TRAC.

Tricycle and wheeled vehicle play for young children becomes a learning experience with Safety Trike Trac, a starter course for promoting cycle handling skills and two-wheeler indoctrination.

Introduced by PlayLearn Products, St. Louis, Mo. — it contains directional arrows, a ramp, Bumpy Bump board and Park-It "garage" for helping develop left-right awareness, turn and speed control, guidance accuracy and visual discrimination. Components of the Safety

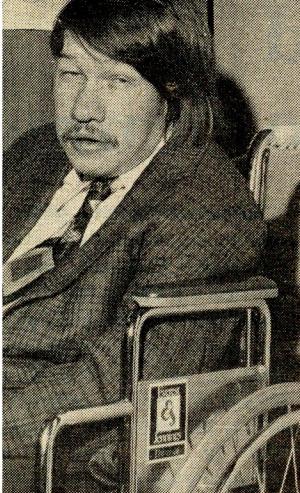
Trike Trac can be arranged in any number of traffic patterns, on any surface, indoors or out.

Played as a game by two to eight-year olds, the program also advances perceptual motor and coordinative development. Extra excitement is added by its up-down ramp and a vibrating ride over a length of "corrugated roadway".

The Safety Trike Trac's heavy-duty reinforced vinyl guidepath arrows grip flooring securely, last indefinitely and clean easily. An application folder with suggested traffic patterns is furnished.

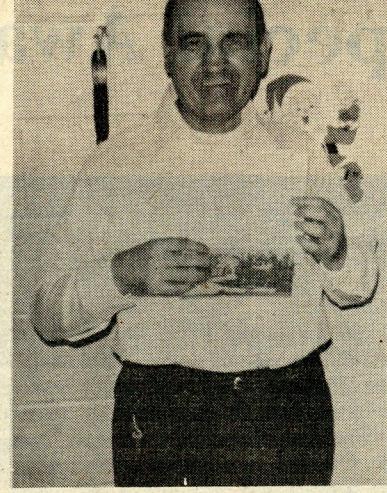
Further information may be obtained from PlayLearn Products, 29-24 40th Avenue, L.I.C.N.Y. 11101.

# Metropolitan Museum shows Christmas entries



ROBERT HOTCHKISS

L. Tarolli,  
Rome Developmental Center



ALBERT ARAMINO

## Christmas Card Design Winners

The interest shown in our Christmas Card Design Contest, our annual exhibit at the Museum of Art (described on the previous page) in response to our annual Christmas Cards designed by the winners, we thought our readers know a little about the winners of this year's award.

Walsh, Director of Rome Developmental Center sent us the above portrait of Robert Hotchkiss, a resident of Rome with the following information: Robert Hotchkiss was born in 1933, in Johnson City, New York, son of Edwin E. and Myrtle Hotchkiss. Robert was one of a family that included an older sister and a half-brother Richard, and a sister Dianna. His parents died.

Robert was a resident at Rome Developmental Center twice. He was first admitted in February 15, 1942, and until he was discharged on January 1, 1945, to live with his family. The death of his father in 1962, led to live with his step-father with his half-brother, Robert Hotchkiss, until July of 1965. As both wife worked, it was arrangements to care for the day. This situation led to readmission to Rome Developmental Center on July 9, 1965, and remained since.

At admission, Robert was placed in public schools, as the district where he lived did not have education or classes for handicapped. At the age of 12, he attended the Eldridge Park School in Binghamton for a year, owing his admission here to the fact that the school classes were not available.

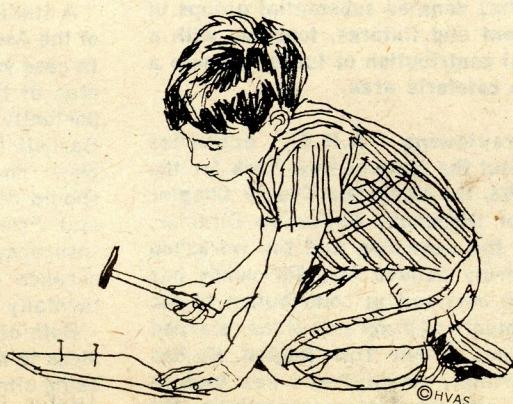
Robert attends the In-

stitutional Rehabilitation Workshop five mornings a week and enjoys participating in living unit recreational activities such as bus rides, field trips, picnics, bingo, and movies. He also attends occupational therapy where he pursues such activities as rug tying, knitting, painting, drawing, and sketching.

It is difficult to say when Robert's artistic talents began to develop and emerge. School Department reports during the period 1942-1945 mention "neat hand-work," "lovely coloring," and the fact that Robert was one of the few children in the class that had learned to weave. We can estimate, then, that the first evidence of manual aesthetic and creative capabilities was noticed at the age of 10 or 11 years.

Mrs. Myra Lewis, Chief of Service at West Seneca Developmental Center sent us the above picture of Albert Aramino, a resident of their center with the following information: Albert Aramino, resident of the West Seneca Developmental Center, was honored by his fellow residents at a reception on the occasion of his winning Third Place in the ARC 1976 Christmas Card Design Contest. In attendance were Dr. Louis G. Huzella, Director; Mrs. Myra E. Lewis, Chief of Service of the Adult Habilitation Service; and Mrs. Toni Parisi, President of the West Seneca Developmental Center Chapter of the Association for Retarded Children.

Mr. Aramino was born 1-19-1920 in Batavia, New York. He has been a resident of the New York State Department of Mental Hygiene Facilities since 1962 because of a seizure disorder. He is able to do some electrical and photograph work and he is quite a talented artist. He is a careful and precise worker and takes a great deal of pride in his work. He deserves much credit for his achievement as do Occupational Therapists, Mrs. Edna Sanchioni, and Mrs. Francis Aprile for their encouragement.



ning....

Stashed away in a remote nook, far removed from his multitudinous admirers, The Thinker sits immobile in the same state of cogitation that Auguste Rodin left him in a long time ago. Ultimately, when his new accommodations are complete, he'll go on public view again.

Meanwhile, visitors to the Metropolitan Museum of Art still have access to a priceless collection of the world's great art hanging from the walls, rising from the floor; an immovable feast.

Yesterday, Robert Hotchkiss joined Utrillo and Rembrandt and Goya and the Wyeths, father and son. So did Albert Aramino. So did some others whose names you've never heard before nor ever will hear again, probably.

Robert Hotchkiss is 43 years old and lives at the Rome Developmental Center upstate. When he was first admitted, these places were called institutions and those housed there were relegated to a life of anonymity.

Robert Hotchkiss' creation is hanging in the Met now, in a public dining room. It depicts the Three Wise Men, bound for Bethlehem. It's a joyful thing of beauty, so much so that it won first prize in a Christmas card design contest sponsored by the New York State Association for Retarded Children, an agency that helps the retarded of all ages.

Part of Hotchkiss' prize is a \$100 government bond. But the bigger part of it is that his design has been imprinted on thousands of Christmas cards being sold

by the association at dozens of outlets across the state.

Unfortunately, his name is not on his work; a sort of residue of a bygone time when it was thought best to shield retardates.

"We're going to put names on those cards next year," said Geraldine Sherwood, program coordinator for the association. "These people can use some ego-building, just like the rest of us."

Aramino's runner-up shows Santa, swathed in whiskers and good cheer, about to embark on his yearly sortie through the frosty sky. In the distance, wisps of smoke curl out of a chimney. The watercolor is awash in Yuletide happiness, as are more than two dozen other entries affixed to the wall.

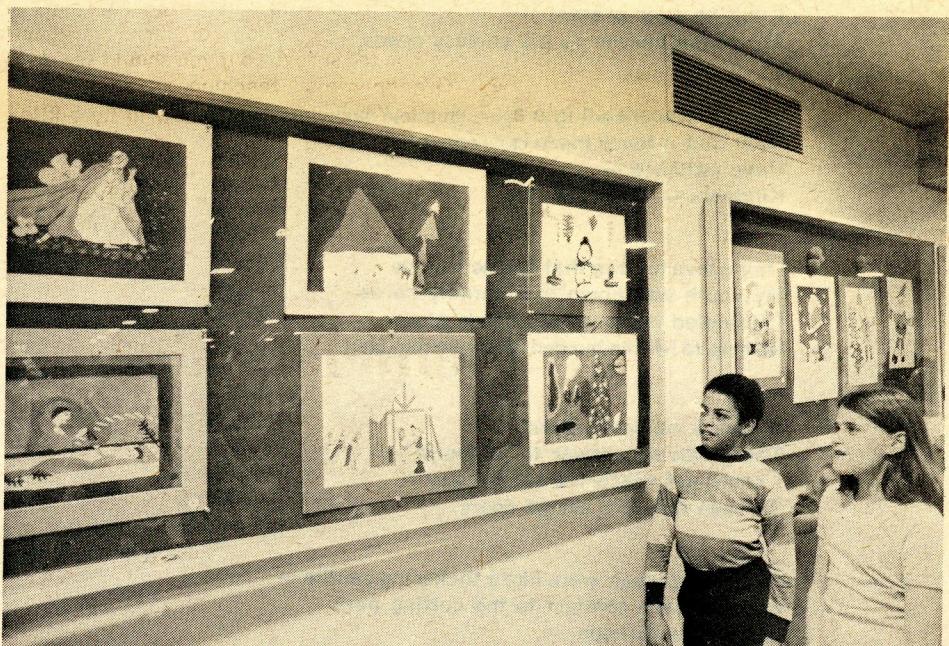
"This is one of the areas we set aside for community programs such as this one," said Cathy Chance of the museum's staff, gesturing toward the dining room.

Inside, Debbie Lampman, 10, and Kevin John, 9, studied the entries. Along with their classmates from P.S. 100, they'd been brought in from Queens for a tour of the museum.

"The creche, that's easily recognizable," said Debbie.

"That's what Christmas is all about," chimed in Kevin, indicating the snowmen singing, sleigh bells ringing, red and white stockings a-filling.

Currier and Ives used to hear things like that all the time. . . .



Kevin John, 9, and Debra Lampman, 10, both of Queens, admire card exhibit.

N. Y. Daily News Photo

## Karin Burgess heads

### S. D. C. Board

Karin Burgess, 19 Circle Drive, Cortland has been elected President of the Board of Visitors of Syracuse Developmental Center, succeeding Thomas W. Pelnik, Jr.,

Syracuse, who was recently elected Vice-President for Developmental Centers of the New York State Association of Board of Visitors of Mental Hygiene Facilities.

Mrs. Burgess has been a member of the Board since 1973 and has served as a volunteer in the field of mental health and mental retardation for many years. She is a past president of the local chapter of the Association for Retarded Children and is currently the corporate secretary of the New York State Association for Retarded Children.

## Legislative Programs

Continued from Page 1

It is interesting to note Chapter 510, Laws of 1973, amends the Social Services Law to extend subsidy payments to out-of-state families adopting children. There is no reason why payments should not be made to private schools outside the State.

### E. Other Matters

1. Provision that life insurance companies may not refuse to insure the lives of mentally retarded persons up to an aggregate limit of \$1,500 on the sole ground of retardation.

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

3. Provision that political subdivisions of the State may not enact zoning laws restricting the use of any property for group homes for the mentally retarded, or enforce any existing laws to such effect.

## 'A Child was Born'

By Frieda Kleinberg

(a mother's memorial to her son)

I knew almost from the beginning,  
That he was born to darkness —  
A life without the knowledge of its very depths —  
Or many of his lofty heights.

The operating room was filled with blinding lights —  
Wispering doctors speaking of urgent needs;  
Busy nurses running back and forth —  
Questioning glances in their fearful eyes.

A dark despair was gripping my wildly beating heart.  
I felt a screaming fear touching my inner being.  
I knew almost from the very first beginning —  
Life's precious gift was never meant for me.

They let me glimpse at him one fleeting moment.  
No beauty of the newborn to behold.  
They did not tell me — yet, knew:  
My child was born unwhole.

Eyes without sight —  
Lips without speech —  
Limbs twisted;  
A brain — too crippled to grasp the meaning of it all.

I held him in my wanting arms —  
I held him to my aching heart.  
No question asked — I knew, I knew:  
The thorny road, the bitter truth.

There will be days without much laughter —  
There will be nights without much sleep.  
I will be ever present —  
My gentle answer to his endless needs.

There will be pleading prayers in those darkened nights —  
Dear God — teach me to care enough —  
Have patience —  
Kindness — understanding.

I felt a love for him that had no bounds.  
My youth was given to his many cares.  
I travelled many empty roads alone —  
No help to lift the burden of my aching soul.

It was a wasteful search —  
There was no answer to be found —  
I could not reach the sacred key —  
To open nature's secret doors.

Hope and despair were like a flickering candle —  
Its light gave comfort to the cutting pain.  
There was no hope —  
I knew it almost from the very first beginning.

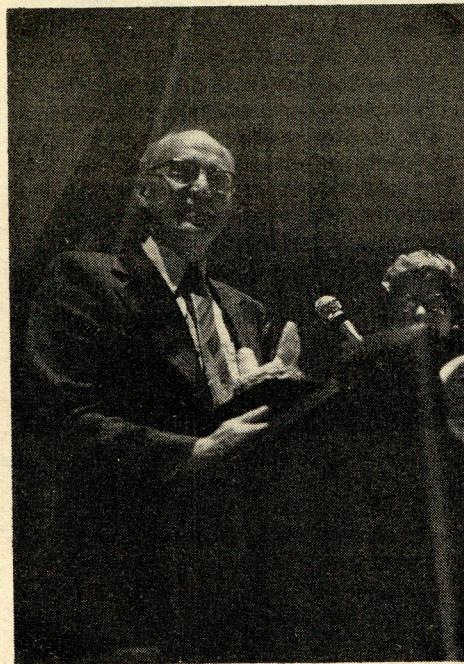
This cross was mine to bear —  
Alone — in utter helplessness.  
I had to find a special strength —  
A God had chosen me.

The searching question ever present.  
Why me — what have I done?  
My painful days must find a path —  
I was deprived of life's great joy.

The answer will be found some day —  
I will bring meaning to his wasteful life.  
I will unlock many hidden doors —  
Remove the skeleton at last.

I found the meaning of his life — wasted life.  
I must help him and others who will never grow.  
A child was born — a mother wept;  
The day of death will heal the ever bleeding wound.

## Special Award to Simmonds



Mr. Howard P. Rowell accepting the special award on behalf of Geoffrey R. Simmonds, as Ann McDonald looks on.

In the June issue of OCV, we ran a story entitled, 'The Company With a Heart'. It was a review of a generous gift of property, given to our Chenango County Chapter by Simmonds Precision Products, Inc., through its Chairman and Chief Executive officer, Mr. Geoffrey Simmonds.

Chenango Co. Chapter was extremely grateful to Mr. Simmonds and were anxious that some recognition of his outstanding gift be made. Their feelings were well expressed in a letter which they sent to the State Association, co-authored by Executive Director, John McHale and State Board Member, William Fowlston. They were nominating Mr. Simmonds for "Employer of the Year", and this is how they put it.

"Mr. Simmonds has made an exceptional contribution to the progress of the Chenango County Chapter during the preceding year. This contribution has not only provided for the employment of significant groups of retarded adults, but more substantially, Mr. Simmonds has contributed a permanent structure to house the executive offices and a modern workshop facility with the capacity for employing in excess of two hundred retarded adults. This facility is structured to provide for educational programs, on the job training programs, as well as normal workshop contracts and product fabrication. The modern twenty six thousand square foot facility located on 2.5 acres of land is appraised at a value in excess of \$200,000.00.

Mr. Simmonds' employment of the retarded has been in the form of granting contract work to the Chenango County Chapter workshop. In addition to the contribution of the building facility and the providing of work contracts, Mr. Simmonds has donated substantial groups of equipment and fixtures, together with a personal contribution of funds to equip a modern cafeteria area.

In reviewing A.R.C. activities throughout the State of New York for the Year 1976, the Chenango County Chapter Board of Directors, Executive Director, staff of the workshop and the workshop clients truly believe Mr. Simmonds has made an outstanding contribution to the employment and programs of the retarded in the Central New York Region. He has most certainly established a new high in personal and corporate responsibility for the victims of retardation that they not be victims of our neglect."

Subsequent to this letter, a second letter came in stating: "The Simmonds Precision Products Inc. have recently notified the Chenango County Chapter that an additional 1.02 acres of land adjacent to our facility and containing three prime housing lots appraised at a value of \$89,000.00 will be donated to our Chapter within the next few weeks. Attorneys are now in the process of completing necessary legal paper work for completion of the transaction.

Please regard this letter as additional support of our Chapter's recommendation of Mr. Geoffrey Simmonds as Employer of the Year."

Our Scholarship and Awards Committee deliberated the issue, but felt that within the guidelines established, the Simmonds Company could not be considered in this category. But what to do? There was unanimous agreement that some recognition should be given, but there were no provisions within the Association for this, and, by now, time had grown short.

Proving once again that our large Chapters are always ready and willing to help the smaller, Dorothy Ganin of Nassau Co., A.H.R.C., came through under pressure. Contacted by the State office, Dot responded quickly and positively. "We have," she said, "a nice desk piece — a little bird in a nest, and its all made by the clients in our programs. We'd be pleased to donate one for the occasion."

And so it was, that at the State Convention Banquet, we were able to present this piece to Mr. Howard P. Rowell, who was representing Mr. Simmonds. But most important, we were able to express our thanks to the man behind "The Company with a Heart."

The little plate on the base of the award said it all —

to  
Geoffrey R. Simmonds  
In Gratitude, With Love  
From  
The Mentally Retarded

## Life insurance for retarded

The New York State ARC was pleased to announce a group life insurance program for mentally retarded persons. The program, which was arranged through the DeMian-Barnett Organization, is underwritten by the American Mayflower Life Insurance Company and provides whole life insurance on a 20 pay life plan for all members of the family.

A mailing has gone out to every member of the Association with details of the plan. In case you did not take advantage of the plan at that time, you have another opportunity to do so by writing the DeMian-Barnett Organization, 393 Seventh Ave., New York, N.Y. 10001. This program should not be confused with the Parents and Friends of the Mentally Retarded Insurance Trust, which offers term insurance at low rates to parents of the mentally retarded.

Both of these plans are additional services to the members of this Association, being offered through the New York State ARC, to provide every possible protection for the mentally retarded and their families.

## News, Views

# Education Committee

Betty Pendler, Chairman  
BUILDING BRIDGES

The Education Committee likes to think of itself as a builder of bridges, with the prime beneficiary being the individual parent. . . . bridges making more accessible links between them and the vast bureaucratic school system that is educating their son or daughter. We think we are getting there, and urge all chapters to have someone act as educational liaison and contact the persons listed below covering your area. If you want to combine with nearby chapters, we can help you set up a parents' workshop, suggest programs, give you information to distribute at your meetings; give you items to put into your newsletter etc.

Lower Hudson — Westchester, Rockland, Orange, Sullivan, Ulster, Putnam, Dutchess, Suffolk, Nassau — GEORGIA SULLIVAN, 11 City Terrace North, Newburgh, N.Y. 12550.

Capitol District, Albany, Rensselaer, Schenectady, Schoharie, Montgomery, Fulton, Saratoga, Washington — Warren, Columbia, Greene — MARILYN WESSELS, 135 Western Avenue, Richardson Hall, Room 175, Albany, N.Y. 12203.

North — Hamilton, Essex, Clinton, Franklin, Lewis, Jefferson, St. Lawrence — JAMES JOHNSON, 30 Morrison Avenue, Plattsburgh, N.Y. 12901.

Central — Oswego, Herkimer, Oneida, Ontario, Schuyler, Seneca, Yates, Onondaga, Madison, Chenango, Broome, Cortland, Cayuga, Tompkins, Tioga, Chemung, Delaware — THOMAS SCHOLL, 701 Forest Drive, Syracuse, N.Y. 13212.

Western — Steuben, Wayne, Monroe, Livingston, Allegany, Wyoming, Genesee, Orleans, Niagara, Erie, Cattaraugus, Chautauqua — MARGE CERVONE, 121 Tracy, Batavia, N.Y. 14020.

All Developmental Centers — SHIRLEY J. REYNOLDS, 864 Colvin Blvd., Kenmore, N.Y. 14217.

Let's keep the lines of communication going in both directions.

### ATTENTION EDITORS

NEWSLETTER EDITORS: PLEASE SEND COPIES TO THE ABOVE MENTIONED PERSONS on the STATE LEVEL — We have built several bridges, one direct to the Assistant Commissioner of Education Bernice Kipfer, in charge of Department of Children with Handicapping Conditions. Tom Scholl and Georgia Sullivan, together with a representative from Senator Schermerhorn's office, had a fruitful meeting where they discussed our concerns. Dr. Kipfer responded to 14 items on which our committee and her office will work in the future on a mutually cooperative basis. We are building bridges with individual school districts, department of Special Education and BOCES Directors, as witnessed by the fact that Mr. Ray Cramer of BOCES in Goshen, N.Y. sent letters to the parents actually REQUESTING INPUT into the 5 year plan. This came about after Georgia Sullivan, in her newsletter to the chapters in her district, urged the parents to ask BOCES for copies of the 5 year plan (EHA-B). We want to share one such input letter sent to him by Ms. Anne Klingmer, and urge all parents to write similar letters to their respective BOCES director. We know others are willing to be as cooperative as Mr. Cramer appears to be: "Dear Mr. Cramer" I am sending you a list of concerns and suggestions that may or may not be helpful in the preparation of the BOCES Five Year Plan. Each item reflects my personal concerns. . .

1. The school day should be expanded to insure the minimum hours of instruction as defined by the N.Y. State Education Law. This means children in the primary grades receive five hours of instruction excluding lunch time, and the older students receive five and one half hours, excluding lunch.

2. I feel the Physical Education Program should be expanded to provide physical activity for each student every day, with individualized programs for the students. The students served by BOCES often need physical activities and exercise to be provided in school because of their handicaps which limit recreation in the community or neighborhood. The PE program could include individual sports techniques, recreational activities not possible at home (such as riding toys for the younger children) individual physical exercise programs with the PE instructor as a PT aide. The PE Program Director could assist classroom teachers in preparing daily activities that can be done in the room or outside if weather permits.

3. I feel all ancillary services required by the BOCES students should be provided within the facility — this should include speech therapy, physical therapy, occupational therapy, psychological and psychiatric counselling.

4. I feel speech programs should be expanded and staff added to insure individual therapy or language stimulation sessions several times a week when indicated. Speech is vital for independence.

5. I feel an intensive pre-vocational program should be offered for the students in the TMR classes who are in the pre-teen and teen years so they can become as independent as possible; for those students who cannot benefit from occupations, some alternative yet constructive program should be offered.

It is possible some or all of the above are already in the process of being implemented. In that case, please do not feel I am criticizing. I am just unaware of all that is happening at BOCES. Thank you for your cooperation." Sincerely, Mrs. Anne Klingner.

A great example of a non hostile letter and an offer to work together.

Your area may have different concerns. I am sure the administrators want to hear from you. In fact, they are eager to get input from you. So exercise your right, as this parent did, and write a letter.

### WASHINGTON BRIDGE

We have built bridges as far as Washington, D.C., because, in August, Congressman Benjamin Gilman, of the 26th Congressional District, became aware of our problems when he wrote to Ms. Georgia Sullivan: "There has been an apparent lack of information and attention to new legislation that is highly beneficial to handicapped children; in particular, the Education for ALL Handicapped Act of 1975. Accordingly, I would like to invite you to join and participate in a 26th Congressional District Advisory Committee for Handicapped Children. The purpose for such a committee will be to more fully advise my office of the needs of the handicapped and more efficiently communicate some of the problems of the handicapped to my constituents. . ."

We hope this will be the impetus to get more such committees formed. How about approaching your own Congressman to see how much he knows about this new Education for All Handicapped Children Act, and refer him to this committee and urge him to follow suit?

We have built bridges with the Executive Directors of all the Chapters, when Betty Pendler, Chairperson of the Education Committee had a very fruitful "dialogue" with them during the recent State Convention.

## Letters to the Editor

### Thanks for support

The Association is in receipt of two letters thanking us for support of programs, which we wish to share with our readers.

One is from Eugene C. Maillard, Coordinator of the Very Special Arts Festival. His letter follows.

"I want to express my appreciation for all the cooperation you have given the Very Special Arts Festival. Our display at the A.R.C. convention in Rye, New York has certainly meant a great deal to the program.

Judging from the reaction of those whom I spoke with, I am now most confident that your membership will be able to advance the Very Special Arts Festival program throughout the state. Your assistance is certainly most invaluable.

Again, thank you very much and please express my appreciation to your staff who made my stay at the Hilton a most enjoyable one. All best wishes."

The second one is from Dr. G. C. Salmoiraghi, Associate Commissioner DMH for Research. His letter follows:

"I am pleased to send you a copy of the Annual Report of the Division of Research for 1975. This volume is our first Annual Report in this format and the first to be widely distributed outside the Division. We hope that by making the work of our scientists known to individuals and groups with a significant involvement and concern in this area, we can provide a medium for disseminating the results of that effort and an occasion for comments, suggestions and questions concerning the research program of the Department.

I would also like to take this opportunity to thank you for the support you have given to this program and to invite you to examine the nature of our work more closely. I, and the Directors of our research institutes, would be most happy to answer any questions, provide any elaboration of work described in this document, and arrange for visits to any of our facilities."

### Worth repeating

This letter is reprinted from the Connecticut ARC who reprinted it from the newspaper of the Tennessee ARC.

Why are we throwing the baby out with the bathwater?

### Rep. Gilman writes

#### to Betty Pendler

In a letter to Betty Pendler, Chairman of the Education Committee, representative Benjamin A. Gilman of the 26th District, New York, expressed his thanks for the ARC resolutions and support of the Congressional Advisory Committee on Handicapped Individuals.

"Dear Ms. Pendler, Thank you for your thoughtfulness in forwarding a copy of the Resolutions adopted at the 1976 Convention of the New York State Association for Retarded Children.

I appreciate your support for the Congressional Advisory Committee on Handicapped Individuals, and I hope that your support for this venture will continue when the next Congress convenes in January.

Please accept my thanks once again, and please continue to keep me apprised of the progress the New York State Association makes in the area of relief to Retarded Children.

With best wishes, Sincerely, Benjamin A. Gilman, Member of Congress".

Representative Gilman has been a good friend to the Association, active in support of our applications to HUD and many others.

The more I learn about mental retardation and the new trends and concepts, the more I seriously worry about the severely and low functioning trainable retarded.

It is my belief, that while we are on the threshold of real help, change and challenge for the MR, we should reconsider just how we are going about getting these services and the people we are hurting by not stipulating more clearly who needs what services.

I address myself to the concepts of normalization and decentralization. First I must ask, is it normal to be born retarded? Is it normal to expect nonhandicapped citizens to become involved, knowledgeable, caring and concerned about the plight of the MR, when they are not directly affected by them or from whom they cannot earn a living? Should we be our brother's keeper?

Romantically, the answer to these questions is yes. Realistically, the answer must be no. This is not to say that MR citizens should not receive adequate services from their communities. Au contraire! What I am trying to point out is that perhaps we are inadvertently trying to make the retarded normal.

With the concept of decentralization, it is becoming increasingly difficult to institutionalize a retarded child.

While it's lovely to speak of the rights of the retarded child, what about the rights of the parents, who unknowingly have given birth to such a child and cannot cope with the situation?

They are now being made to feel that there is no way out for them. They are stuck with this burden regardless.

For even considering institutionalization, they are branded as being selfish, neglectful and uncaring and for those who have already done so, administrators and employees of institutions are attempting and succeeding in making the parents feel guilty.

Unless I am sadly mistaken, I do believe that there is only one God. Please let us have the option to institutionalize any medically proven retarded citizen without additional pressures being put upon us and please let us continue to improve our institutions.

Above all, we must draw a line between the differences in mental retardation. The EMR, the TMR and the SMR are really quite different. Ask any parent of these retarded citizens.

Lynn Labbe

### Appreciation....

"Dear Mr. Weingold: May I use a paraphrase 'We are in good hands with Joseph T. Weingold.'

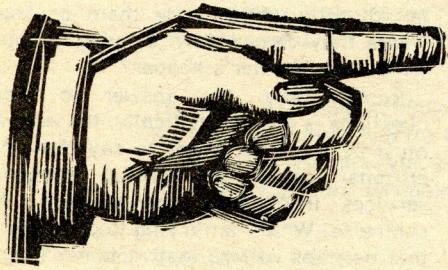
I was at the hearing Wednesday, (Nov. 17th) at the New York City Hearing for the Council on the Handicapped. I know and believe from the few hours I heard in testimony yours was the most effective.

Keep up the good work. Stay in good health. Good to know how we're part of an organization who fights for the handicapped."

You  
are  
her  
voice



Learn  
this.



It can  
save  
a  
life!

## A person choking on food will die in 4 minutes - you can save a life using the **HEIMLICH MANEUVER**

Food-choking is caused by a piece of food lodging in the throat creating a blockage of the airway, making it impossible for the victim to breath or speak. The victim will die of strangulation in four minutes if you do not act to save him.

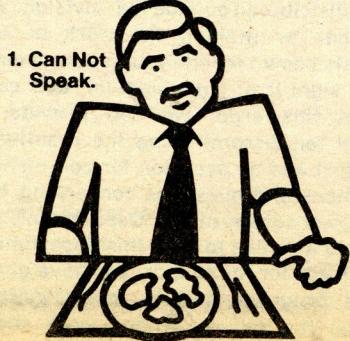
It is sometimes possible to reach into the back of the throat with your fingers and remove the food. This applies particularly to children.

Using the Heimlich Maneuver (described in the accompanying diagrams), you exert pressure that forces the diaphragm upward, compresses the air in the lungs, and expels the object blocking the breathing passage.

If no help is at hand, victims should attempt to perform the Heimlich Maneuver on themselves by pressing their own fist upward into the abdomen as described.

### WHAT TO LOOK FOR

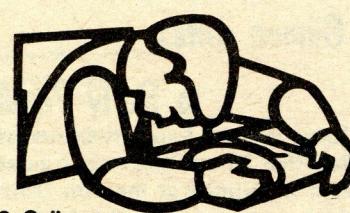
The victim of food-choking:



1. Can Not  
Speak.



2. Turns  
Blue.



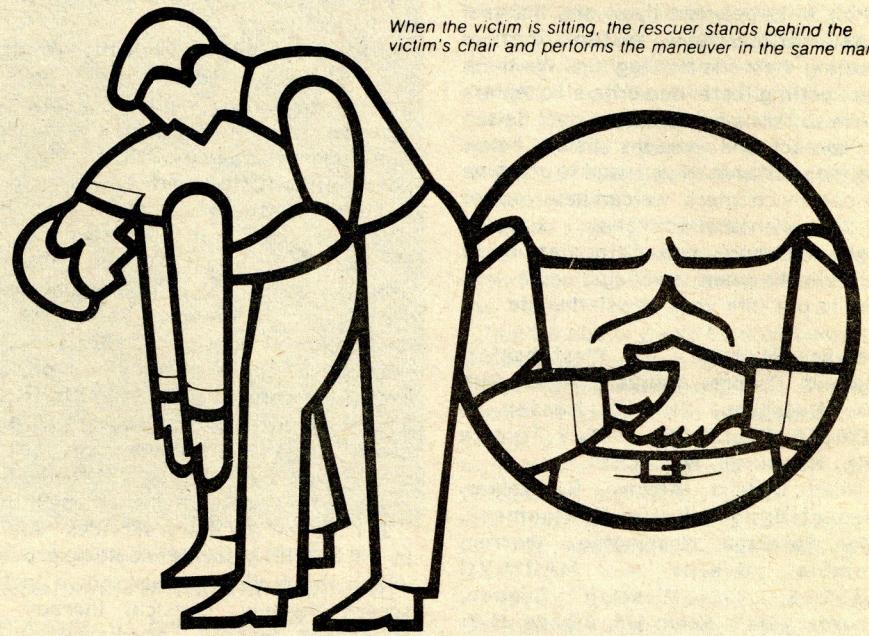
3. Collapses.

### HEIMLICH MANEUVER

RESCUER STANDING  
Victim standing or sitting

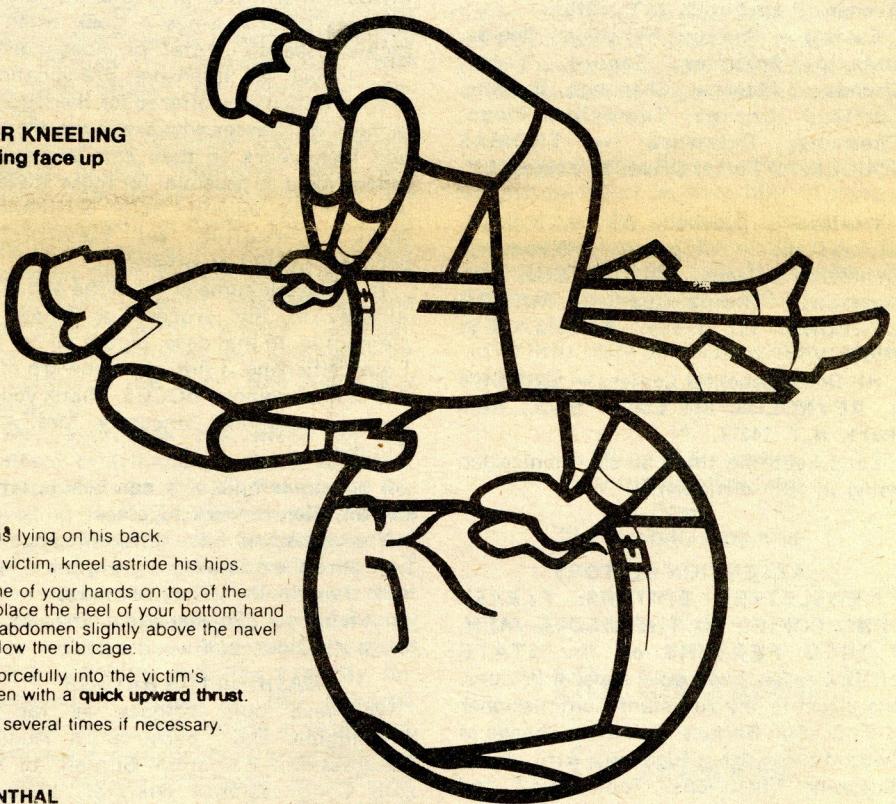
- Stand behind the victim and wrap your arms around his waist. Allow his head, arms and upper torso to hang forward.
- Grasp your fist with your other hand and place the fist against the victim's abdomen, slightly above the navel and below the rib cage.
- Press your fist forcefully into the victim's abdomen with a **quick upward thrust**.
- Repeat several times if necessary.

*When the victim is sitting, the rescuer stands behind the victim's chair and performs the maneuver in the same manner.*



OR

RESCUER KNEELING  
Victim lying face up



- Victim is lying on his back.
- Facing victim, kneel astride his hips.
- With one of your hands on top of the other, place the heel of your bottom hand on the abdomen slightly above the navel and below the rib cage.
- Press forcefully into the victim's abdomen with a **quick upward thrust**.
- Repeat several times if necessary.

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

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