

# Our Children's Voice

Retarded Children Can Be Helped!

Vol. XXVIII No. 1

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

January 1976

## 1975 Convention

### Legislative program

#### SEPARATE M.R. FROM DEPARTMENT OF MENTAL HYGIENE:

First among the priorities of the Legislative Program for 1976 adopted by the State Convention in Buffalo, by unanimous vote of the board and the delegates, was the establishment of an Office of Mental Retardation in the Executive Department. It was the consensus of the convention that nothing that the Department of Mental Hygiene has done since the Governor vetoed the bill in 1975, shows any promise for meaningful improvement in the lives of the mentally retarded or the development of community services for them.

The following is the complete Legislative Program for 1976:

#### A. STATE SCHOOLS 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.

3. Amendment of recent amendment to the Mental Hygiene Law (Chapter 804, Laws of 1975) to provide for consent of, not merely consultation, with parents of patients under 16 years of age prior to release, etc.

#### B. COMMUNITY MENTAL HEALTH SERVICES

1. Provision for reimbursement of communities by the state at the rate of 75 per cent for mental retardation services provided locally.

— 2. A bill to amend the Mental Hygiene Law to provide that the interest paid on any mortgage, whether HFA or other, by the Association for the acquisition, construction, or remodeling of a facility to serve the mentally retarded, be a reimbursable expense under contracts with mental health boards 1975 legislation merely provided that that part of the rental paid to a mental retardation services company, representing interest on HFA mortgages, be reimbursable. This was attached by the Governor as discriminatory, and the committee believes it is time to redraw to make it more general.

3. Net income realized in the operation of specific programs be deducted from operating costs. Action recommended: Substitute bill to repeal MHL Section 11.5, sub. 11 (b) which provides that income derived from other activities under a mental health board contract be deducted from the contract.

4. Provision that Community Mental

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## George Hirsch heads State Association



PRESIDENT, GEORGE G. HIRSCH

At the Convention in Buffalo, George G. Hirsch, one of the founders of the Association for Retarded Children, was elected the new President of the State Association.

Mr. Hirsch served as vice president of the N.E. Region of the New York State Association for Retarded Children in 1966 and from 1971 to 1975 as treasurer.

He was one of the original board members of the Association for the Help of Retarded Children, New York City Chapter, and served continuously since its inception in 1949. He was President from 1958 to 1960 and has held posts of vice president, financial secretary and treasurer.

He has been chairman of numerous committees, including the Vocational Rehabilitation Committee of the New York State Association as well as its Executive Committee.

He is a member of the board of the Comprehensive Health Planning Agency of the City of New York, the Department of Mental Health's Task Force on Residences and a member of the National and State Committees dealing with the handicapped.

Mr. Hirsch is head of Brown Brothers Limited, an export finance house which is a subsidiary of Unity City, Merchants of London.

He is married and the father of two daughters and one son, and the proud grandfather of four.

## Legislative run down for 1975

The 1975 Legislature passed only two bills of the State Association's Program. These were the bill to establish an Office of Mental Retardation in the Executive Department (vetoed by the Governor), and a bill to provide that that part of rental paid to a mental retardation services company representing interest on HFA mortgages be a reimbursable expense under contracts with mental health boards (also vetoed by the Governor).

The following bills on the program either died in Committee or passed one house or the other without going to the Governor.

— Elimination of parental liability for fees for children under 21 years of age in institutions operated by the Department of Mental Hygiene, S. 1696, Giuffreda, died in Committee.

— Reimbursement by the State at the rate of 75 per cent for community mental retardation services, S.2395, Pisani, A. 7470 Marchiselli, died in Committee.

— Provision that only net income realized in the operation of specific programs be deducted from operating costs, S. 2589A., Flynn, passed June 3rd; A. 3283A., McCabe, died in Ways and Means Committee.

— 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, 2393, Pisani; A. 7340, Passannante, died in Committee.

— Amendment to the Education Law to make effective the mandate for free public education for every child and reimbursement for education of the handicapped shall be in full, was embodied in a bill introduced by Senator Giuffreda, S. 5967C., which purported to amend Article 89 of the Education Law to do the following:

a. require school districts to establish committees on the handicapped;

b. mandate education for the handicapped below age 21;

c. eliminate Family Court procedure and have the State pay all the additional cost over and above what the school district would have spent wherever a child is educated in a private residential or day facility;

This bill passed the Senate, but died in the Assembly Education Committee.

#### OUR OBJECTIONS TO THE BILL WERE:

a. that the committees on the handicapped did not include enough parents;

b. that the age for education be mandated from 3 to 21;

c. it did not make absolutely clear the total cost of education would be picked up

by the State over and above what the school district contracted.

— Mandate Section 4407 of the Education Law, S. 402, Conklin; A. 475 D'Amato, died in Committee.

— Amendment of the Education Law to provide education of the handicapped be mandated from age 3, S. 2392A., Pisani; A. 7378 Stavisky, died in Committee.

— Transportation over age 21, S. 1212, Giuffreda, passed. S. 2394, Pisani, died in Committee. A. 7341, Passannante, died in Committee. The Giuffreda bill got nowhere in the Assembly.

— Amendment of the Insurance Law to require all insurance companies and plans to include mentally retarded dependents in family health and hospital policies, S. 2235A., Dunne. Passed the Senate. A. 4268A, Silverman. Passed the Assembly.

Unfortunately, these two bills did not coincide exactly and therefore, there was no bill in spite of the fact that Mr. Silverman, Chairman of the Assembly Insurance Committee, promised in the last five days of the Session he would try to get together with Senator Dunne on a bill.

— Amendment to the Insurance Law to forbid insurance companies to refuse life insurance to the retarded up to an aggregate limit of \$1500 solely on the grounds of mental retardation. Never introduced.

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# Nassau Rose Ball honors Aronin



Nassau County Chapter Executive Director Helen Kaplan, presents Humanitarian Award to Elliot L. Aronin, left, with Chapter President Hy Clurfeld.

Highlight of the annual Nassau County Chapter Rose Ball was the presentation of the 15th Annual Humanitarian Award to Elliot L. Aronin. A past President of the Chapter, and for three years President of

the New York State Association for Retarded Children, Elliot Aronin, and his wife, Rose, are an important part of the Chapter's history and accomplishments. They have endeared themselves to all who have worked with them in Nassau County and this year's award had a very special meaning to all those assembled. A specially designed bronze sculpture by Monte Belden, the award bore the inscription "... he expressed his friendship by dedicating 25 years of his life to the mentally retarded, and knowing him is their special treasure . . .".

Under the leadership of Co-Chairpersons Gertrude Merinoff and Louis Silver, and through the extraordinary efforts of members, the Chapter's top money maker overcame fears of possible cutbacks in donations, and receipts climbed close to \$250,000! In addition, special thanks for the evening's success must go to Journal Chairman John B. Cullen and to Reservations Chairwoman Dorothy Ganin. And from those of us who were there to enjoy the evening, applause and thanks to Long Island Press newspaper columnist and Chapter Board member Walter Kaner, whose masterful job as Master of Ceremonies brought a steady round of giggles, guffaws, and groans to the gala proceedings.

## Legislative Run Down

Continued from page 1

### OTHER LEGISLATION AFFECTING THE MENTALLY RETARDED

The following legislation affecting the mentally retarded passed and became law.

1. A. 6180A. McCabe, to amend the Mental Hygiene Law to provide

a. that the Department of Mental Hygiene Commissioner inspect and issue operating certificates to all community residences of all kinds including family care,

b. creates a release procedure as transition status for in-patient care for a patient placed in a community residence and creates legal rights and remedies in connection with that status, including the Mental Health Information Service and court review,

### C. EDUCATION

1. Amendment of the Education Law to make effective the mandate of the New York State Constitution for a free public education for every child.

— 2. Amendment of Section 4407, Education Law, to make it mandatory instead of permissive.

— 3. Amendment of the Education Law to provide that education of the handicapped be mandatory from age 3 to age 21.

4. Amendment of the Education Law to clarify and liberalize the provisions relating to transportation of the handicapped.

5. Amendment of the Education Law to permit school districts to transport persons under 5 and over 21 years of age to and from rehabilitation facilities without state aid.

### D. OTHER MATTERS

1. Amendment of the Insurance Law to require all insurance companies and plans to include mentally retarded dependents in family health and hospital policies.

2. Amendment of the Insurance Law to forbid insurance companies to refuse life insurance up to an aggregate limit of \$1,500 on the life of a mentally retarded person on the sole ground of his retardation.

3. Amendment of the Criminal Procedure Law to conform the provisions relating to ability to stand trial to recent decisions on constitutional rights.

— 4. Provision for an "Ombudsman" for all handicapped persons; such "Om-

budsman" to be in the Executive Department.

— indicates high priority.

c. prior to discharge or release of a patient or resident, a written service plan must be developed and all patients or residents discharged since December 31, 1970, who had been on continuous in-patient status for two years or more prior to discharge, be located and written plans be created. (Chapter 804, Laws of 1975).

2. S.5260B. Donovan, amending Sections 9.03, 13.03, 13.23 of the Mental Hygiene Law and adding 13.02 as well as amending Section 757 of the Executive Law to require the Mental Hygiene Commissioner to prepare for the Governor and the Legislature annual evaluation reports regarding the delivery of care and services, family care homes, and other community residences. It prohibits the provider of services such as family care homes for mentally disabled persons from engaging in such activities after April 1, 1975 unless possessing operating certificates which shall be valid for two years and shall be issued to natural persons only and not to corporations for profit. It requires the Mental Health Commissioner, no later than April 1, 1976 to submit to the Legislature a plan for the creation of a central office of such residences and homes. (Chapter 805, Laws of 1975).

3. A. 6182A McCabe, amending the Mental Hygiene Law to authorize the commissioner to lease facilities of the Department and permit local government units providing services to the mentally disabled pursuant to the Unified Services Plan to lease facilities for the department, hospital, school or institution also providing services pursuant to such Unified Services Plan, (Chapter 564, Laws of 1975).

4. A. 6655 McCabe, amending the Mental Hygiene Law requiring at least 3 individuals who are parents or relatives of patients or former patients be members of the boards of visitors and the remainder include only persons who shall have expressed active interest in or shall have obtained professional knowledge in the care of the mentally disabled. (Chapter 574, Laws of 1975).

5. A. 6178 McCabe, to amend the Mental Hygiene Law, Article 11 to provide that local plans be developed with the in-

## Convention resolution

# Kolb directive condemned

The State Association for Retarded Children at its Convention at the end of September 1975 in Buffalo, passed a resolution calling upon Dr. Lawrence C. Kolb, to withdraw his memorandum to the Mental Health Boards concerning conflicts of interest. The memorandum, dated September 9th, states that since some members of Community Mental Health, Mental Retardation and Alcoholism Services Boards also are members of the boards of service agencies, which contract with the county, it may lead to prospects of conflicts of interest and, indeed, such situations may inadvertently occur.

He recommends, therefore, whenever a Mental Health Board is evaluating a program, considering a program plan, etc., where a member of a Community Mental Health Board is also a member of the Board or staff of an agency whose program is under consideration, such member should refrain from actively participating in the preparation, abstain from voting, and absent himself from the room whenever a vote is taken which will

### Dr. Feinstein dies recently

Dr. Samuel Feinstein, once director of West Seneca Developmental Center, from its opening in 1961 until he retired in 1971, died recently. In 1967 Dr. Feinstein was honored by the Erie County Chapter of the New York State Association for Retarded Children for distinguished service to the mentally retarded. In 1969, he was presented the Department of Mental Hygiene's distinguished service citation. In Dr. Feinstein's death, the retarded have lost a very good friend, indeed. He is survived by his wife Rose, a son Paul and a daughter, Joan Feinstein Simon.

Involvement of consumers, consumer groups, voluntary agencies and other providers of services, passed. (Chapter 516, Laws of 1975).

### MORE LEGISLATION CONCERNING THE MENTALLY RETARDED

1. A. 6173 McCabe, requiring the Commissioner of Mental Hygiene to have possession and control of golf courses in the institutions; that such golf courses be declared surplus property and the funds from the sale of these shall be used for planning grants to voluntary agencies in the local communities, died in committee.

2. Amends Mental Hygiene Law to repeal the provisions relating to the Mental Hygiene Council's Advisory Committee and enacting a new provision reconstituting the Mental Hygiene Council as the "Unified Services Council", vetoed.

All in all, not too productive a year in the opinion of a spokesman for this Association.

affect the agency with whom he also serves.

The resolution of the State Convention states that such a suggestion by the Commissioner is a violation of the Mental Hygiene Law, Section 11.11 which provides that members of the board shall "represent the community interest in all the problems of the mentally disabled and shall include representatives from community agencies for the mentally ill, the mentally retarded and alcoholics"; that furthermore any conflict of interest that may exist in such a situation was contemplated by the Legislature in the adoption of such statute and that the memorandum of Dr. Kolb is contrary to the intent of the Legislature as expressed in the statute and that application of this memorandum would have a chilling effect on the employment of knowledgeable and experienced people to Community Mental Health Boards that would wrongfully deprive a member of his legal right to vote.

The resolution, Resolved, therefore, that Dr. Kolb be asked to withdraw the memorandum.

Although our Executive Director met with Dr. Kolb after this resolution was passed and requested that he withdraw the memorandum, there has been no response to this effect from Dr. Kolb up to this point.

### Joseph Tholl dies in October

On October 23rd, 1975, Joseph Tholl died at the age of 66.

Joe Tholl was one of the founders of the State Association and active throughout his life and the life of the Association in helping the mentally retarded.

Joe was a very personal friend of mine (Jerry Weingold), always ready to help, even when ill, and stalwart in situations that needed his support.

One can truly say that he devoted his life to the affairs of the retarded and gave unstintingly of the reservoir of life that he had.

We will all miss him. He leaves behind his family, Emma, his wife, and Susan, his daughter. They reside at Colony Towers, 420 Sand Creek Road, Albany, N.Y. 12205.

## 1975 Convention

Continued from page 1

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

5. We again recommend to the Legislature a thorough and complete revision of Article 11 of the Mental Hygiene Law.

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NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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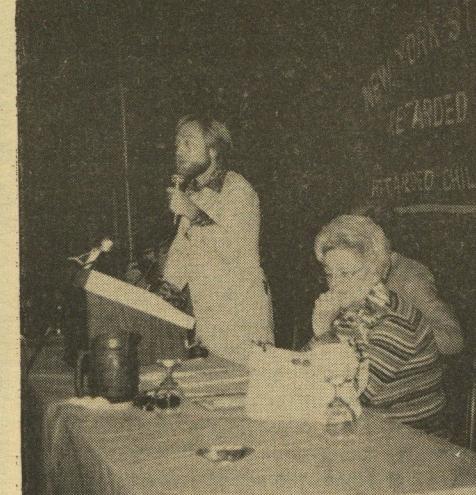
# Scene at the Convention



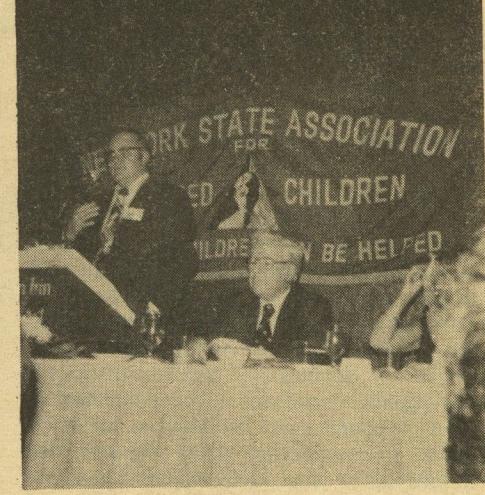
Our faithful credentials couple, Mr. and Mrs. Charles Cowart, pose in a brief moment of respite.



George G. Hirsch accepts his new position, as State President, with a smile. Senator Conklin drinks to that — with water.



Tom McCarley must be saying something nasty that makes Shirley Epstein turn her head.



Convention Co-ordinator and M.C. Charles Kerrigan greets the Saturday night diners as Senator William T. Conklin listens.



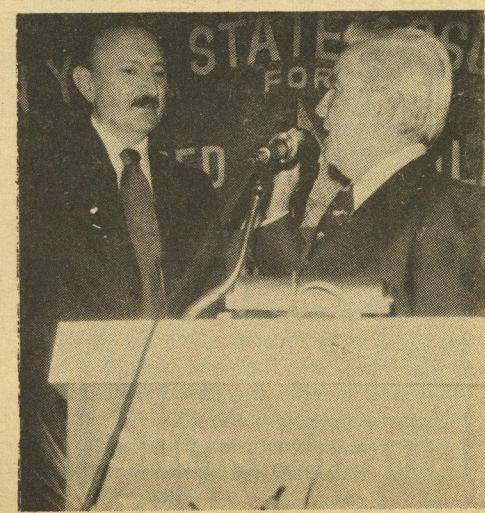
Betty Pendler tells of educational gains while Elliot Aronin and Shirley Epstein check her statistics and Senator William T. Conklin observes.



A round of applause greets "new" Deputy Commissioner of M.R. Tom Coughlin at the dinner. L to R — Incoming President, George G. Hirsch; Joan Coughlin; the smiling Commissioner and Fr. John Aurielio.



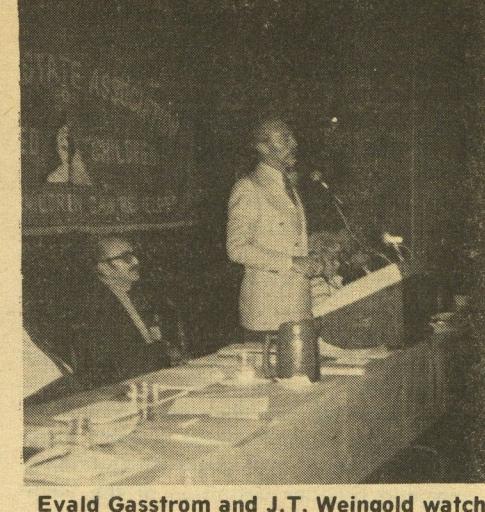
Assemblyman Arthur Eue addresses the Friday legislative session while J.T. Weingold and A.M. Jacobs (foreground) listen.



A serious visaged George G. Hirsch is installed as State President by Senator William T. Conklin.



What a combination! Senator William T. Conklin and the New York State A.R.C.



Evald Gasstrom and J.T. Weingold watch the crowd as outgoing President Elliot Aronin wrap up the business session.

## Court rules on patient retention

In a decision which raises as many questions as it answers, the U.S. Supreme Court ruled unanimously in July (O'Connor v. Donaldson) that mental patients who present no danger to themselves or others may not be involuntarily confined to institutions without treatment.

In the case, Kenneth Donaldson, who spent nearly 15 years in a Florida State Hospital before he was voluntarily released in 1971, sued two doctors at the facility for damages for allegedly denying him his Constitutional right and failing to provide him treatment. A jury awarded Mr. Donaldson \$38,500.

In the high court opinion, Associate Justice Potter Stewart said "One might as well ask if the state, to avoid public unease, could incarcerate all who are physically unattractive or socially eccentric. Mere public intolerance or animosity cannot constitutionally justify the deprivation of a person's physical liberty." Thus, while the high court ruled that a finding of mental illness alone cannot justify retaining a patient against his will and keeping him indefinitely in "simple custodial" confinement, it refused to answer two related constitutional questions: Does a dangerously mentally ill person have a constitutional right to treatment when involuntarily confined, and can the state involuntarily confine a non-dangerous mentally ill person for the purpose of treatment?

One of the questions raised is how many of the 200,000 or more patients involuntarily hospitalized for mental illness in this country would be released as a result of the decision. Prominent spokesmen clashed on this issue.

Justices said that they had ruled on a narrow legal issue that excluded an additional crucial point — whether patients in mental hospitals have the constitutional right to psychiatric treatment.

Incidentally, the Mental Hygiene Law gives the patients and residents of psychiatric centers and developmental centers the right to treatment in New York State.

Another unanswered question concerns what constitutes minimum therapy for the wide variety of disorders that are collectively classified as mental illness. Dr. Jerome Lackner, a physician and lawyer who directs the California State Department of Health, said that he believes the state is already conforming to the Supreme Court's ruling. Dr. Douglas Skelton, director of the Georgia mental health division said that the ruling would have no effect in Georgia because the state was already in essential compliance.

Dr. Judd Marmor, president of the American Psychiatric Association said that his group was "disappointed" that the Court had not ruled on a mentally ill patient's right to treatment.

He said, "It was a decision on freedom, not on the right to treatment. We are concerned that if those patients (who are released under the Supreme Court ruling) still need treatment, there should be some mechanism to see that they get it."

"To let them wander out into society like derelicts is not right. Treatment should be provided within the context of freedom, such as in half-way houses or outpatient facilities. If they need treatment, we feel that they should have the right to it."

Bruce Ennis of the New York Civil Liberties Union, who argued the case in Supreme Court, predicted that the decision would lead to the release of many of the patients involuntarily hospitalized. He labeled as "sham treatment" the therapy received by many other mental hospital patients.

The trouble, according to Mr. Joseph T. Weingold, executive director of the New York State Association for Retarded Children, with this approach is that there is no provision for treatment in the community after these patients are released. The evidence is overwhelming that of the thousands and thousands of patients released by the Department of Mental Hygiene in New York State almost none has received any treatment in the community but are relegated to the scandalous single occupancy rooms and "freedom" of the community.

## Coughlin is Deputy

### M. R. Commissioner

Early in October of this year, Governor Hugh L. Carey announced that Dr. Lawrence C. Kolb, State Commissioner of Mental Hygiene has appointed Thomas A. Coughlin, III of Watertown, as Deputy Commissioner for Mental Retardation in the State Department of Mental Hygiene.

Tom Coughlin, age 37, was President of the Jefferson County Chapter from 1962 to 1968. He served as an unpaid executive director from 1964 to 1968 and from then on was paid in the position.

He was an active member of the State Police from 1962 to 1968 and went on educational leave from 1968 to 1972 and resigned in 1972. He is a graduate of Goddard College, Vermont, and attended law school at Syracuse University.

In making the selection, the Commissioner said that Mr. Coughlin developed a program at Jefferson County which has earned recognition and admiration across the state.

In announcing the reorganization of the Department at the same time the Governor said, "This administration intends to make certain that those who suffer from mental disorders have the best possible treatment and help available."

Tom and his wife, the former Miss Joan Frey of Watertown have three children, Laurie 17, Kelly 16 and Tracy 14.

All of us in the Association welcome Tom in his new job and wish him well.

# The Washington Scene

The 93rd Congress, has seen extremely important legislation passed, others renewed, that will mean a great deal to the handicapped in the years to come.

A summary of this legislation follows.

**A. Housing and Community Development Act of 1974 (P.L. 93-383)**, signed by the President in August, 1974. The great significance for the retarded is that the bill authorizes the Secretary of Housing and Urban Development to borrow up to \$800 million from the Treasury Department to make direct government loans for housing the elderly and the handicapped. Non-profit groups, limited-dividend developers, consumer or cooperatives in public agencies will be eligible for such loans. Under Section 202 of the Act, the definition of the term handicapped is broadened to include both the mentally and the physically handicapped. In addition, the specific languages included to clarify the fact that developmentally disabled individuals as defined in public law 91-517 are considered handicapped persons for purposes of Section 202 loans. In the past some projects involving mentally retarded individuals were refused HUD loans because the retarded did not meet the definition of physically handicapped" contained in the Act.

**B. Education Amendment of 1974 P.L. 93-380.** This extends the elementary and secondary education act of 1965, the education of the handicapped act and a variety of other federal education statutes. Of significance to the handicapped is that funds are sharply increased to assist in educating handicapped children in the public schools to help the state faced with meeting court or legislatively imposed "right to education" mandates.

It also extends the existing authority for grants to the states under part b. of the Education of the Handicapped Act for two additional years.

In addition, a provision is added to the Act which permits a state agency, for purpose of determining its Title I ESEA entitlement, to continue to count the handicapped child when responsibility for the child's education is transferred from a state operated supported facility to a local school district. In other words, this is aid to state supported schools.

**C. Rehabilitation Act Amendments of 1974 P.L. 93-517.** This act removes the rehabilitation services administration from the Social and Rehabilitation Service and places it in the Office of the Secretary of H. E. W.

It authorizes the President to call a White House Conference on the handicapped within three years (in addition a new and broader definition of the term "handicapped individual") to focus on substantial limitations to an individual's functioning in one or more of his major life activities, rather than on handicapped through employment, vocational objectives or potential benefits from vocational rehabilitation services.

**D. Social Service Amendment of 1974 P.L. 94-647.** Three years of conflict between Congress and the Executive Branch ended on January 4, when President Ford signed into law the Social Service amendment of 1974. (P.L. 94-647).

Of special significance to the handicapped was a new Title XX, the Social Security Act authorizing grants to the states for social services. This title is designed to consolidate, under a single authority, present authorizations for social service grants under Title IVA. and VI, which are repealed.

The new legislation provides that social service grants must be directed toward the achievement of the following goals:

- achieving or maintaining economic self-support to prevent, reduce or eliminate dependency;
- achieving or maintaining self-sufficiency, including reduction or prevention of dependency;

- preventing or remedying neglect, abuse or exploitation of children and adults unable to protect their own interests;
- preventing or reducing inappropriate institutional care by providing for community-based care, home-based care or other forms of less intensive care.

Although the current \$2.5 billion ceiling on appropriations for the program remains unchanged, 50 per cent of the state's allotment of Federal social service funds must be used for services to recipients of aid to families with dependent children, SSI and Medicaid as well as so-called "essential persons".

Under P.L. 93-547, the States have complete discretion to define social services. However, the use of Federal funds to the poor in a number of activities was prohibited, including financing services for individuals living in any hostel, skilled nursing facility or intermediate care facility, etc.

A foster family home or group home for the mentally retarded, emotionally disturbed, etc. could be reimbursed directly for the cost of social services to meet special needs of individuals living in the home, provided they are not Title XVIII or XIX (Medicaid) eligible facilities.

**E. Social Security Amendments (P.L. 93-256), (P.L. 93-335), (P.L. 93-368), and (P.L. 93-484)**

During 1974, the Congress continued its efforts to eliminate inequities and problems created by the initiation of the Supplemental Security Income Program. (P.L. 92-603). Under 93-256, time was extended during which SSI benefits could be paid to persons on the basis of presumptive disability.

Under 93-335, there is an extension of an additional twelve months until July 1, 1975 for the eligibility of supplementary security income recipients for food stamps.

Under 93-368 the federal government is authorized to reimburse states for assistance to individuals who have applied for but have not received SSI benefits; and automatic cost of living increases wherever there is a similar increase in Social Security benefits. A mandatory requirement that states impose an enrollment fees on the medically needy is removed.

Although the new amendments make no mention of facilities for the mentally retarded, Social Security officials feel the language is broad enough to encompass persons in such facilities.

Of great importance to the retarded is an amendment which provides that an individual living in a non-profit retirement home or similar institution will not have his SSI benefits reduced because of support or maintenance provided by the facility or another non-profit organization. The new amendment should help residents of non-profit group homes and similar facilities, who were previously found to be ineligible because a sponsoring non-profit organization underwrote a portion of the cost of providing room and board.

**F. Wagner O'Day Act Amendment (P.L. 93-358)**

This amendment does the following:

1. change the name of the "Committee for Purchases of Products and Services of the Blind and Other Severely Handicapped" to the "Committee for Purchases from the Blind and Other Severely Handicapped";
2. provides a continuing authorization for the operation of the Committee;
3. increases the Committee's membership from 14 to 15;
4. clarifies the definition of "direct labor" so that it, expressly covers the provision of services as well as the manufacture of commodities.

Of the greatest importance to the education of the handicapped is the bill to

which the Senate gave final approval in November of this year (1975) to make "free appropriate public education" available within five years to all the Nation's handicapped persons from ages 3 to 21.

The bill expanding and extending programs for handicapped youngsters cleared the Senate by a vote of 87 to 7 was sent to the White House. The House approved this 404 to 7. It was signed by the President.

"This is not only an act of law for quality education, but an act of love for our handicapped children," said Senator Robert T. Stafford (R-Vt.).

Written into the bill is a declaration of Congressional findings that more than half of the Nation's estimated 8 million handicapped youngsters are now denied equal educational opportunity with 1 million excluded from public school systems altogether.

To remedy that situation, the bill envisions appropriations exceeding \$300 million through September 30, 1977, primarily in grants to the States to support educational programs for the handicapped.

To be eligible, a State would have to demonstrate that it could provide "a free appropriate public education" to handicapped youngsters between the ages of 3 and 18, no later than September 1, 1980.

States would be required to concentrate aid first on those children now receiving no educational services, and then on those not receiving "adequate special education".

Under a proposed amendment to the regulations of H.E.W., all states would be required to identify and serve all resident handicapped children and take steps to assure the confidentiality of the records of those children.

New York State will receive \$7,940,709 Federal aid for these purposes.



John Heierman and Jean Lockwood preparing salads.

## ARC salads

### move to stores

During the past summer and fall, a new brand of deli-salads has been sold at 10 area grocery stores in Binghamton.

The salads, consisting of macaroni, baked beans, German potato and potato salad, all sold under the "Country Valley" label, are made by the trainees and workers at the Broome-Tioga ARC workshop.

Mr. Harold Shelp, the ARC Food Service manager, gives high rating to his present work force. On the basis of his experience, which ranges from dish washer to owner, he claims the four essentials for a good worker are contained in the workshop — honesty, punctuality, congeniality and willingness to work.

Salad making is just one of the ARC projects. The 110 clients, grown from 10 in the early '60's, make products such as tent poles for Eureka Tent, Inc. and trimmed cables for Stow Manufacturing Co.

"The idea behind these salads was to give these people more experience in the preparation of a wider variety of foods," explained Shelp. "Also we tried to market something no one else had."

The salads' major selling point, according to Shelp is the recipe - no preservatives or additives are included.

Though the salads seem popular, they aren't a money-making operation because the system hasn't gotten down to an efficient system yet. But after the salads, Shelp plans to begin a line of frozen Italian dinners which the ARC can sell to restaurants and groceries.

While the outlook for the ARC program is bright, it is running up against roadblocks. A local store owner, who had been getting salads through a Pennsylvania firm and who liked the Country Valley product, said he couldn't buy them because he "really couldn't buy a salad made by those people."

Occasional bouts with prejudice - though bothersome - aren't about to deter either Shelp or his workers. The nine workers in the kitchen are all busy doing their thing and the chapter is going to market it under the label "Country Valley" and people are going to buy it.

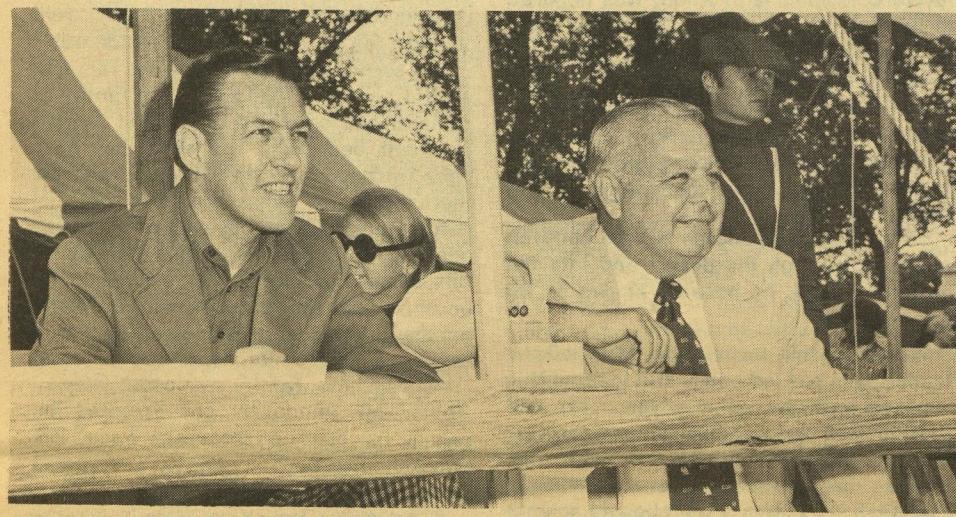
She is co-author of a book, *Basic Apparel Design*, and is helping make a series of instructional films.

Mrs. Caddell may be reached at the Texas Tech University, P.O. Box 4640, Lubbock, Texas 79409.

Thank you Justin Israel for sending us this interesting item.



Winner of the Rheingold Grand Prix, Michael Matz on Grand, accepts a handshake and a check from Lawrence Gershman, Executive Vice President of Chock Full O'Nuts, Rheingold parent company, as Nassau Chapter President Hy Clurfeld and Chairwoman Honey Franklin offer congratulations.



Town of Oyster Bay Supervisor John Burke, left, and Honorary Chairman Assemblyman Joseph M. Margiotta watch from their boxes.

## Rheingold sponsors Grand Prix

Under the co-chairmanship of Assemblyman Joseph M. Margiotta, Nassau County Chapter's second annual Horse Spectacular for the benefit of retarded children attracted the nation's top riders and an estimated 8,500 spectators who turned out for the Class "A" show at Long Island's C.W. Post College Equestrian Center in mid September.

Rheingold Breweries sponsored the \$10,000 Grand Prix, the major competition of the show, for which thousands of spectators packed the grandstand, filled the boxes and lined the rails. They watched as some of the nation's top horsemen and women competed on a course specially designed by Olympic Coach

Bertalan De Nemethy. Top winner of the \$10,000 Rheingold Grand Prix was Michael Matz on Grande owned by F. Eugene Dixon, Jr. The winning cash prize was presented by Lawrence Gershman, Executive Vice President of Chock Full O'Nuts, parent company of Rheingold Breweries.

In addition to Mr. Margiotta, the committee of community leaders and dignitaries included Senator John R. Dunne, Town of Hempstead Presiding Supervisor Francis T. Purcell and Olympic Equestrian Team winner Neal Shapiro. Chairwoman of the event was Honey Franklin, past president of the Chapter's Bellmores-Merrick Auxiliary.

## Family Care payments to parents possible

### TONI PARISI'S IDEA ADOPTED

An idea first presented by Toni Parisi to the Board of Governors of the State Association, that family care payments should be made for an individual over 21 years of age in the home of his parents, has been adopted by the Department of Mental Hygiene.

According to the Department, in reviewing the regulations covering family care, it became apparent that there is nothing to preclude such payment. The parent has a legal responsibility for a child under age 21, but upon achieving maturity the child is no longer the natural charge of the parent, according to law.

It was pointed out by Toni that adults in the community and those placed in the

community from Department facilities are eligible for SSI and a variety of other support services through the Social Security or Social Welfare.

In many instances, she said, a family would like to take an adult resident back into the home from the facility but lacks the resources to do so where support from other services is not available.

The Department has seen the wisdom and justice of this and now will pay family care rates of \$208 upstate and \$263 in New York City as of July 1975.

Only persons who have been in institutions for more than two years will be considered for this program. The home must meet all other criteria for a family care home set up by the Department.

## Nyquist proposes due process procedure

Proposed regulations to implement due process procedure for the handicapped were distributed early in September to a number of agencies, including the ARC.

The regulations seem to be essentially for the creation of committees on the handicapped and the procedures thereafter. Although we consider them a considerable improvement over the present procedure, we have several comments to make to Mr. Raphael Simches Director, Division of Developmental Support Services, Education of Handicapped Children.

In the first place we objected to the composition of the committees on the handicapped, which state that such committees would include a qualified school psychologist, teacher or administrator of special education, school physician, other responsible school authorities designated by the chief school officer, and two parents of children with handicapping conditions.

"I find," wrote Mr. Weingold to Mr. Simches, "this is weighted heavily in favor of administration and may work to the detriment of the parents and their children. Here you have two parents of the handicapped who may be two parents of blind children with no knowledge of mental retardation or emotional disturbance, and any number of other people, because the phrase 'other responsible school authorities' could mean 10-15-20 or 25 or however the chief school officer wishes to pack the committee."

"I recall," continued Mr. Weingold, "a meeting of administrators and others called by Dr. Mark Costello in Syracuse last year, where it was unanimously agreed that any committees on the handicapped shall consist of at least 51 per cent parents. Furthermore, there should be parents representing each disability and not just parents of the handicapped."

With regard to impartial hearings, the proposed regulations read that the chief officer shall personally hear and determine the proceedings and designate an impartial hearing officer to conduct the hearing."

In criticism of this, Mr. Weingold wrote that the chief school officer should never personally hear and determine a proceeding. The hearing should be before a panel, one member of which shall be chosen by those representing management, another by the parents and a third by common consent.

Very strong objection was made to the regulation which stated that the burden of proof as to the inappropriateness of any proposed classification or placement of a child should be on the "parent or person in parental relationship to a child". This, wrote Mr. Weingold, is absolutely turning around our whole system of jurisprudence. The parents should not have to prove a negative. To date, we have not seen the final regulations.

## N. Y. C. M. R. Services threatened

A running battle between the State Department of Mental Hygiene and the New York City Mental Health Commission and Health Department threatens services for the mentally retarded being delivered by the voluntary sector.

Essentially, the quarrel is about how much state aid for local services will go to New York City. The state now says the city is going to get \$50 million, whereas Dr. June Christmas, Commissioner of the City Mental Health, said she needs \$78 million in state aid or at least \$60 million she says she had been led to expect this year and last.

The city has been overspending at the rate of \$35 million for the last two years in the hope that there would be a roll-over or a deficiency appropriation in this amount this year. This is not forthcoming. Discussion between Dr. Stuart Keil, Regional Director for the Department of Mental Hygiene and Dr. Christmas centers around the protection of the program being delivered by the voluntary agencies.

The New York City Mental Health Department has been funding city operated programs under the Health and Hospital Corporation, Community Mental Health Centers at 100 per cent city money for matching funds and the rest from the state whereas the community agencies have been contributing some \$15.4 million in voluntary funds, which has relieved the city of this responsibility. New projects have been developed with total city matching funds but the voluntary agencies raising money have not received the same consideration.

It is feared that the voluntary agencies will forego the little bit of money they would get from the city altogether and go directly to the Commissioner of Mental Hygiene for a direct contract in protest against the meager contracts being offered by the city.

Mr. Weingold, when interviewed in the office of the Association, said that tens of millions of dollars of state money for local assistance have been illegally spent on the Bureau of Child Guidance of the Board of Education. Such money cannot be spent for child guidance or psychiatric centers in school districts unless under the control, direction of the Mental Health Board, which, indeed, the Bureau of Child Guidance never has been in any shape, manner or form. Such money could much better go to the voluntary agency for development of community services instead of being shortchanged as they have been in the City of New York for many many years.

## Florida "Bill of Rights"

A so-called Bill of Rights measure for the mentally retarded in the Florida institutions (euphemistically called "Sunlands") has become a law in Florida. The bill provides \$3.6 million to improve the conditions of the more than 5000 retarded people in "Sunlands".

It is contemplated it will take five years to implement the rights in the bill to better care in the institutions and for the development of group homes for alternatives to institutionalization in the community.

The bill, according to some, was passed to prevent a court action by the United States against the State of Florida, similar to the Willowbrook action in New York State; brought by the New York State Association for Retarded Children against Carey and the Department of Mental Hygiene.

## At the Convention

# President's message

"Looking Ahead", the theme chosen for this convention, symbolizes a new era in planning, thinking and direction.

It may be wise to spend a few minutes looking at where we were and where we are today. The past 26 years have seen our organization progress from the zero mile marker, to a point in our development where our Chapters and State organization have budgets totaling well over \$15 million. It is an unprecedented accomplishment, and thanks should be given to the tireless efforts of parents, friends, and staff in and out of the ARC Movement.

Almost every need in the lives of the retarded has been touched upon, in some way, in our planning and development — from diagnostic clinics, pre-school, schooling, vocational rehabilitation, sheltered workshops, day centers, hostels, improvement in public education, involvement in the State Residential Schools, recreation, camping, family counseling, parent education, public education, guardianship, trusts, advocacy, stimulation of educational and medical research. It has not been easy. For every moment of elation at accomplishments, there have been times of sadness and rejection.

I wish I could say to you. "Sit back, Relax, Sleep well. Our problems are solved". But you and I know it is not so. We are aware that time does not stand still. The security we seek for the retarded would be seriously threatened if we were to relax our vigilance even for a fleeting moment.

Looking ahead, we have no "crystal ball". Only logic dictates what must be done. I would like to mention a few items, not in any order of priority, but as they came to me during the preparation of this message to you.

1) Strengthening of the membership and financial stability of our Chapters.

2) Improvement and reevaluation of the services our Chapters are providing and for which they are contracting.

3) The continuance of and increase in public education and information as to the nature and needs of the retarded. There is an entire new generation to educate, with deference to our YOUTH movement. There are many people who were children yesterday and are adults today, who have not been exposed to the nature and problems of the retarded; for example, the problem of community hostility to hostels and residences.

## Exec. order bans outside jobs

An Executive order prohibiting employees of state departments and agencies who either earn at least \$30,000 a year or hold "policymaking positions" from engaging in any outside money-making activities has run into fierce resistance from employees.

Strangely enough, this resistance came from two of the Governor's own commissioners - the heads of the Department of Health and Department of Mental Hygiene, where large numbers of the physicians and other professionals have been traditionally allowed, and even encouraged, to teach and see patients outside their state jobs.

Dr. Kevin Cahill, the Governor's top advisor on health policy, who has not participated in drafting the order, said that a resolution of the problem was "a

4) The increased vigilance and awareness of conditions in our State operated residential facilities.

5) The establishment of policies and standards for private and non-profit residential facilities; to prevent these facilities run for profit or non-profit, (the latter, a debatable name) from becoming a thousand little Willowbrooks. Some of us have seen and heard of such facilities where the residents were mistreated physically and mentally, and where the food served has been on a bare subsistence level, and where programs, although represented to be adequate, were not worth the paper upon which they were written.

6) Continue to call, loudly and clearly, for a halt to the indiscriminate dumping of retarded individuals into the community from State facilities, and develop a viable system of checking available residential facilities and programs before the retarded individual is released into the community.

7) To keep our local and State Legislators and Departments on their toes, and through the courts, if necessary, achieve results that will improve the lives of the retarded.

8) We must increase our membership, not only parents, but friends and relatives of the retarded. I believe that every aunt, uncle, grandparent, adult sister and brother, owe it to themselves and their retarded siblings and relatives, to become members of our organization, so that our law-makers and public servants know by numbers, that the retarded are not alone.

9) Finally, I feel we should begin to think about, and develop a program for the older retarded. There should be some geriatric program brought to the drawing boards of our various chapters who are, or will be, facing the problem of the older retardate within their supervision.

With the dedicated help of our staff and the staunch support of our Chapters, and with the cooperation of all groups interested in the welfare of the retarded, I pledge the efforts of myself and your officers and resolve to be ever vigilant to preserve what we have, and to look ahead with enthusiasm to the future; to accomplish those goals that remain to provide a better life for the least of God's children.



Senator William T. Conklin (R), accepts congratulations from Convention Chairman Charles Kerrigan (L), shortly after Larry Abrams, (C) offered a special resolution of thanks. J. T. Weingold is off and running in the background.

## Special Resolution honors Conklin

At the 1975 Convention of the New York State Association for Retarded Children, Inc. in Buffalo, New York, State Senator William T. Conklin, the champion of the cause of the mentally retarded through his forward looking legislation, was honored at the Association banquet by the passage of a special resolution recognizing his outstanding efforts.

Offered by outgoing board member, A. Lawrence Abrams, of Broome County, a member of the Resolutions Committee, the resolution of our thanks to Senator Conklin read as follows:

"WHEREAS, as Moses led the children of Israel through the desert and into the promised land, he became known as the Lawmaker,

We, too, of this Association, have had our leader, who has led and is still leading this State through the desert of ignorance and indifference, toward the promised land for the mentally retarded and who has become our Lawmaker. Senator William Conklin has devoted his public and private life to the cause of the mentally retarded, and as he has advanced in political stature he has advanced the cause of the mentally retarded with him.

Now, therefore, be it RESOLVED, that this Convention of the New York State Association for Retarded Children, assembled at Sheraton Inn-Buffalo East this 27th day of September, 1975, expresses to Senator William Conklin its endless gratitude for his leadership in the New York State Legislature in obtaining public

1975

## Top employees named

As has been custom for the past ten years, the New York State Association for Retarded Children, Inc. recognized one employee of each of the State of the Developmental Centers for Outstanding services during this year. In a change from the award certificate to each of the Outstanding Employees in connection with the Employee Recognition day held by the Department of Mental Hygiene. Arrangements were made for individual name plates, recognizing each employee, which will go on plaques at their institutions. A \$100 check for each Outstanding Employee will be presented in special ceremonies at their respective local levels.

For the first time, a number of the new smaller facilities were recognized this year, including Broome, Bronx, Brooklyn, O.D. Heck, Manhattan, Queens and Monroe Developmental Centers.

These individuals were selected as Outstanding Employees for 1975 at the respective centers.

Broome Developmental Services - Mrs. Betty D. Rannings; Bronx Developmental Services - Ms. Joan Lake; Brooklyn Developmental Center - Ms. Agatha

## ARC urges SSI changes

In a letter to every member of the New York State Delegation to Congress, Executive Director, Joseph T. Weingold presented two problems with regard to SSI "of the utmost urgency and significance to the Association." The first was the matter of interpretation of unearned income in determining financial eligibility of an applicant for SSI. This differs materially from Social Security where only earned income is taken into consideration. Under the laws and regulations, a mentally retarded adult otherwise eligible for SSI is denied eligibility when he is in a private school for the retarded and tuition is paid by his parents. The tuition paid by the parents is considered unearned income to the SSI applicant, and therefore, he is ineligible if the amount of tuition exceeds the amount he can earn in any one year.

The delegation was urged to introduce legislation to remedy this. It was pointed out to the delegation that the amount SSI receives as a rent subsidy under Section 8 of the Housing Finance Act is not deemed unearned income, why then is the rent subsidy the parent pays so considered.

The second point dealt with the fact that an SSI recipient living with his family or relative has one-third of his SSI income payment deducted. The bills that have been introduced in the Congress address themselves to this problem but incompletely because they reduce the 33 and one-third to 20 percent. "The rationale for this escapes us," wrote Mr. Weingold. "If anything, SSI should be increased when a person is living at home since this puts a drain on the family resources in most instances. The family has legal responsibility for the adult, but assumes expenses it would not otherwise have. For this they, and the SSI recipients are being penalized."

Although the New York State Delegation uniformly expressed interest and concern, there has been no movement towards any legislation in this regard.

Representative Ottiger of Westchester, in fact, wrote that, in the present climate of the administration, it would be useless to introduce such legislation as it probably could not pass, and, if passed, would be vetoed.

recognition of the rights of the mentally retarded and acceptance of the obligations of government toward them."

Hopkins; Craig Developmental Center - Mrs. Eileen Kline; O.D. Heck Developmental Center - Ms. Denise Sartoris; J.N. Adam Developmental Center - Mr. Charles Stewart; Letchworth Village Developmental Center - Mrs. Lucinda Lanier; Newark Developmental Center - Mrs. Josephine Marsh; Manhattan Developmental Center - Mr. David Marrero; Queens Developmental Center - Mrs. Cora Walker; Rome Developmental Center - Ms. JoAnn Bowers; Suffolk Developmental Center - Mr. Joseph Siele; Sunmount Developmental Center - Mrs. Emma L. Helak; Syracuse Developmental Center - Mrs. Betty J. Thater; Wassaic Developmental Center - Rabbi Harry Zwick; West Seneca Developmental Center - Rev. John R. Aurelio; Willowbrook Developmental Center - Mrs. Charlotte Zinicola; Wilton Developmental Center - Irv Collins; Monroe Developmental Center - Penny Barnes; Kings Park Mental Retardation Unit - Mary Aiello. The Association salutes these people for their outstanding efforts on behalf of the mentally retarded and is honored to add their names to those of their fellows from previous years.

very top priority because it would drastically influence the quality of the people who would work for the state".

"You can always fill positions with bodies," Dr. Cahill continued, "but don't you try to get people who are willing to do the job, provided they can also teach?" The protest from the Health official seems to have taken the Governor's staff by surprise. The Commissioner takes the stand that teaching and research are of direct benefit to both the individual employees and to the state. They fail to state how private practice outside the job benefits the state.

The situation, says the New York Times, illustrates the ambiguous nature of any effort to change long standing practice in government even in the name of reform. Amen, say we!

**Conversation:**

# E. W. Martin, Jr. & R. Simches

Extract of an article in "Education and Training of the Mentally Retarded", publication of the Council for Exceptional Children, Vol. 10, No. 1, Feb. 1975, Trends, Issues and Needs in Mental Retardation. What's to happen with the mentally retarded in the years ahead? Have educators planned carefully the programs to promote the well being of these children? Dr. Edwin W. Martin, Jr., Associate Commissioner, Bureau of Education for the Handicapped, and Raphael Simches, President, The Council for Exceptional Children, and Assistant Director of the Division of Handicapped in New York State Education Department discussed this question. Below are a few of the pertinent remarks which apply to you and your child in the public school....

Dr. Martin challenges special educators to become involved in the political process and public forums. Mr. Simches stressed the need for cooperation between the public and private agencies, as well as overcoming the attitudinal barriers. Very important is the development of effective public policy. Here the development of community attitudes toward the retarded, which has led to legislation and the recognition that all retarded children can profit from education has been tremendously important.

The education programs as they are offered by private agencies have to be seen as a catalyst to public programming . . . there should be continuing education programs for retarded adults, which would include not just substantive education but also recreational education and daily living programs. This is an area where private organizations can show leadership.

If we move into mandatory legislation below age 5, we have to deal with some attitudinal problems of local school administrators and also boards of education (editor's note — parents, this is our job right now — help shape proper attitudes in the school your son or daughter attends — get to know your administrator and "educate" him.)

Mr. Simches rightly says "what the special educator has to work for first before consideration of teacher training, and even before the architectural barriers, is attitudinal barriers — if one is to achieve full community involvement as well as achieving support of legislators or boards of education toward the objective of providing education for children below age 5 or severely handicapped.

## Religious Ed. for Jewish children

To provide Jewish retarded children an opportunity to learn about their religion, the Brotherhood Synagogue of New York conducts a special program directed by Kenneth Fried, a qualified Special Education teacher. Open to children from ages 6 to 18 who have no limiting physical handicaps, the class is held each Sunday morning, 10:30 to 12:30, at the Brotherhood Synagogue, 28 Gramercy Park South (East 20th Street off 3rd Avenue). The program also offers socialization with other children, and is in its eighth year at The Brotherhood Synagogue. For further information telephone: Mary L. Cummins, 212-475-6041 (evenings) or Suzette Unger, 212-477-0798 (evenings) or write either of them care of The Brotherhood Synagogue.

On the question of what steps can special educators take as advocates or change agents to reorient society to the needs and capabilities of the retarded, both gentlemen agreed that special educators and other professionals can play an important role in the political process — speak up in public forums about the state of their programs. We (educators and professionals) know more accurately than anyone else when a system is really failing to provide what we think it should — when children are failing to be evaluated properly, when they are not getting the kind of treatment they should get — that's courageous business, and sometimes an individual teacher may not feel as though he or she wants to take that on alone. That's where parent associations can step in — at the urging of those of us who are professionals to comment on these issues.

(editor's note: Parents — this is really parent - teacher cooperation — so get to know your child's teacher, the school's problems — budget, supplies, etc. etc., etc.)

Question of future directions. Mr. Simches states he foresees we will be moving into early childhood education on a mandatory level in our schools, for ages 3-5, breaking the 21 year old barriers for continuing education for both educable and trainable — emphasis on career education, greater emphasis on screening and identification procedures at earliest possible age.

Another direction is the increasing involvement of parents in the processes of identifying retarded children, establishing the kind of program that the child should have, and selecting whether this program is to be public or non public. I see the parents becoming much more involved in what one might have considered years ago to be educational decisions primarily made by the professional educator.

(Editor's note: There's hope for us yet — so keep on pitching, parents — in your school system).

## Mary, we'll miss you

An editorial in the Evening Sun of Chenango.

"When she first came here I remember we were a little skeptical. We didn't know how long she would stay," a fellow worker recalled of the day she met Mary Barden.

She worked in the circulation department at the Evening Sun, under a cooperative program with the Community Workshop in Norwich, where the handicapped are employed and assisted in finding jobs in the community.

She was quiet, yet effervescent. And she gave meaning to old cliches which often are bantered about with little thought or application.

Her face was twisted by affliction. Her fingers knotted together since birth. Her complexion wasn't fair, her figure never would draw a second look.

Her walk and her speech were affected. Her mind was crystal clear.

Mary went to a Binghamton Hospital earlier this week to have her appendix and gall bladder removed.

She told her friends here she expected to return to work in a week. She was excited about a fast recovery because, after a three-year struggle over red tape and personal obstacles, she was about to try for her driver's license.

The surgery went well, doctors said. She was recuperating when her heart stopped. Before assistance could be provided, Mary



Evald Gasstrom, WARC Board member and Vice-Pres. Southeast Region, welcomes conferees. Waiting to speak are Jack Bernstein and Tom McCarley of SOAR staff.

## Report on S. E. Conference

Although this is rather late, we think it important to report that nearly 100 representatives from 8 New York State Chapters in the Southeast Region met at the Westchester Association for Retarded Children for a one day conference last year. Board member, Evald Gasstrom, Vice President of the Region, welcomed the conference participants.

Two new projects of the State Association, funded with the aid of a grant from Developmental Disabilities were discussed. One was the program for Advocacy and the other dealt coordination of

services to retarded persons coming out of institutions and the prevention of institutionalization. Staff also explained the mid-Hudson regional hostel project under which 10 new hostels are to be constructed under a grant arranged through the Department of Mental Hygiene.

President Hirsch has urged the Regional Vice Presidents to hold meetings with the presidents and treasurers of each of the chapters in their region to discuss issues of financing, programs and board participation on a local level.

## Separate M. R.

### Dept. for Conn.

The Legislature of Connecticut has created a separate Department of Mental Retardation divorcing it from the Department of Health, under whose aegis it has been. Governor Grasso signed the bill into law.

suffered massive brain damage. She died Wednesday.

Mary never missed work, whether the snow lay two-feet deep or she was feeling a little tired.

When others might let down, Mary was zipping along, brightening up tasks, which sometimes can become too routine.

There are thousands of young women like Mary Barden, whose fierce determination to overcome personal and social handicaps remain tucked away behind the "grandeur" of more glamorous causes.

Mary will be missed by her friends at the Evening Sun. But the ultimate tribute to her is the knowledge that her work will be missed.

Mary forced her crooked hands to perform tasks which many times are beyond the grasp of non-handicapped persons.

It would have been easier for her to reject the reality of her situation, or to accept her condition and wallow about in self pity, living a sheltered life without self help.

Mary won't come bouncing off the Community Workshop van, anymore, smiling and ready to tackle another day.

She won't be here to swap jovial lines which enabled us all to share a laugh during a hectic day.

"She was a beautiful woman", a fellow worker remarked shortly after her death. "She really was."

## Group home

### OK'd by judge

In a ruling that a group home is equivalent to a single-family residence, a Jamaica N.Y. Supreme Court justice has cleared the way for the purchase and renovation of a brick home on Gaskell Road in Little Neck for use as a permanent home and training center for 10 retarded children.

Justice Angelo Graci ruled that the group home's sponsor, the Working Organization for Retarded Children, has the right to operate the group home, and that the residential street of single - family homes is an "appropriate neighborhood" for the facility.

The ruling turned down pleas by an opponent of the facility, the Little Neck-Douglaston Residents Committee, which claimed that establishing a quasi-institution in its neighborhood violated zoning laws.

Opponents of the group home claim that establishing an institution of the type envisioned by the agency not only violates zoning laws, but also goes against the wishes of the community's planning board and the area's elected officials. The residents have tried to persuade both the city Social Services Agency and the state Department of Mental Hygiene to withhold funds from the agency.

These pleas, however, haven't been heeded. State Mental Hygiene Commissioner Lawrence C. Kolb informed a legislator recently that "group homes for children will be located in residential areas. We do not think that a small number of youngsters living in a family-type situation should appreciably change the character of a neighborhood."

State and city officials have cited a State Court of Appeals ruling in a Westchester case that a group home is allowed in an R-1 zone (single family homes).

# CHAPTER NEWS

**CORTLAND COUNTY CHAPTER** delighted by the response to their 6 week Summer Camp, 40 clients and 13 staff made it the largest ever ... **WEST-CHESTER COUNTY CHAPTER** bubbling over with their expansion, very excited about the opening of their new training center in Yonkers. As their newsletter states, "A Presidents list of thank yous is always lengthy, but one man's contribution stands up. Herbert Katzenberg almost singlehandedly raised the volunteer contribution to make the Yonkers Training Center possible, we give him a special thanks". The Yonkers Center is a beauty. And how about the great job done by Marian Slomowitz, Westchester's Chairman for Christmas Card sales. Arranged a special showing of art to be submitted for our Christmas Card Design Contest at the Bloomingdales store in Scarsdale, to which Bloomingdales very kindly added a contribution for every artist whose works appeared. A very interesting story on this unusual and worthwhile effort in the October newsletter of Westchester County Chapter. Write to and ask them for a copy if you're interested — Sorry to hear that Anne Burgess, Executive Director of Greene County Chapter, has been in the hospital for an extensive period of time and will probably be out of action for some time to come. Following Anne's YOUTH orientation of the past, a first Bike-A-Thon was held in the Greene County last Spring, and, following the lead that Bill Bunter began several years ago, they handled their annual golf tournament in September, open house at the new Activity Center was held September 26, and the newsletter bulges with the activity of their summer camp, also bigger, better than usual ... **MONTGOMERY COUNTY CHAPTER** indicates their most successful summer camp with over 65 in attendance. More than 200 members in attendance at their Kiwanis-Chapter Picnic, and noting the awarding of their first grant for a full time Rehabilitation Counselor. High point was the newsletter page discussing contract procurement which says simply, in large letters, WOW! -Quadruple increase in production .... **COLUMBIA COUNTY CHAPTER** has begun special morning



Hilltop Industries, Livingston - Wyoming Chapters workshop, celebrated an Open House on the occasion of its first anniversary earlier this year. Three clients are seen here, rushing to complete a job on stereo tape reels prior to anniversary clean-up.

services for Jewish Clients in their workshop ... **ULSTER COUNTY CHAPTER** made approximately a \$650 profit on their third annual dinner. Nice work by State Board member Marion Weinstein of the Chapter .... **WELFARE LEAGUE'S League Letter** has taken on a whole new look. Write them to ask for copy of their newsletter; a very interesting new make up — held their annual luncheon on November 22. Speaking of luncheons, we missed the full report on the 23rd annual luncheon of **COMMUNITY LEAGUE** which was held back last Spring. High points of that beautiful affair included a presentation by past President Dorothy Fixler to Michael and Dorothy Styler, long time members of Welfare League, honoring them for their total family commitment and service to the retarded — a special fall festival held by Community League at the Developmental Center on October 18th. The Community League bus brought residents to Queens Developmental Center October 26 where League members were on hand to help these residents for a days trip to visit their relatives.... **SULLIVAN COUNTY CHAPTER** held their annual gala at the Concord Hotel on October 15th. Assemblywoman Jean Amatucci was the recipient of the Chapter 1975 Humanitarian Award. The award was given to Assemblywoman Amatucci because, as Executive Director Marc Brandt stated, "No individual citizen could show more interest or extend themselves to a greater degree, unselfishly, toward the welfare of those in need than Assemblywoman Amatucci. She has continuously afforded us her friendship, understanding and benevolence when called upon."

**BROOME COUNTY CHAPTER'S** newsletter highlighting something not too many of us do any more. This is the awarding of 7 scholarships to residents of the County continuing their education in the field of special ed. Is good to see the Chapter helping those who will, in the future, help us ... **SUFFOLK COUNTY CHAPTER** was the scene of our summer YOUTH Convention this year and from all indications it was a wonderful program. Their paper has taken on a little different look of recent date with the appointment of Fred DeJong as the new managing editor

**FULTON COUNTY CHAPTER** this past year to create a magazine called "Lexington Center - Summer of 75". A most interesting sheet for which some of you might want to write to preview. Other good news, Lexington Center successfully placed 16 disabled clients in competitive industry during the first nine months of 1975. Placements were made in the following areas: Groundskeeper, dishwasher, housekeeper, maintenance, leather worker, machine operator, toggler, heat sealer, general labor and child care. Of the above, 13 were placed from public assistance rolls. We keep telling Government that this is what we can do. How do we get them to listen? One last statement for the Lexington Center Weekend '75, which was held on May 9-11. \$12,000 was raised and 15,000 persons in the County were involved in some way with the Lexington Center. **FULTON COUNTY**, our hats are off to you! ... 40 members of the Queens Chapter of the Painting and Decorating Contractors of America donated June 14th so that the **NEW YORK CITY CHAPTER QUEENS WORKSHOP** could be painted inside and out. They also donated the paints and all necessary supplies. This is not the first time that the painters have come forward to assist and we extend appreciation to these wonderful people for their help in the city ... **ALBANY COUNTY CHAPTER** added a Daily Living Skills Program to its program for adults. 45 adults participated in a Swim Program. They are operating an exercise class twice a week and as an added bonus to these classes, the Chapter received 6 exercise bikes which are being used to good advantage in these courses. How about those **SCHENECTADY COUNTY YOUTH**? Made \$2600 of their Annual Walkathon for the Chapter. That's what you call spending shoe leather in the right direction. **FRANKLIN COUNTY CHAPTER** announced the birth of their



Faces beam at one of the candle holders charity ball presented by the Saratoga County Association to benefit the building drive of the ... The decorations were made by clients including Mike McCarthy and Danny Varone, Walker, co-chairman of the event, Nan ... neale, Chairman, and Paul Smith, ARC pr



At Community League Luncheon, Dorothy Fixler presents special award to Dorothy (L) and Mike Styler (R), while J. T. Weingold prepares to remove his pipe, so he can say "Congratulations".

## What our chapters are doing and saying for our children.

new newsletter. They indicated that it was made possible by a non-profit bulk mailing permit and the leasing of a Pitney-Bowes addressing machine. Does Planned Parenthood know about this? ... **BENEVOLENT SOCIETY - WILLOWBROOK CHAPTER** will finally be having a long awaiting wish come true when they open their own office on the grounds of the Willowbrook Developmental Center. The Chapter's newsletter also bursting with information on the proposed Hostel of the **WILLOWBROOK CHAPTER** ... Congratulations to Ray Lewandowski who is serving as an Acting Executive Director of our **MADISON COUNTY CHAPTER** in place of Gerald Matthews. In the game of musical Executive Directors, Jerry has moved over **ONEIDA COUNTY** to replace Ray Pennell who has gone to another position in Massachusetts ... See, **MONROE COUNTY** is not the only one. **ONONDAGA COUNTY CHAPTER** indicating in the recent newsletter that their workshop has bundles of wood chips and kindling for your fireplace on sale at bargain prices. Our thanks to the Chapter for the excellent work assisting with the recent Educational Conference held in connection with

Syracuse Developmental Center. Must give credit where it is due to **CAYUGA COUNTY CHAPTER**, one of a few Chapters, that the publishers, not only their list of officers very clearly, in advance, but gives a rather complete resume on each person running for a Chapter office ... **SARATOGA COUNTY**

**CHAPTER** pushing hard searching for an Executive Director. This is in keeping with their decision to really push for a sheltered workshop in **SARATOGA COUNTY**. We wish them every success with this venture as we close this first column of 1976.



The Batavia Council No. 325, Knights of Columbus, one of Genesee County Chapters most staunch supporters, kick off their annual fund-raiser from which the Chapter benefitted. From left, seated, Grand Knight Elect Rev. Roy W. Crissy, pastor of St. Mary's Church, Edward Attea, general co-chairman, Ann Schiavone, Grand Knight Joseph W. Gauck, standing, Anthony Scalia, deputy Grand Knight - elect, Henry Valerych co-chairman, David Peters, president of the Genesee County ARC and John Bertrand, assistant director of State Assn. for retarded children.

### Albany employees

#### of the month

In a move to honor the workers in the rehabilitation workshop of the Albany County Chapter, Joanne Brodsky, Senior Rehabilitation Counselor, has been instrumental in introducing a concept of **Employees of the Month**.

Effective June 1975, the Albany Chapter established two awards for outstanding employees in the sheltered workshop. They are presented on a monthly basis, one for employee of the month and one for most improved employee.

The two winners in June were John McDonald in Porter-Maintenance and Patricia Sammons in Food Service. Each employee was awarded a plaque and received a bonus of \$5.00.

"It is our feeling," writes Mrs. Norma Weiner, Secretary of the Association, "that those employees who are performing very well should be rewarded for their efforts as employees in competitive industry are often recognized ... We feel that the recognition as 'employee of the month' is an added incentive to our workers to put forth their best effort in the rehabilitation process at our agency."

We hope that this idea will find merit in the eyes of our other chapters and be followed.

### Essex makes NEWS

The little Essex County ARC has a full page with photos in the Mental Hygiene News of October 10, 1975.

Within one year, the Essex County Chapter of the ARC has brought a greatly expanded program to the community. It has established a vocational rehabilitation workshop in a one story former Catholic school building, under a grant from Developmental Disabilities Council and has proceeded to open its first hostel, a beautiful home on a hill overlooking Lake Champlain.

Able to accommodate about 14 residents, the opening of Maple Knoll, as the hostel is known, was the occasion for a town celebration in Port Arthur where it is located.

Sunmount Developmental Center and St. Lawrence Psychiatric Center, the two department facilities serving Essex County are located outside its borders. Both have, however, provided outreach services and share staff with county programs and the ARC.

Essex County, small, very isolated, basically poor should be an inspiration to all of us in the ARC.



ers that will decorate tables at the first annual County Hotel, Restaurant and Liquor Dealers of the Association for Retarded Children (ARC). In the ARC's occupational activity center, in Barone, seated. Observing are, left to right, Bill Walsh, ARC program coordinator, Art Carman, ARC president.

## Wassaic grant aids families

A \$100,000 grant to assist families of mentally retarded residents to bring their children home has been awarded to the Wassaic Developmental Center.

The "Homecoming Project" will provide 32 New York City families \$3,000 a year to obtain the specialized services required to keep a mentally retarded child at home.

Staff from the Center will provide continued consultation to each family, meaning day-to-day, as well as acute problems.

The grant was made under the Federal Hospital Improvement Program with Wassaic eligible for continuation funds at \$100,000 a year over a 3-year period.

If a family is found to be unable to take the young retarded member home, said Miss Susan Neil, Chief of Community Services, efforts will be made to find a suitable relative or other person known to them, willing to accept the child. If willing, they would be paid the regular family care program funds, rather than through the grant.

Families of Developmental Center residents now over 21 years of age may receive family care support if they bring their relative home. Younger resident's families are not now eligible.

### Parents ordered to contribute

In a decision which is at marked variance with decisions of other family court judges, Judge DiBiasi of the Queens County Family Court ordered the parents in the matter of Mark Butcher, David Baker and Charles Chandler to contribute to the maintenance of such children in the services.

The action was brought by the petitioners for an order under Section 232 of the Family Court Act granting the cost of the tuition, plus maintenance at the Summit Residential Treatment Facility.

Although the Judge very piously stated "A handicapped child is entitled to as good an education as one not so afflicted," he then went on to say, however, "such a child is not entitled to the 'best' that money can buy when it is public money that is doing the buying."

Extraneously, the Judge brought in the fact that this center seems to have high administrative costs and a high ratio of staff to pupils.

"This Court holds, therefore, that it may use its discretion as to the reasonableness of expenses charged by a facility which provides services for handicapped children, wherein reimbursement for such costs is mandated under the Family Court Act."

### Transferred

50 young people were recently transferred from Willowbrook Developmental Center to a new home in the Nina Eaton Treatment Center at South Beach Psychiatric Center operated by the United Cerebral Palsy Association of New York State.

Robert Schoenhorn, executive director of the United Cerebral Palsy of New York State, pointed out that the facility is an outgrowth of a project which UCP has had underway at Willowbrook for more than two years under a contract with the Department. Mini-teams of professionals have been developing specialized physical therapy programs and training Willowbrook staff to continue them. In addition to the building to house the program at South Beach, the Department is providing \$750,000 to UCP to begin operation.

## HEW funds programs

In an effort to improve educational opportunities for the handicapped, HEW's Office of Education awarded some \$200 million to the States and to special programs during Fiscal year 1975.

"Recent court decisions and resulting laws show an awareness among the States of the fact that a handicapped child has a 'right' to education," said Edwin W. Martin, Acting Deputy Commissioner of the Bureau of Education for the Handicapped.

At the same time, States are beginning to realize the importance of finding and working with handicapped children as early as possible."

Some \$100 million is expended under the State Grant program to help States plan, begin, and improve programs for the handicapped children from preschool through secondary school level.

Despite the fact that this program has been going on for several years, we find, that in fiscal 1975, only \$13.3 million went to 150 early childhood classroom demonstration projects. The question is how much more demonstration do we need, according to Betty Pendler, Chairman of the Education Committee of the New York State Association for Retarded Children, until we decide that education for the handicapped, including the mentally retarded, should be mandated from at least the age of 3.

It is interesting to note, of the \$200 million, only \$2.8 million went for specific projects for the severely handicapped children and youth.

### Drug helps biters

Four young boys suffering from a rare hereditary disease that caused them to bite their lips and fingers compulsively are now playing with toys instead, thanks to drug treatment.

The illness, called the Lesch - Nyhan syndrome, is transmitted, like hemophilia, through a mother to her sons and so affects only males. Victims are generally crippled and mentally retarded, but the most tragic aspect of their plight is that unless their hands are continuously tied down they chew their lips and fingers to shreds.

At a recent National Foundation - March of Dimes birth defects meeting, Dr. William L. Nyham, co-discoverer of the disorder, explained that the disease's symptoms appear to be caused by the patient's inability to produce enough of an enzyme whose name is abbreviated as HGPRT.

The drug Nyham is using, 5-hydroxytryptophan, does not cause the body to produce HGPRT, but it does stimulate the brain to produce a brain chemical called serotonin, whose manufacture ordinarily depends on the presence and activity of HGPRT in the blood.

The doctor said that 5-hydroxytryptophan is not effective unless used in conjunction with another medication, Carbo-dopa.

Nyham, professor of pediatrics at the University of California in San Diego, used the treatment for the first time in March and has begun to treat a fifth patient, a baby, in the hope that his biting behavior can be stopped before it begins.

The treatment does not appear to improve the intelligence of the patients, but the relief of the biting compulsion is gratifying in itself.

A film made by Nyham of one of the boys shows him screaming in terror when restraints are removed from his hands, in anticipation of the pain of self-mutilation, and his face wreathed in smiles after finding that the drug has made him secure from the threat of tearing himself to shreds.



Donald Geist (L), Executive Director of Clinton County Chapter looks on as Mrs. Joan Sommer presents a Certificate of Appreciation to Col. Floyd J. Geiger, Base Commander, Plattsburgh A.F.B., in honor of the selection of the Base as the "Employer of the Year" for 1975.

### Air Base

## Plattsburgh Employer of Year

The Plattsburgh Air Force Base was named 1975 Employer of The Year by the Scholarship & Awards Committee of New York State Association for Retarded Children, Inc. A plaque commemorating the selection of the Base was presented to Joan Sommer, President, Clinton County Chapter at the State Convention in Buffalo, in honor of the award. Mrs. Sommer was representing Col. Floyd J. Geiger, Base Commander, in accepting the award from the Association. The Air Base was honored on the basis of its providing employment for mentally retarded persons in full time positions. There are 6 persons employed full time at the Base, where such jobs began for the mentally retarded in 1973. The Base employs one retarded person as a painter's helper, three as janitors and two as dishwashers. The pay for these jobs ranged from \$2.27 per hour to \$3.50 per hour, for the painter's helper.

Clinton County Chapter of the Association made the nomination of the Base for the 1975 consideration.

In addition to the winner, Certificates of

merit went to the other excellent nominees for the award. These included: Mary Felice, Food Services supervisor, nominated by Westchester County Chapter; the Quadrangle Restaurant and Bernie's Diner, both nominated by Suffolk Developmental Center; Marist College, which was nominated by Dutchess County; De Roo Food Products, Inc. which was nominated by Wayne County Chapter; the Brookview Diner, nominated by Warren Washington Chapter; Pavilion Nursing Home, nominated by Monroe County Chapter; Becker Electronics, nominated by Greene County Chapter; and The Elks Home, Batavia, nominated by Genesee County Chapter.

Donald Geist, Executive Director of the Clinton County Chapter, summed up the feeling of the Association for the hard work of all the named employers when he said "It is fitting, that the Air Force, one of the strongest elements in the local community and the country, should lead the way by demonstrating that retarded persons can be productive, contributing members of our society."

### No consolidations, closings planned

According to an article in the September 26th issue of Mental Hygiene News, Governor Carey states that no plans are being contemplated to close or consolidate Department of Mental Hygiene Facilities.

The Governor made the announcement at a press conference dealing with reorganization of the Department where he said, "There is no outright closing of any institution planned." "We do want better adaptation of those institutions for the community role."

Dr. Lawrence C. Kolb, State Commissioner of Mental Hygiene confirmed the Governor's position. Dr. Kolb explained that the Department of Mental Hygiene proposes to develop some projections for the next five years dealing with population declines in state facilities.

All the Governor said, however, does not seem to be exactly what is meant. Dr. Lawrence C. Kolb, although confirming the Governor's position, noted that "a time may come when consolidation may have to be considered as a means of achieving additional funding to carry out support services in the community."

## Appointees urged to resign posts

In outlining his plan to reorganize the State Mental Hygiene Department, Governor Carey urged politically oriented members of the Mental Hygiene Council, including the State Republican Chairman, to resign so that he could appoint replacements "who have a professional or community interest" in mental health problems.

The Governor named Richard L. I. Dunham, former state budget director who is now a key member of Vice President Rockefeller's staff; Ronald A. Maiorana, press secretary to Mr. Rockefeller when he was Governor, now performing a similar function for Maurice H. Nadari, the special state prosecutor and the Republican State Chairman, Richard M. Rosenbaum.

Mr. Rosenbaum, when asked if he would comply with Governor Carey's wishes said, he would "think about it" if the Governor also would urge Joseph F. Crangle of Buffalo, the Erie County Democratic leader, to resign as the chief of staff of the Democratic controlled State Assembly.

In a letter to Governor Carey on September 23rd to which the Association has received no answer, it was urged by our executive director, after applauding this action, this be carried down to "where we really live, which is on the local level."

The letter stated that the local mental health, mental retardation and alcoholism boards are loaded with political appointees made by the chief executives of the counties or the county legislature and sometimes are packed to reach decisions contrary to what we in the Association desire, citing the Franklin County experience.

"In New York City," said Mr. Weingold, "for example, there has never been someone that we thought represented the mentally retarded on the mental health board, and yet decisions are made every day affecting the lives of thousands of children our New York City Chapter is serving. Perhaps parents on a board would not gain anything, but certainly the Mental Hygiene Law should be revised in some way so that these appointments should be reviewed from time to time by the commissioner or by you (the Governor) and there should be a requirement that a very significant portion of the boards consist of the parents of the mentally ill, mentally retarded, etc."

Mr. Weingold also called attention to the "archaic and political" methods of choosing boards of visitors through clearance by the county leaders of the party in power.

Although copies of this were sent to Dr. Kevin Cahill and Lawrence C. Kolb, the reply has been absolutely deafening by its silence.

## Westchester workshop

On Wednesday, October 1st, Westchester County Chapter of the State Association dedicated a new workshop in Yonkers — the Yonkers Training Center on Yonkers Avenue.

More than 100 people listened to dignitaries praising the chapter for its work on behalf of the mentally retarded and inspected this beautiful building.

A special vote of thanks should go to Dave Berman, who conceived the idea and did so much to make the property useful and to Herbert Katzenberg, whose efforts to raise some of the money have been so outstanding. Congratulations Westchester.

# Sen. Conklin accuses M. H. Dept. of waste

Addressing a legislative conference at the Convention of the New York State Association for Retarded Children in Buffalo, Senator Conklin cited a four-fold increase in Mental Hygiene spending in more than a decade since he has been state legislator.

The Department's budget now is over \$1 billion.

One-tenth of this allocation fails to find the target, Conklin claimed, because of the "unwieldy structure" of the massive state agency, and administrative fumbling.

Co-chairman with Senator Conklin was Assemblyman Arthur O. Eve, D. Buffalo, who said that in past legislative sessions, human needs were considered with the intention of seeking ways to supply services. "Those days are over. Now they are all scrambling for the few dollars that remain," he said.

Eve expressed interest in helping black parents of handicapped children become involved in organizations such as the ARC.

A copy of Senator Conklin's remarks at the Convention follow:

"The year 1975 has been a period of tremendous public exposure of the conditions under which too many of us in the field of mental retardation have had to live for too long. The brightest spot in many long months of work, has been the recognition — by the public, and the State's governmental leaders — that we will not accommodate bankrupt policies and programs for the State's mentally retarded.

We hope that a message has been made clear to a new administration, to the Department of Mental Hygiene, and to the Legislature — we demand a real and meaningful turnaround in State policy.

Where our efforts have not reached fulfillment, we have made our point loud and clear. Where we have gained success, we must be diligent in seeing that those successes are instituted.

There has been detailed documentation, for the first time, of the wrongs within the Department. These disclosures, I believe, have set in motion some important changes.

The recent appointment of Tom Coughlin to the post of Deputy Commissioner for Mental Retardation is an important beginning. We expect to have available the talent of a creative force from the community at the State's highest level. But, Tom's abilities can only be utilized if he is not the captive of the huge bureaucracy which constantly pits disability against disability in a scramble for resources.

I take lesser heart at the Willowbrook Decree. While a parital victory in our fight for services on the community level and improved care at the institutions; the Willowbrook Decree represents the extremes to which parents and concerned citizens had to go in order to get the barest minimum standards of human care for the retarded from our own government. And, at this point, it is only a promise which must be met. It is unfortunate that it was the parents and friends of the retarded that had to take our government to Federal court to gain services and enforce policies that were enacted years ago.

If 1975 is to be remembered as a year we turned things around, then 1976, and 77 and 78, or as long as necessary, are going to have to be years we keep the pressure on to guarantee that future standards are upheld.

We didn't get a separate office for the retarded, but we broke through the barrier of bureaucratic attitudes that mitigated against separate consideration for the needs of the retarded. Today, in Albany, separate concern for the services to the retarded may be more in evidence because of our efforts. At least, we hope so!

Today, we must begin to produce very definite goals for the Department to achieve. How many of the institutionalized will move into the community this year? I want to know that number. I want to see that number produced! How many staff positions at the institutions will be moved into the community this year? I want to know that number. I want to see that happen! How will the quality of care be improved at the State's Developmental Centers? I want to know that. I want to see that fulfilled!

The appropriations are there, but they are misdirected. I want to see them spent where they should be: in community-based and supported programs, in improved quality of care in the institutions. These time tables must be produced and they must be accomplished!

The time is past when red tape, bureaucratic bungling, and civil servant featherbedding will prevent change on the part of a complacent bureaucracy. We must speak with one voice toward our objectives: quality, compassionate care and training for the retarded in our communities and in our institutions, which is promised under law. It is not only the moral, but the legal requirement that state officials meet these objectives. They have sworn to uphold the law and the Constitution of the State of New York. Any official who feels that he will not recognize legislative intent has not fulfilled his oath of office.

All of us, the parents and friends of handicapped children and adults, stand together at this time, and are drawn together by a compassionate understanding for our mutual concern. That concern is to see, that wherever possible, the potential of each and everyone may be attained through our efforts."

## Right to counsel

# Bill for patients in residence vetoed

A bill (S. 6896) to amend the Mental Hygiene Law to provide for the representation of patients at disciplinary proceedings involving mental hygiene employees was vetoed by the Governor.

The bill required the Mental Health Information Service to inform patients of their right to counsel at any grievance meeting. It also provided that the Mental Health Information Services could represent such clients if they could not retain their own attorneys. The Governor's veto stated, "The bill's language is so broad as to permit any patient residing in a facility where the disciplinary proceedings take place to participate." According to a spokesman for this Association, the bill does nothing like that.

In addition, the Governor stated that he considered the care and treatment of a patient in an institution an executive responsibility of the highest order. He,

therefore, directed the head of the Office of Employee Relations to begin discussion with the Civil Service Employees' Association on the subject of patient representatives' observation or participation in disciplinary proceedings involving patient abuse or mistreatment.

"At this time," wrote the Governor in the veto message, "it would be highly inappropriate for me to sign into law a bill which sets no parameters for the patient's right of representation and makes no provisions for the balancing of patient rights with those of an employee."

According to Mr. Augustus M. Jacobs, Chairman of the Legal and Legislative Committee, this is exactly what the bill intended to do, give the patient equal rights with the employee who may be represented by counsel, rights of appeal, etc. without the right of the accuser to confront him in person.

## McCurry to Ohio

Frederick C. McCurry, Executive Director of Rockland County Chapter, has left his position to assume the directorship of the largest contract agency in the State of Ohio. The basic goal of the agency will be to provide group homes and appropriate clinical services for all children and adults living in State institutions whose families reside in the Cleveland area.

He will be working very closely with Dr. Timothy Moritz, who is presently Commissioner of Mental Retardation and Mental Health in the State of Ohio. Dr. Moritz previously was the director of the Community Mental Health, Mental Retardation and Alcoholism Services Board in Rockland County. Coincidentally, Fred served in Rockland County as well.

Good luck Fred, and let us know how you make out.

## Karin Burgess in N. Y. S. post

Karin A. Burgess, a member of the Board of Governors of the State Association and now Secretary, was elected treasurer of the New York State Association of Community Mental Health Boards at the organization's 20th annual spring conference at the Ramada Inn, Binghamton, May 18-20.

Mrs. Burgess, of 19 Circle Drive in Cortland, has been a member of the Cortland County Mental Health, Mental Retardation and Alcoholism Board since 1968 and has served as a member of the Executive Committee of the State Association for the past two years.

In addition, Karin is a member of the Board of Visitors of Syracuse Developmental Center.

# Developmental Disabilities Services Act extended

On October 6, President Gerald Ford signed the extension of the Developmental Disabilities Services Act (94-103).

One of the major changes in the Act is that it adds autism to the definition of Developmental Disabilities and dyslexia, when it has organic-neurological basis. It further provides for the Secretary of H.E.W. to contract for a study to assess the appropriateness of the definition and provides for the Secretary to do his own study of disabilities to be included.

The Developmental Disabilities program is assigned to the Assistant Secretary for Human Development and the Office of the Secretary of H.E.W. and is extended for three years.

The authorization levels are also increased to \$40 million for FY 1976, \$50 million FY 1977 and \$60 million FY 1978, but no appropriations have been made.

It further fixes the local participatory share at 25 percent instead of 30 percent.

It further fixes the local share at 25 percent instead of 30 percent.

a. Treatment, services and habilitation appropriate to the needs of such persons,  
b. adequate nourishment,  
c. protection from physical and chemical restraints,  
d. visitation.

It further requires that each developmentally disabled person receiving services have an individual habilitation plan.

Another outstanding change is that the state plan must show an effective system to protect and advocate the rights of developmentally disabled persons. The system must have the authority to pursue legal, administrative and other remedies to protect the rights of developmentally disabled persons and such system must be

independent of the state agency providing services. \$3 million is authorized for FY 1976, 1977 and 1978 for states to initiate such systems.

The Secretary is also required to review the Standards for Residential Facilities and Community Based Programs required by:

Rehabilitation Act; Elementary and Secondary Education Act, and titles of the Social Security Act.

The Secretary is to provide an evaluation model for the developmental disabilities programs to be adopted by the state for the two years of completion. Furthermore, 10 percent of the allotment must be obligated for the purpose of deinstitutionalization and institutional reform by FY 1976; 30 percent by FY 1977 and 1978.

Only 10 percent of the allotment may be used for construction.

# YOUTH Group News

For and About our YOUTH  
ARC Chapters around the state

## Goodbye Tom; Hello Gerry

It is with mixed emotions that the Association announces that Geraldine Sherwood has joined the staff of the Association as a Program Coordinator. The mixed emotions are not caused in any way because we are unhappy to have Mrs. Sherwood with the State staff, but only because all those who knew Tom McCarley, know that he will be very much missed by those who worked with him.

Tom left the employ of the Association on November 1st, to accept a position with the Department of Education of the State of Maryland. Currently working out of Baltimore, Tom is engaged in a computer project with the Maryland Department of Education, in which information on handicapped persons is fed into one central system, for the purpose of trying to help them get to needed services along their educational path.

We are sure, however, that everyone who meets Tom's replacement will be delighted with her. Geraldine Sherwood earned her Bachelor degree at Dominican College where she majored in history and had a minor in Sociology. She received her Master of Science degree in Special Education at Yeshiva University where she is continuing post graduate studies in

Administration. She also received Montessori Teacher Training at Fairleigh Dickinson University and interned at the Montessori School of Early Learning. Her teaching experience includes both regular and special education classes. No stranger to ARC by background, Mrs. Sherwood had been employed for four years by the Rockland County Chapter as the Director of Children's Services. During her years there, areas of Language Development and Physical Education were developed and an Early Intervention Program was started.

Since being employed by Rockland County Chapter, Mrs. Sherwood has stayed active in the field, working as a Coordinator of Staff Training for the Homemaker - Upjohn Program where she designed and implemented an orientation program for paraprofessionals working with a multi-handicapped population. A member of the AAMD and CEC, Gerry has already moved into high gear in following up the work begun by Tom in determining how mentally retarded persons placed out of institutions in the Community can be more appropriately assisted by Community agencies.

## Tom appreciates

In place of "Tom Asks", I'd like to say Tom Appreciates.

To say that the last two years have been wonderful, would hardly be an overstatement. YOUTH has certainly been an inspiration to me. I can comfortably say that the ARC members and professionals in the field of the future are going to be

more motivated, better informed, and the most sincerely dedicated because of their affiliation with YOUTH ARC.

My thoughts and hopes will be with each of you as I begin my new position as Director of the Early Identification System for the State of Maryland. I hope you will keep in touch.

It's true what we say, Together We Can!

## YOUTH activities

The Suffolk County Y.O.U.T.H. Council is comprised of two representatives from each of the twelve junior auxiliaries in Suffolk County. The representatives elect the council officers and meetings are held on the second Monday of each month. It is important to note that any junior auxiliary member who wishes to attend the council meetings is welcome.

The Y.O.U.T.H. Council made this a good Christmas for all the residents of the Suffolk Developmental Center and Kings Park Developmental Center. They held a Salvation Drive. Clothing, toys, furniture, and other items were collected by junior auxiliaries in their own neighborhoods. Then the items were distributed among the residents as Christmas gifts.

October was membership drive month. During the month of October all the local auxiliaries visited local high schools in their area for speaking engagements. The junior auxiliary members will try to encourage other teens to become involved in the association. Once we have the members, we are going to try to reorganize the auxiliaries that need reorganization and help them to provide direct service to the retarded in their communities.

The Schenectady County Y.O.U.T.H. A.R.C. is presently running two recreational programs that are available to the mentally retarded of all ages in our area.

The first program is a Saturday respite, which is run from 10:00 a.m. — 4:00 p.m. It includes many different activities, such as arts and crafts, cooking, gym and music. Our activities are geared for different age groups, and clients may drop by for a few hours or stay for the whole day.

Our other program, called "Friends, Hand in Hand" is a one to one trip program, where a Y.O.U.T.H. member and a child, or adolescent client go to common places, such as stores, movies, and special seasonal things like Trick-or-Treating, to see the Easter Bunny, etc. Our first trip will be to a "Hundred House" in the area, and the volunteer will arrange the times, rides, etc. with the parents of their friends.

Along with our group's services, we have a babysitting service where parents can leave their children to be entertained while they attend meetings.

Recently, our local group had a 20 mile walk-a-thon as a fund raiser. We had a good turn-out, a nice day, and a great amount of cooperation from people in the area. All in all, it was a great success, and we raised approximately \$2700.

Our goal for this year is to raise enough money to buy a van that we would donate to our adult A.R.C., and that we could use to transport clients to our programs. Hopefully, this will be one way to make our programs accessible to the public.

## Fund raising guide

State Office has compiled a "Guide to Fund Raising" which is available to all local Youth groups in New York State.

The Guide includes essential information which may make the difference between success or failure in your attempts to raise funds.

Please contact your local officers or the State Office if you require additional copies.



L. to R. Peter Wagner (Walk-A-Thon Chairperson), Adam Strickland (Y.O.U.T.H. Council Advisor) and Tony Steier (Y.O.U.T.H. Council President) evidence smiles of approval as Annual Y.O.U.T.H. Walk-A-Thon terminates at Walt Whitman Mall in Huntington, N.Y.

## Hundreds in Walk-a-thon

Lucy Bernard, President of the Suffolk Junior Auxiliary, reports that, last August, a group of young people, deeply committed to helping the Mentally Retarded, began to plan their major fund raiser, a mammoth Walk-a-thon. Under the leadership of Peter Wagner, their chairman, Tony Steier, the Youth Council Prexy, and Advisors, Jackie Mott and Adam Strickland, a goal of \$10,000 was set.

Young Walkers signed their friends, relatives and business people to pledge a certain amount for each mile walked. Periodic meetings were held to check organizational progress of the campaign. East enders also geared their campaign to more walkers and money than they had raised last year.

And then it was time to walk . . . October 13 . . . Columbus Day, 1975. After a brief exhortation by Mary Jo Iovino, President of the Suffolk County AHRC, the young people stepped off the first mile. The police were super, the kids were great and as they approached the first rest stop, the Mid-Island senior Auxiliary prepared juice and cookies and an offering to appease those first pangs of hunger and thirst. A boy walked past with "20 miles or bust" inscribed on the back of his blue denim jacket. The "Mouse Racers" of the Smithtown Jr. Auxiliary passed and suddenly it was quiet. The Mid-Island Auxiliary knew it was time to clean up the cups and papers generated by the hungry youth. Down the road a few miles, advisors, Bob Sansone, the Smithtown Sr. Auxiliary and a young retarded woman awaited the walkers. A Suffolk County motorcycle patrolman appeared at the turn and there they were . . . a column of walkers stretching over a half mile. As the walkers descended upon the check point, happy chaos ensued with everybody presenting their check point cards for signatures of check point personnel. Eat . . . Drink . . . and as suddenly as they had appeared, they disappeared. Many miles, rest stops and check points later, they began to arrive at their final destination; Walt Whitman Mall, in Huntington, having accumulated over 3,900 miles and over \$10,000.00 in pledges.

On October 13th the annual South Fork Walk-a-thon raised \$3,650. The 14-mile walk from East Hampton to Southampton was unique because there was a junior auxiliary member carrying a retarded boy on his back, another member on roller skates, and another member pushing a little boy in a wheelbarrel.

## Young teens can help

Legislation amending a State law which has curtailed the volunteer services of approximately 6,000 students to work in mental retardation was sponsored by Assemblyman Joseph M. Reilly (R-Glen Cove).

Assemblyman Reilly said that the measure was drafted in response to a request made by Steven Grill, a 15-year-old resident of Reilly's district.

"This young man had organized the Jericho chapter of the Association for the Help of Retarded Children which grew to a membership of about 50 students," said Reilly. "The group participated in fund raising and volunteer work with their major participation being volunteer work at Suffolk State School in Melville. The group visited the school every Saturday and brought recreational enjoyment to the retardates at Suffolk State. In September, Steven Grill and his group was informed that, under State law, persons below the age of 16 were no longer allowed to volunteer.

"As a result, Steven Grill wrote me asking what could be done to enable 15-year-olds to do volunteer work, particularly in view of the fact that he had gathered so many young volunteers and was on his way to increasing the membership this year.

"State facility directors, volunteer coordinators and high school officials agree that young volunteers provide a valuable service and that their work should be allowed to continue. Volunteer services with the State Department of Mental Hygiene are professionally organized, oriented and administered and the guidelines for volunteers are strict and clearly spelled out with professional safeguards. It is certainly to the best advantage of those currently in our State mental health facilities to obtain the services of dedicated young people who wish to bring some source of enjoyment into their lives," Reilly concluded.

## DMH reorganized

On September 22, 1975, Governor Hugh L. Carey announced that the Department of Mental Hygiene will be reorganized to "improve the delivery of service to those with mental disorders and other disabilities."

The major features of the plan include, according to Governor Carey, the creation of an Office of Social Rehabilitation which would direct the Department's efforts to move persons out of institutions and to community based programs; creation of a Division of Internal Management; reduction of the central office staff and increase in the regional field staff to enable the department to respond more effectively to area needs.

"To restate and reemphasize my personal commitment," said Governor Carey, "to provide more effective care for the mentally retarded and to insure conformance with the Willowbrook standards, will bring new staff into the Division of Mental Retardation within the Mental Hygiene Department."

The reorganization also involves a major talent search by Arthur B. Krim, chairman of the board of United Artists Corporation, and Thomas J. Watson, Jr., former Chairman of the Board of International Business Machines, who will review personnel for the top jobs in the Department.

The strengthening of the Division of Mental Retardation is demonstrated by the summary of staff changes where the Division of Mental Retardation in the central office loses 20 persons. It is presumed that these are to go into the regional offices, but as of this writing on a high decision making level, we see no one in the regional office in the field of mental retardation. It is interesting to note that although the Division of Mental Retardation will have 24 in the central office, the Division of Administration will have 638, 454 of them belong to the Bureau of Patient Resources positions. Those are the fellows who go after the parents to pay for their children in the state schools and psychiatric centers.

A detailed analysis of the reorganization chart cannot but leave one wondering what the Governor means by strengthening the Division of Mental Retardation and his commitment to the Willowbrook Decree. In this connection it is noteworthy that the review committee before its six month report to Judge Orin Judd has protested the snail's pace at which the state is proceeding to implement the Decree consented to by the State.

Perhaps something good will come of this, but one has to wonder what input there was from the community to this reorganization which seemed to have been an in-house task force operation. Certainly this organization speaking for 600,000 mentally retarded in New York State was not asked anything about such reorganization.

In any case, according to a spokesman of the State Association there seems nothing in this that in any way would change our mind for the necessity of a separate Office of Mental Retardation, divorced from the Department of Mental Hygiene.

## Rome cuts protested

A half-dozen mothers have protested the Rome Developmental Center's cutback in the number of hours it sends relief persons to private homes to care for severely retarded children.

This program developed by the Rome Developmental Center provides 8 - 12 hours a week at the convenience of the mother to assist with the child. In many instances, this has saved an institutionalization with a cost of \$12 to \$15,000 a year to the state. Although Dr. Vorhees, Regional Director of the Department of Mental Hygiene was present at the hearing on the budget, he was unsympathetic to the mothers.

## Willowbrook improvement

# "Limited" - Levitt "Apathy" - others

In the two years since state investigators found widespread violations of hygienic and other standards at the Willowbrook State School, "limited improvements" have been made, according to a follow-up study released recently by state controller Arthur Levitt.

Controller Levitt reported that of 127 violations cited in 1973, 84 had been fully corrected, 35 partially corrected and 8 not corrected at all as of May 31st.

According to a report, the major impetus for improvement came from a reduction in the resident population from 5,000 to 2,950 while the number of employees increased from 3100 to 3900. In addition, the 1975 budget totaled \$49 million, a \$15 million increase over the preceding year.

Despite the positive change, the Controller found Willowbrook still represents "an institution much in need of improvement."

The findings of the report included the following:

The danger of an infectious disease epidemic is still high because patients are not isolated pending outcome of tests.

Many buildings remain overcrowded, although there has been improvement. As of the audit date, 14 of 25 buildings were still overcrowded.

There has been a positive change in employee motivation and productivity, but more progress needs to be made. Disciplinary enforcement requires further improvement. The report contends that the number of employees on unauthorized leave has risen from 350 to 600 over the last two years.

Although sanitary conditions have generally shown marked improvement, occasionally floors, walls and ceilings were smeared with feces. The report attributed this to the lack of patient supervision and delays in clean-up by the ward staff.

In contrast to this even limited improvement reviewed by the controller, we quote from a visit to Willowbrook by staff and others from our Broome - Tioga Chapter. The report follows:

"This past month two of our staff had the opportunity to visit Willowbrook Developmental Center, Staten Island, N.Y.

Although we had heard about dismal conditions at Willowbrook and were familiar with Geraldo Rivera's story we were not prepared for what we saw.

Conditions observed on first entering the grounds seemed to indicate a prevailing atmosphere of apathy. The grounds were unkempt, messy, etc. showed no evidence of any landscaping. The exterior and interior of the buildings showed lack of maintenance and repair. The paint on the ceilings was peeling and the floors looked like they haven't been swept over a period of time, nevertheless washed. Furniture was old and dirty.

After a tour of the school, a three-story brick building, we observed a music therapy class of six children. Another class consisted of six deaf children. According to a court order, the ratio is four children to one teacher, which was in effect. The school services approximately 1,000 children up to age 21, with a few in family care homes.

We understood that many of the people were taken out of Willowbrook and sent to other state schools, such as Broome

Developmental Center, and they were left with the more profoundly retarded at Willowbrook.

Next we toured the hospital building which was much of the same type of atmosphere. Although the ratio of four clients to one staff was in force, there wasn't any evidence of interaction between the clients and staff. The psychiatric wards were dismal and depressing. It appeared that the people were just sitting around and looking at one another. The program did not appear to be structured. The supervisor of the psychiatric unit had one puzzle, some beads to make dolls, and a child's toy custard machine for the entire unit of 28-30 clients.

From conversations with the teachers and hospital personnel, it appeared that there wasn't much of any type of program for those over twenty-one years of age, except to sit in the wards and rock away.

Security in the hospital building was at a minimum. After stopping to inform the chief supervising nurse of our presence, she told us to go wherever we wanted on our own, without asking our names or the agency we represented. This attitude seemed to prevail throughout the building, as one client was discovered to have a screwdriver wrapped up in a tissue in her hand while we were there.

The visitation in all was interesting but very depressing. We were refused any brochures or literature, since these were the rules and regulations of Willowbrook.

## Suit filed on behalf of 1000

The State Supreme Court has asked the Board of Education for clarification on how it plans to continue the education of about 1000 handicapped children who would have left specialized private schools but for this order.

They were leaving because the board has refused to pay tuition due to cuts in its overall budget. The 1000 are new students who entered school for the first time this term. At the same time the board is continuing to pay for other handicapped students who attend private schools from previous years.

A group representing parents of the private schools involved took the case to court, asking for a preliminary injunction to stop the board's action.

"We object to the disruption of taking handicapped kids and shifting them around in the middle of the year," said Michael Revell, lawyer for this group.

Lawyers for the Board of Education presented a "phasing-in" plan which would transfer 100 at one time, 200 at another, etc. When Justice Irving Kirschenbaum asked what would happen to the children between leaving the private schools and entering the public schools, the board's lawyer said they assumed the children would be put on home instruction.

The judge subsequently blocked this board of education's plan.

"We are talking about the education of children and irreparable damage can be done," said the judge as he granted a temporary injunction sought by the parents of the children who oppose the switch.

Kirschenbaum rejected the board's plan as not "definitive enough" and said he wanted it approved by the State Education Commissioner before he would accept it. Meanwhile, the board must keep the children in their private schools.

## SSI payment increase

The Legislature, this year, passed legislation that provided a cash increase in SSI payments at state-local expense to the low-income aged, blind, and disabled in New York State to help them meet the rising cost of living.

For persons living alone, this would mean an \$11.70 monthly increase in SSI benefits for a total of \$218.55 a month. For couples it would mean an increase of \$17.60 a month, for a total of \$312.54.

According to Governor Carey, the submission of this legislation did not reduce the responsibility of the Federal government providing SSI recipients in New York State with the same cost of living increase that is being provided at Federal expense in other states.

"However, New York can no longer allow such abrogation of responsibility at the Federal level, penalizing its highly vulnerable population. Someone must stand up for the needs of the low income aged, blind and disabled who are being hit especially hard by the twin problems of inflation and recession." If the Federal government refuses to recognize these needs, said the Governor, the State government must do something within its fiscal capabilities.

The Governor criticized the Federal government for the double standard in SSI administration. On July 1, 1975 the Federal government provided an increase in the basic Federal SSI grant, but this increase was provided automatically to SSI recipients only in those states which do not supplement the basic Federal SSI grant. In large states like New York, which already supplements the basic Federal grant, the state must finance any cost of living increase completely as state-local expense.

Thus, SSI recipients, in states not contributing a cent of state money to SSI program costs, receive cost of living increases in Federal expense, while those living in states like New York must rely on the state and local treasuries for such increase.

## Gold in them thar hills

The board of education, for some time, has been contracting for the education of many such students in special private schools, among them prominently the Association for Retarded Children. About two-thirds of the tuition is reimbursed by the State.

This year, however, with its budget undergoing severe cutbacks, New York City Board said it could not advance the money needed for new students, but would continue to contract those attending private schools last year.

It is estimated that as many as 8000 now are on waiting lists and going uneducated in spite of the Commissioner of Education's decision in the Riley Reid Case. Kirschenbaum said he was not going to broaden the issue but suggested that Commissioner Ewald Nyquist be made a party to the proceedings.

## When our Onondaga County Chapter attempted to get an HFA mortgage on the building in Syracuse, it was found that the title to the building might be defective because the land was obtained through auction from the State. The Letters Patent had a reserve clause which stated "Excepting and Reserving to ourselves all gold and silver mines."

It was necessary to have legislation, which was so introduced by Assemblyman Pesce and Senator Tarky Lombardi, to eliminate this reserve clause for gold and silver mines. It was passed in 1975 and became Chapter 748 of the Laws of 1975. A vote of thanks is due to these legislators as well as to John E. Shaffer, Attorney and Counsellor at Law who aided in the endeavor.

## Sink or Swim

The following is a quote from "Education and Training of the Mentally Retarded, December 1974" by Dr. Wolf Wolfensberger. It deals with mainstreaming.

"I think we are going to have a catastrophe on our hands because of the mindlessness in which the term 'mainstreaming' is used ... If integration is not successful, it really isn't integration, it is dumping. If a handicapped child is put into a regular classroom and he just sits there and vegetates, he may be mainstreamed, but he is not integrated ... he is dumped. The educational establishment is failing to make that distinction, and so people can be dumped without adequate preparations, support systems, etc. A lot of educators are just jumping on the bandwagon without any sensitivity to what's involved here."

"Put them in the mainstream and see if they swim or drown," says Weingold.

## Parents rap transfer

More than 200 parents of Westchester's retarded children, scheduled to be moved to facilities in Dutchess and Rockland counties, demanded their children be left at Willowbrook and Wassaic Developmental Centers unless and until the promised facility in Westchester is built for them.

The move is planned to depopulate those institutions in order to meet the standard of HEW and not lose Medicaid money. The parents have protested that Rockland Psychiatric Center and Mid-Hudson State Hosp. as well as Harlem State Hospital are inappropriate facilities for the mentally retarded and that this money to make them ready could well go into community facilities in Westchester.

To the cry, "Where is our promised facility on Bryant Avenue (White Plains)? Why is the state delaying?" Mr. James Forde, Regional Director said a facility could be expected there in 3 to 4 years.

29 acres of land in White Plains were purchased almost 6 years ago and paid for. So far, no construction has been done at the site. It is the stand of the parents that Westchester children should be brought back to Westchester even though, eventually, they might be put out into Westchester residential alternatives to institutionalization.

Mr. Forde suggested to the parents that they had worked and fought hard for better programs where the children are. They won and now they can do the same in the new facility.

## Visit our new library

A new service has begun with the revamping of the library at the State Office. During the summer months a library consultants team has been cataloging and classifying all the material. Dr. Stanley J. Slote, professor of Library Science at Queens College, Mary Tomaselli, M.L.S., Lisa Gasstrom, Saratoga County Chapter member, and Jon Slote have readied the library for use by all the members of the State Association, and any other interested individuals or groups.

The collection is current as well as retrospective and covers such subject areas as Education, Family and Guardianship, Vocational Rehabilitation, Research and Programs for the mentally retarded. The library will now accept requests for information by mail or in person; just don't telephone.

Chapters are encouraged to send their annual reports, etc. to the State Office in care of the library.

Come up and see us!



Sally Smith, a trainee, cuts the ribbon. L. to R. Senator Warren Anderson, Majority Leader; Russ Mahoney, Mental Health Commissioner, Tioga County; Joseph Missavage, Commissioner, Broome County Department of Planning, Assemblyman James McCabe, Chairman, Mental Health Committee, and Robert Salankiewicz, Chapter President.

## Broome-Tioga Center Dedication

On Saturday, June 7th, the Broome-Tioga Center for the Retarded in Binghamton was dedicated in a colorful ceremony.

The building is a result of planning between Broome and Tioga County Chapters through the aegis of Broome County with strong involvement by the Broome County Legislature and grants from the State.

A comprehensive program of vocational services with 115 clients involved on a full-

time basis is part of the program. There are 25 on a waiting list. The 37 staff members oversee the educational vocational rehabilitation aspects of program.

The steady growth of the programs of the Broome-Tioga County Chapter should be an inspiration to everyone. It is another piece of a network of services being developed by the chapters of the State Association for the mentally retarded in New York State.

## Where are members?

Are you one? Where are they? These unknowns are the 25 persons who failed to submit their 1975-76 membership dues, and left us just that number short of reaching the coveted 30,000 mark.

Paced by three super-chairmen who increased their memberships by more than 100 per cent, the Association reached a new high membership figure of 29,975 for 1975-76. This is an increase of only 206 over our 1974-75 final figure of 26,769, one of our smallest percentage gains in years.

Two of our Chapters, Essex County Chapter and West Seneca State School Chapter, led the outstanding efforts by increasing their memberships over 400 per cent. Essex County, under the leadership of Mrs. Margaret Kolodzey, increased their membership from a total of 36 last

year to a 1975-76 figure of 166 memberships, an increase of approximately 460 per cent. Close on their heels, however, is the outstanding effort by an institutional Chapter, West Seneca State School Chapter, under the leadership of Helen Donnelly. West Seneca increased their membership from 83 last year to a final of 350 for this year, an increase of about 425 per cent, and more than three times over their goal of 110!

Georgia Sullivan of Orange County Chapter headed our third record breaker, compiling a list of 506 memberships for 1975-76, up from a total of 203 for her Chapter last year. The outstanding Chapters who reached or bettered their goal and their hard working chairmen are:

| County & Chairman                             | 1974-75 Membership | 1975-76 Goal | 1975-76 Membership |
|---|--------------------|--------------|--------------------|
| Essex County<br>Mrs. Margaret Kolodzey        | 36                 | 60           | 166                |
| West Seneca State School<br>Helen Donnelly    | 83                 | 110          | 350                |
| Orange County<br>Georgia Sullivan             | 203                | 300          | 506                |
| Suffolk County<br>Hugh McTeague               | 1200               | 1400         | 1492               |
| Sullivan County                               | 564                | 625          | 680                |
| Montgomery County<br>Mrs. Joseph J. Tokarczyk | 81                 | 125          | 128                |
| Syracuse Developmental School                 | 36                 | 60           | 61                 |
| Comm. League<br>Mrs. Hilda Benjamin           | 508                | 575          | 576                |

## Carey remarks

The following are excerpts of remarks by Governor Hugh L. Carey that were read to the annual meeting of the State Association of the Boards of Visitors of Mental Hygiene Institutions in Albany on October 21st.

"As soon as I took office, it was apparent to me that this State's government in its institutions and in its programs was not adequately meeting the needs of the people who depend upon it."

"For our elderly, our government created what is tragically, yet accurately described as 'the nursing home industry'."

"For those who suffer from mental retardation and mental illness, Willowbrook stood as a monument to the insensitivity and lack of commitment and concern of this state's government to meet the real needs of those in its charge with the most modern and effective programs possible."

"I am here tonight to assure you that the years of Willowbrook — and all that institution stood for — are over in New York State."

"Each Board of Visitors in this State has to be concerned, not only with the institution it oversees, but with the direction all the institutions in the State must take during these times of fiscal restraint."

"Therefore, I will be asking each of the Boards of Visitors of this State's institutions as well as the directors of these institutions to work with my administration to bring about an equity of services to all those served by the Department of Mental Hygiene in formulating programs and policies."

"We have to rely more on parents and professionals; concerned citizens and community groups and dedicated organizations to share our goals."

"I seek to appoint more concerned citizens, parents and professionals to that important Council (Mental Hygiene Council). Their service is wanted and needed."

"We know that most people who suffer from mental illness and retardation can realize their full potential as individuals better in community settings rather than in institutions. We know that those who must be institutionalized can reach their full potential better in smaller institutions with a full complement of staff and programs to serve their needs."

"In keeping with our policy of keeping politics out of the field of mental hygiene, Dr. Kevin Cahill, my special advisor for Health Affairs, rather than our Appointments Office, has the responsibility of approving all key positions in the Department of Mental Health, its Councils and its Boards of Visitors".

"Those in the care of the New York State Department of Mental Hygiene have their future in our hands. They deserve much more than the State has done in the past; they deserve all we can do in the future."

## State activities

We are sure no one is wondering what the State Association is doing, but thought it would be informative to share with our readers some of the activities of this past year under the direction, operation and control of the State Association itself, other than the Chapters.

These included the In-Service Training Program of Teachers of Young Severely Retarded in April 1975, an In-Service Training Conference for Hostels Dealing with Retarded Persons in October 1975 and setting up the program for Camp Catskill this past summer.

In addition there were the two projects: (a) coordinating institutional and community services through the development of cooperative efforts funded by Developmental Disabilities Council (b) System of Advocacy for the Retarded, also funded by the Developmental Disabilities Council.

## Your child in public school

BETTY PENDLER, CHAIRPERSON,  
EDUCATION COMMITTEE

Parents are on the move, and have found out that when no one complains, nothing happens, but we continue to publish the successes of various education committees in the different chapters. Even the not-so-successful attempts serve the purpose of rocking the boat and raising the consciousness of the school community — so don't give up.

The very active committee in Orange County, Barbara Deluca, Georgia Sullivan and Judy Shalvey have made such inroads within a short period, that now their Asst. Supt. of Special Services, who heretofore hardly knew them, at this point seeks them out for advice, and looks forward to meeting with them — all because they formed an ARC Education Advisory Committee and began to speak up. Call it by any name you wish, but set up an advocacy group in education — and look into your school district.

On the positive side, Orange County not only created awareness within the school district that there are handicapped children in the system entitled to the same rights, but they have been able to get additional classes for the neurologically impaired and the multihandicapped; they were instrumental in increasing the instruction time for the trainable classes, for getting the educables into the regular school building, instead of in a separate building, and together with teachers and school principals, have succeeded in getting official monitoring of the bus situation, so bus pickups arrive on time, and the hassles with transportation are considerably decreased.

Their movement has spurred parents in other school districts to speak up, and in Warwick Valley, Joan Surita, with persistence, and official correspondence and telephone calls from our SOAR office, has succeeded in getting non-mandatory transportation for children age 3 for preschool programs so the legal cloak of SOAR must have impressed the bureaucrats. She didn't do so well with getting a parent on the Committee for the Handicapped, as her superintendent told her that under no conditions would he permit that as he feels he would not have control over the parents, and unless it was mandated by law he would not comply — this is ammunition for all education committee members to start talking to local legislators to look into the possibility of getting this into law, and write to the state education department expressing your concern. Jerry Weingold has been recommending mandated parent representation on this committee for years — so letter writing might help.

However, other chapters have reported successes in getting on some committees for the handicapped through persuasion and meetings with educational committees. Schenectady County Chapter has two live wires — Dorothy Murray and Marilyn Wessels, among others, and report that their activities have been fairly effective by just writing and contacting various school districts reminding them that, in keeping with the intent of Commissioner Nyquist's statement that parents should be on the committee for the handicapped, they got affirmative action in some of their districts, as well as being successful in getting parents on the BOCES Special Education Advisory Council. Their education committee has also been successful in playing a real advocacy role in individual cases to achieve a better understanding between school district administrations and parents with special placement problems.

Get your chapter to devote some space in its newsletter to items of interest for the parents who have children in the public school. A good example is the column called SPECIAL ED in the Lamplighter, full of information about the types of classes in their school system. Thank you Suffolk County Chapter — and how nice it is to see that you plan to have it a monthly column.

Suggestion from Herkimer County: FREE COPY of excellent booklet "What are Facts About Genetic Diseases". Write for single copies to Office of Research Reports, National Institute of General Medical Sciences, National Institute of Health, Bethesda, Maryland 20014. Thanks to Leona Perkins for so much book and general education information.

The Exceptional Parent — continues to be the most valuable periodical for parents, with articles written by parents as well as professionals. Remember, for every subscription, the AHRC State Office gets \$2.00 Commission. Subjects in this magazine range from curriculum testing, evaluating schools and coming up is a series on Sex Education. Send \$10.00 to Exceptional Parent, PO Box 964, Manchester, New Hampshire 03105 — but be sure and mention AHRC in your subscription.

Worth Repeating — SEIMC — Special Education Instructions Material Center — has all kinds of educational materials available for loan - free - to parents-kits, films, books etc. Contact your local office or write to the N.Y. State Education Office, Regional SEIMC Office, 55 Elk Street, Albany, N.Y. 12234 to get the address nearest you. They also issue an interesting Report to Parents. If you have any items of interest you would like to share, send it to Mr. Lawrence C. Gloeckler, Editor, address as above.

Parents of children in the public school. We repeat... This is your column, so let us hear from you with suggestions, news items etc. Write to the State Office at 175 Fifth Avenue. Let's share news and views of your child in the public school.

Betty Pendler

## ARC replaces attorneys

The New York State Association for Retarded Children announced the substitution of its attorneys in the case of the New York State Association for Retarded Children et. al. against Governor Hugh L. Carey, otherwise known as "Willowbrook Case." For the past three years, the State Association has been represented by Mr. Bruce Ennis of the New York Civil Liberties Union and some others in the legal battle to obtain quality services for the mentally retarded at Willowbrook. The Association will now be represented by S.O.A.R., System of Advocacy for the Retarded. The S.O.A.R. counsels for the plaintiff will be Hyman Clurfeld, Augustus Jacobs and Jack Bernstein.

The substitution of attorneys representing the State Association resulted from a disagreement the State Association had with its attorney with regard to the composition of the Review Panel appointed to implement and carry out the provisions of the judgment. It is felt that the Review Panel has no representative of the major plaintiff, the New York State Association for Retarded Children on it, and that the suggestion of the State Association for its representative on this Review Panel was rejected by its own counsel.

## The way to educate public?

In a recent article in the Sunday News, the Westchester Developmental Services seemed to be trying to educate the public to the fact that the retarded are not to be feared.

"Fear that the mentally retarded are menaces to society — potential rapists, criminals and murderers — are depriving these people of the opportunity to be assimilated into society," declared Dorothy Harth, WDS community relations director.

Unfortunately, she also failed to mention that the mentally retarded are not potential rapists, criminals and murderers. Further on, the article states that the Westchester Developmental Services started a campaign to find suitable homes for those "patients" of a "mental institution" deemed fit to leave for resettlement.

Further on Ms. Harth stated that there were between 500 and 800 Westchester residents awaiting release from institutions "with only the problem of finding a proper home to keep them." The article then went on to speak, apparently quoting Ms. Harth about "released inmates."

In commenting on this article Mr. and Mrs. George Nehrbauer of Westchester stated that this article was a good example in which "unaware" readers would be caused a definite negative reaction. It further takes the writer to task concerning the differences between mentally ill and mentally retarded people, mental institutions and developmental centers.

"If you think", writes Mr. and Mrs. Nehrbauer in a letter to Kendon W. Smith of the Westchester Developmental Center, "that the use of the term 'released inmate' conjures up anything in a person's mind but some jail bird, at one time or still a menace to society, coming to live in your neighborhood, you are mistaken."

## in Willowbrook case

Although the final judgment in the Willowbrook Case was handed down on April 30, 1975, there remains the long process of enforcing the judgment. The State Association feels that the implementation of the Decree will be the real test of their real struggle for change in the Department of Mental Hygiene. It is felt the Association now has to be represented by counsel who most nearly represent community oriented interest with respect to the mentally retarded.

Since S.O.A.R. and the counsel chosen have a long history in defending the rights of the mentally retarded, the Association feels they are best qualified to assist in carrying out the judgment and to make sure the Review Panel will be reconstructed to contain representatives chosen by the Association.

"The present composition of the Review Panel", said Mr. Hirsch, President of the State Association, "in so far as the representatives of the plaintiffs are concerned, in our opinion, do not have one real expert in community organization for the mentally retarded in New York State." The panel now consists of an attorney from Washington, an employee of the state in Nebraska (Eastern Nebraska) and an

"We consider this news item as having done a lot of damage to community relations and feel you should again in some way contact the News and ask for fair and accurate treatment in publicizing the need of your retarded clients."

What was as disturbing as anything, was the fact that they seem to be seeking just a home to live in without the concomitant services that the retarded need to make a place in which they live, meaningful to them as people.

If our friends will not understand, who will?

## Family care

### size limited

The New York State Department of Mental Hygiene has announced its new policy to limit the size of family care homes to no more than 10 persons from Department facilities.

Under the family care program, patients and residents from department facilities are placed with families in the community who receive a monthly stipend plus support services for each person for whom they provide a home.

Residents selected for family care usually require special individualized attention and the physical and emotional demands placed upon family care parents becomes too great with a large number of residents in the home.

The New York State Association has protested to the Department that family care homes should be limited to six and not ten. According to the Department, existing family care homes with more than 10 must be phased out to convert to another program within the next 18 months.

attorney from New York City, a parent of a retarded child.

In an interview, Mr. George Hirsch, said of the substitution of counsel, "The Association appreciates all the New York Civil Liberties Union has done in the Willowbrook Case. But as the major plaintiff in that case we feel the Association has not been represented to our satisfaction by its attorneys in a number of matters ending with the plaintiff's designees for the Review Panel. The expertise in community services in New York City lies with the ARC input. We intend to present a number of names to Judge Judd to consider for possible changes in the Panel."

The Willowbrook Review Panel or Committee is composed of seven members, two chosen by the defendants, three by the plaintiffs, and two mental retardation experts selected by both parties. As a group its task is to oversee the implementation of the judgment provision. The functions of the panel include insuring quality operation of Willowbrook as well as establishing community facilities for the care or placement of the mentally retarded.



**A WISH COME TRUE** — Three youthful volunteers collect coins thrown into the main lobby fountain of the Sheraton Inn-East for the West Seneca Developmental Center Chapter of the State Association for Retarded Children. The inn promised the chapter the three-month collection of coins — \$225 in this case — from the wishes of passers-by.

## Color for retarded

Big teardrops welled up in 7-year-old Marlene Daley's eyes as she glanced around a large room with all the strangers dressed in white.

It took a few moments for the retarded youngster to realize that the men in white were not doctors but a group of painters donating their time to spruce up one of Marlene's favorite places, the Association for the Help of Retarded Children Workshop in Elmhurst Queens.

The painting project began to take shape after one of the painters, Thomas Gigliotta, visited his retarded daughter Patricia, 27, at the Center, a former Post Office at 86-18 Broadway.

"I could see how badly it needed a fresh coat of paint. And when I said I thought I could get it done for nothing, the people jumped at the idea," said Gigliotta.

After the issue was raised at a recent meeting of the Queens Chapter of the

Painting and Decorating Contractors of America, a call went out to the Benjamin Moore Paint Co. office in Queens that brought a donation of paint, brushes and rollers came gratis from the Imperial Brush Co., a New Jersey firm.

Then, one Saturday morning, 20 painters began arriving at the center at 8:00 a.m. as adults and children enrolled in the workshop readied the interior of the two-story building for the day's activities.

By 4:00 p.m., pale green paint covered the walls of the large workshop in the ground floor and the smaller offices on the second floor. The window trim on the exterior of the brick building also got a fresh coat of paint.

"I wish the painters could have seen the wide eyed expression of joy on the faces of our people when the workshop opened on Monday morning," said Bryant Williamson, shop manager.

## ARC exhibits "Christmas Scenes"

The first three prize winners, and the nineteen finalists, in our 1975 Christmas Card Design Contest were presented again as an exhibit, entitled "Christmas Scenes", at the Metropolitan Museum of Art in New York City.

All mentally retarded persons, ranging in age from elementary school children to senior citizens are eligible to enter our annual contest which is sponsored by the State Association. The award-winning designs were submitted by:

**First Place**  
(\$100 U.S. Savings Bond)  
Charles Russell, age 34  
Rome Developmental Center  
Building 56

**Second Place**  
(\$50 U.S. Savings Bond)  
Rita Ann Gennusso, age 24  
Dunkirk Achievement Center  
Dunkirk, New York

**Third Place**  
(\$25 U.S. Savings Bond)  
Eddie Booker, age 17  
Niagara State School  
Niagara Falls, New York

Committee; Ms. Dolores Wright, Director of Community Programs at the Metropolitan Museum and Mr. Thomas McCarley, former Program Coordinator with the Association.

This exhibit affords us an opportunity to demonstrate to the public, in a very concrete and effective manner, the wide range of capabilities which exist among persons who are retarded.

The exhibit is now available on loan to all local chapters and YOUTH groups throughout the state. If art truly constitutes a universal mode of expression, it is our hope, then, that the circulation of our "Christmas Scenes" Exhibit will communicate to the public the simple statement that, although a person happens to be mentally retarded, he can, nevertheless, be creative and productive - when given an opportunity and the incentive.

We invite those interested in participating in the state-wide display of our "Christmas Scenes" Exhibit to contact the State office for additional information.

## Right to talk

Judging this year's design were: Ms. Bernese Sobel, the originator of our first Christmas Card Design Contest; Mrs. Edward Licence, wife of Chairman of the Association's Scholarship and Awards

## Dental care

An announcement from the School of Dental and Oral Surgery of Columbia University announcing a grant from the Robert Wood Johnson Foundation to make it possible to establish an intensive program of dental care for ambulatory patients with a wide variety of handicapping conditions, including the mentally retarded, has brought again to our attention the fact that the offer of such services from individual petitioners goes almost unnoticed.

For example, Dr. Philip Garson of Gouverneur, New York writes us, that after taking H.E.W. courses at Long Island Jewish Hospital, he was later made dental consultant at the following:

1. St. Lawrence County ARC
2. Sunmount State School in Tupper Lake
3. Cerebral Palsy in Saranac Lake

He then adds, "Still waiting to treat a first patient."

At the clinic of the School of Dental Surgery at Columbia University, located on the 9th floor of the Vanderbilt Clinic building, admission of a handicapped patient can be arranged by calling 694-4185. The area code is 212.

A recent issue of the Special Report of the President's Committee of Employment of the Handicapped, from Bernie Posner executive director, discusses - "Do mentally retarded people have the right to express themselves?"

"Sometimes," writes Mr. Posner, "they are deprived of that right by those who love them most, their parents."

"Only their parents are not always aware they are trampling on a human right, the right to speak."

John E. Winters, Executive Director of the Escambia County (Florida) Association for Retarded Citizens, has witnessed in his office a number of instances of deprivation of the right to speak, where the parents speak for the retarded persons.

Posner cites three instances, one of which will be given here.

### SCENE I

Cast: Mother; Father, George, 17; John

Mother: Is there an opening in your workshop? You know, George is now out of school.

John: Yes. But George is going to need 16 weeks of evaluation, like everyone else.

Mother: Oh, he doesn't need it. We know he'll make a good worker.

Father: He likes to do things around the house.

John: (to George, slouched with his head down). George, would you like to work in the workshop?

Mother: Of course, he would!

Father: Of course!

Any of you parents see yourselves here?

# Our Children's Voice

Retarded Children Can Be Helped!

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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