

# Our Children's Voice

Retarded Children Can Be Helped

Vol. XXXII No. 2

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

June, 1980

## "Best Boy" wins "Oscar"

A documentary, "Best Boy", produced and directed by Ira Wohl, cousin of Philip, a retarded man 50 years old, has won universal acclaim and an Academy Award for its treatment of a difficult situation.

The film describes, over a three year period, the development of Philip, the death of his father and the deep concern of his mother for Philip's future.

It is finally resolved when Philip is provided with a group home by the New York City chapter.

How did it all come about? Here is a note from Michael Goldfarb, executive director of the New York City Chapter about how it all happened:

Three and a half years ago, a young hirsute gentleman visited me in my office. He was Ira Wohl. Ira told me about his cousin, Philip, who was retarded, 50 years old and living at home in Queens with his elderly parents. Philip, although severely retarded, had never been enrolled in any kind of day program. Further, his parents were increasingly unable to provide him with the care he required because of their age and health.

Ira, recognizing plans had to be made for Philip's future, discussed with me the possibility of AHRC providing Philip with a day program and ultimately with a group home. I stated we would be interested in exploring the possibility of providing those programs for Philip. Ira also mentioned that he was a film maker and he was interested in chronicling Philip's progress in the program. I replied this would be possible but I wanted to see some of the footage he had already shot. My staff and I were most impressed with

his powerful and accurate rendering of the difficulties faced by families of retarded people. After the Board of Directors and the AHRC approved the project, we proceeded to develop a variety of possible funding sources. These included the New York State Council for the Arts, the National Arts Endowment and One to One. Pooling these resources, and working collaboratively with Ira, we participated in the development of Best Boy, a powerful and pointed documentary about the impact on a family of a retarded child.

From our point of view, the film was a significant gamble. One never knows in advance whether or not the finished work will present the point which motivates the sponsor (which in this case was us). The outcome has exceeded our fondest expectations. The City Chapter owns Best Boy, which has already received tremendous critical acclaim, and is currently being shown theatrically in New York City. We are, of course, most delighted that this feature length documentary received the prestigious Academy Award. Best Boy has also received significant awards at the Toronto, Chicago, Houston and Miami Film Festivals. Rarely, if ever, has a documentary received the public recognition afforded Best Boy. We are convinced this acclaim is justified, for the film presents a moving, accurate, sometimes disturbing and often uplifting portrayal of a family dealing with its own needs.

We will make every effort to make this film available for showing at the State ARC Convention in Lake Placid this fall.



Philly (left), enjoys a park outing with his cousin, filmmaker Ira Wohl, in a scene from "Best Boy", award winning feature documentary sponsored by the New York City AHRC. It opened in New York in February. Produced and directed by Ira Wohl, the film records, over a 3 year period, the experiences and training of Philly as he learns to be more independent of his aged parents.

## Chapter sponsored film acclaimed

About four years ago the Association for the Help of Retarded Children, New York City Chapter of NYSARC, decided to sponsor the making of a movie which it felt would add to public understanding of the problems of the retarded and their families.

The result of that decision is "Best Boy," a critically acclaimed feature film which has won an Academy Award in the documentary feature category. The color movie opened its New York run at the Sutton Theater in Manhattan on February 29, an event celebrated by an AHRC special invitational showing.

In prior showings, the film had won the Best in Festival and Best Documentary awards of the 1980 Greater Miami International Film Festival, and was the winner of the only award given in the prestigious Toronto Festival of Festivals, and was singled out for prizes in competitions in Chicago and Houston, as well.

"Best Boy" is the sensitively filmed story of Philly, mentally retarded since birth, who, at age 50, begins his training for greater independence from his aged, ailing parents.

Produced, directed and edited by independent filmmaker Ira Wohl, Philly's cousin, the movie is also a dramatic record of changing family relationships. These occur as the mentally retarded man undergoes expanded experiences in the

world outside his parents' home, and as he adapts to the preparation for living in a group home.

In one of the award winning film's touching scenes, Philly visits Zero Mostel backstage at "Fiddler on the Roof" and the pair join in singing "If I Were A Rich Man."

"Best Boy" was three years in the making. Philly's father died before the film was completed and his mother died last February. Today Philly resides in an AHRC group home.

Kathleen Carroll, N.Y. Daily News movie critic, gave "Best Boy" a Four Star rating and wrote it is "one of those rare films that radiates love and affection." Vincent Canby of the N.Y. Times called it "fine, unusually moving . . . genuine drama."

Rex Reed praised the film and included this trenchant observation, "With so much nasty news about neighborhood dissension in those communities where homes for the retarded are fighting to exist, 'Best Boy' should be required viewing for citizen groups and frightened homeowners screaming about declining property values."

AHRC's sponsorship of this outstanding film and the message of humanity it conveys can be a source of great pride to be shared by members and by friends and families and all retarded persons.

## Group residence controversy rages ARC continues to fight

In a "hidden war" against the creation of group homes for the mentally retarded, community opposition is being strongly pushed while at the same time the opponents declare their sympathy for the retarded, "but not on my block".

This controversy rages all over the state, but Westchester might be used as an example of what is going on. The community is using the Site Selection Law of Senator Padavan as its basis for objection. This law requires 40 days notice to the municipality of the intent to create a group home. The requirement is that the group home would not substantially alter the community by a proliferation of residences for various disabilities. In effect, this 40 day notice, without going into the constitutional rights of the mentally retarded to live wherever they wish if they are not a danger to themselves or to others, is a signal for the opposition to mobilize its forces and carry its fight even into the courts.

For example, a crowd of 400 New Rochelle residents packed their way into

City Hall to protest the selection of a group home. In the town of Mamaroneck more than 100 residents protested the selection of a different group home.

In North Tarrytown, residents opposed a group home site proposed there a year ago. While opposition to group homes reaches a high-pitched intensity in many communities, the state says some group homes have been selected and established in relative calm — such as Bronxville, Lewisboro, Mount Vernon, Ossining, Rye City and Yorktown. The objections most often repeated against group homes are:

— Group homes would diminish market prices of neighborhood houses.

— A group home would disrupt the neighborhood's character. It would attract added traffic. The retarded residents would make people feel uncomfortable and be a threat to children. Moreover, the homes would violate zoning laws by destroying single family housing districts.

— The neighborhood chosen is too far away from the business center of town.

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## Guest editorial

# The Medicaid Model

By Robert Sansone

Some very fine traditional and well proven adult habilitation and rehabilitation programs over the State, if not the country, are changing their good and effective formats because of Title 19 Medicaid funding. Many states, and New York is certainly one, have chosen to use federal funds by way of Title 19 to take the place of state aid to the local providers, such as, the AHRC. In New York State, for example, medicaid is being used to supplant state aid. I say "supplant," not "supplement," since there has been no discernable increase in state aid to the counties for several years, Suffolk being one. In turn county mental health boards and divisions and departments of mental health have responded in kind by not increasing their contract nets, encouraging local providers to make up their large deficits for adult services through other governmental sources of income, such as state medicaid and another relatively new form of Title 19 called Subchapter C. Some county mental health contracts are even being reduced in anticipation of this great Title 19 windfall. As a matter of fact, last year, Suffolk County tried to cut our contract net by nearly \$300,000. with the expectation that Subchapter C was forthcoming and would take care of our deficit. Fortunately, the whole thing turned out alright, but other chapters of the ARC should beware. Federal windfalls can be dangerous since they tend to be unreliable in duration and do their best to help destroy local determination, as is, indeed, the case with this new Subchapter C, Title 19.

An equal, if not more serious, concern with these funds is that the State has regulated totally inappropriate treatment approaches to programs funded under Title 19 by virtue of the medical and remedial care origins of Medicaid. As a result, some of the most widely accepted and rational developmental program approaches to the habilitation and maintenance of the permanently mentally disabled are being compromised. For example, according to the regulations, the culturally conforming formats of paid work and production play little or no role in the day treatment program for purposes of medicaid reimbursement. In this connection the regulations are painfully overworked with medically based therapeutic terminologies. The implication becomes quite clear that the program objectives should be curative in nature and that the client, notwithstanding the severity and permanence of his disability, will be brought by way of the healing arts eventually out of his condition. All of this, of course, is not true, as everyone knows, including those who have prepared the regulations. Everyone knows that regulations were contrived for purposes of medicaid reimbursement and for no other reason. In its zeal to generate more and more federal dollars the State is forcing us into a totally false, if not, dishonest program treatment model.

This compels us to raise some basic questions concerning the services of a therapeutic workshop and the common features which make our permanently disabled clients appropriate for our programs. What are we really treating? To answer this question, the most widely recognized problem we see in all of our clients is that they are apparently unemployable. That is, for a wide variety of reasons they all appear unable to meet or tolerate ordinary working conditions. In other words, for therapeutic purposes our clients are vocationally disabled and we are "treating" a general condition called vocational disablement, a very serious condition in a contemporary society which places its highest values on human productivity and job achievement. That

we could ever attempt to treat this condition without the trappings of a business-like environment and a basic curriculum of work, productivity and remuneration is totally illogical. Medicaid says that the "treatment" program must limit all of these. In place of a basic curriculum of work, productivity and remuneration the regulations permit crayons, coloring books, recreation, finger painting and a variety of other pre-school activities which are supposed to "treat" vocational disablement. For purposes of medicaid reimbursement some agencies in the State are running their adult services like the Hobby Horse Nursery. I am against recreation as an absolute therapeutic model.

Work, on the other hand, is an absolute therapeutic model since it conforms to cultural expectations and provides a range of intellectual, social, interpersonal and motoric stimuli. We use work as a basic stabilizing activity; we do not program work for work's sake. Our program services are concerned with the long-term stabilization of permanently disabled individuals through ongoing medical, therapeutic and casework supervision in a work and production oriented environment, namely, the workshop — classroom. Through this format, and by keeping the "treatment" feature subdued and infused with work, production and normal activities of daily living, we are able to get our disabled people to some level of economic usefulness, thus treating their vocational disablement. In pairing this clinical function with the normalizing aims of work and production, we are able to achieve, in great measure, a therapeutic goal and at the same time have our handicapped people contribute goods and services back to the economy.

I, personally, cannot see how we can with integrity take literally hundreds of handicapped people with a wide variety of problems, most of which are rather permanent, and teach them strategies to guard their self-esteem with crayons and scribbling. I, personally, cannot see how we can therapeutically get them to incorporate or internalize the precepts of a work oriented society without offering them work or the rewards of work. Medicaid and the regulations say we can. Obviously, the money does the talking in this instance.

## Ottinger puts Westchester in Congressional Record

Representative Richard L. Ottinger entered the Westchester Chapter with a place in the Congressional Record of March 6, 1980.

In addition to a complete reprint of an article from a Westchester newspaper, by Phyllis Riffel, profiling the WARC Training and Placement Program Ottinger presented this preface:

I am pleased to have in my congressional district one of the most active organizations serving the developmentally disabled—the Westchester Association for Retarded Citizens. It is the largest agency in Westchester County which provides day training programs for the mentally retarded. WARC operates facilities in White Plains, Yonkers, and Mount Kisco; more than 600 persons benefit daily from the sheltered workshop programs run by WARC.

Once a client has developed the necessary skills, a great deal of time is devoted by WARC to the process of placing a client in the proper job setting. The rehabilitation counselors and other support staff do a fantastic job of finding places with local employers for clients.



## A salute to Guideposts

A salute to guideposts — Dr. Norman Vincent Peale and his wife, Ruth Stafford Peale, receive a special citation from the NYS Assoc. for Retarded Children honoring Guideposts Associates for giving gainful employment to retarded people employed in the sheltered workshop operated by the Putnam Association for Retarded Citizens. With them in the photo are, Mrs. Vickie Friel of Mahopac, a member of the board and former secretary of the NYS Assoc. for Retarded Children, and Arthur Battistak placement counselor of the Putnam County organization. The presentation was made in the Peales' office at Guideposts on Seminary Hill Rd. in Carmel.

## PRESIDENT'S MESSAGE

It is always difficult to write this message when I realize that it won't be published for several months. What are problems now may well be solved by the time these words are read — internal friction within chapters hopefully will be solved, delayed checks from the State of New York will have finally arrived to ease cash flow crises, red tape obstructing logical flow of service delivery will have been untangled and warm weather will have returned to the Northeast once

again

Nevertheless, surely as the seasons will change, new, and maybe even different, problems will crop up again and again.

One of the marvels of the age, however, is that an aura of optimism continues to be evident wherever I travel in the State. — I think it has something to do with the fact that what we are doing is positive, just and necessary.

Who could ask more?

Ellie Pattison

# Our Children's Voice

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NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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

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

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# Budget discriminates against community retarded

Analysis of the budget submitted by Governor Carey to the Legislature, for local assistance of mental retardation, shows an unreasoned bias in favor of placement in the community of those of the 14,000 mentally retarded now in state institutions against the more than 500,000 in the community who need similar services.

Of the almost \$100-million dollars recommended for 1980-81, about \$75,000,000 is directly aimed at aiding the de-institutionalized. These come under chapter 620, 620 Community Residences and ICF-MR's. Although it may be argued that ICF-MR may be for community residents also, the thrust is obviously towards de-institutionalization.

When we consider that voluntary agencies are now providing community services for more than the 14,000 — the total population of the institutions, at a cost to the state, according to the Governor's figures of some \$17,000,000 for 1979-80, one has to wonder at the rationale behind a budget that raises this by some \$3,000,000 while raising the state aid for the de-institutionalized by at least \$45,000,000.00.

At the very least, this is a violation of the equal rights of the mentally retarded and developmentally disabled who have never been in the institutions and who have been a concern of their parents all through their lives, in terms of living at home.

The Association urged the Legislature to mandate that the state pay 100 percent for all community services for the non-institutionalized as they do for the institutionalized, but all we have received is vague replies from the leadership.

In addition to this, the Governor recommended, in a capital construction budget, a first instance amount of \$33,600,000 tied into ICF-MR's, which was completely eliminated by the legislature.

We can only wonder at such actions, at best a blind reaction to the elements in the community that do not want community residences no matter what.

We also note the legislature cut some \$7-million dollars from the operating requests from about \$100-million submitted by the Governor but we can't find out exactly what was cut.

The legislature did pass the deficiency appropriation for capital construction for \$11-million dollars, but this does not provide funds for a new construction acquisition or remodeling of houses for group homes.

Unless something has been done by the time you receive this copy of OVC, it is quite possible that the program for the establishment of group homes for the mentally retarded and developmentally disabled in this state will be left almost entirely to the voluntary agencies whose resources are already stretched to the limit.

## Equal treatment for parents who keep retarded at home

The State should take steps to "resolve a long-standing discriminatory inequity" in the matter of retarded children kept in their homes instead of institutions, State Assembly members Elizabeth Connelly (D., Staten Island) and John C. Dearie, (D., 85th A.D.) and at a parent's meeting held recently. The lawmakers say that the parents should be awarded \$346.37 in "added expense for home care."

Citing a survey finding, Mr. Dearie stated that "something is wrong when the State spends \$30,000 yearly on a child in an institution, \$12,000 in a group home program, but balks at sharing the load upon parents, estimated at about \$4200 a year.

He said that the study made among 80 parents of retarded children put the home care for the youngsters at \$346.37: for food, \$97.67; medical, \$32.21; clothing, \$39.15; shelter, \$91.09; and special services for the handicapped, \$86.25. The session was attended by a dozen parents, some with their children, and mental health advocates.

Ms. Connelly, chairperson of the Assembly's mental health committee, is sponsoring legislation to establish a demonstration district for 300 parents to provide services for retarded children at a cost to the State of about \$1.1 million. "Among the broad range of mental health issues, few are more legitimate than the appeal of parents whose choice to keep children at home form an increasingly difficult financial burden that to date they have shouldered along, without any State assistance," she says.

Among expenses under "special handicapped services," Mr. Dearie notes on the basis of the survey, are recreational programs, day camps, sleep-away camps, special clothing, special appliances, diet, special equipment adaptation of housing such as ramps and special locks, and transportation.

The assembly members noted that they are aware of a recent Federal Court decision which orders New York State to pay \$331 monthly to approximately 5000 parents who took their retarded children out of Willowbrook to care for them at home.

"This court order does not apply to parents who never have institutionalized their children" Mr. Dearie states. He and Ms. Connelly noted that as result of a case brought by a group of Bronx parents, a Supreme Court decision stated that the State could not single out only one group of parents, — "the Willowbrook class," for aid without offering similar assistance to all parents who choose to keep retarded children at home.

Henry Villegas, chairman of the Bronx Mental Retardation Council, who aided in conducting the survey states that "it is unfair to penalize parents who elect to keep their children at home, since they are performing a function that would have to be undertaken by the States if the parents did not assume it."

The two Assembly members stated that despite fiscal constraints, "the time is now for the State to begin to move programming, services and funding to resolve this long-standing discriminatory inequity."



Rally of Retarded for equal funding takes place on steps of Capitol.

## Rally of Retarded



Jerry Weingold addresses the Rally. To his right, Senator Frank Padavan and Ellie Pattison, President of the New York State Association.

## Teacher union in state fight

A state move to reclassify teaching positions at state-run institutions for the mentally retarded has met with resistance from the teachers and their union, the Public Employees Federation (PEF).

Up to 700 teachers statewide — all of them civil service employees — stand to be affected by the change, including about 100 at the Staten Island Developmental Center, Willowbrook.

Covering six teaching levels, the state's package, effective May 15, would introduce new job titles accompanied by alterations in workload and pay scales, which union leaders consider detrimental to 40 to 45 percent of the teaching force.

"The union is not happy with this situation, because we believe it to be a coercive situation," Robert Bush, PEF regional coordinator, said yesterday.

Although the reclassification is optional, teachers who did not sign for it by March 27 will be offered another opportunity to do so. But future hiring, according to the package distributed by the State Division of Classification and Compensation and the Division of the Budget, will be carried out under the new classification system.

The teachers' contract does not expire until April 1982, but civil service law permits the state to reallocate jobs without engaging the pertinent union in collective bargaining.

Teachers who refused to sign over the new titles would forego their present option to work two unscheduled months, at least in a teaching capacity. The package suggests that they could find summer employment with the state as "camp

counselors, food service workers, etc."

Meanwhile, teachers at the Staten Island Developmental Center collected funds against the possibility that "as a last resort," they would hire their own legal counsel, rather than rely on the union, according to David Bienstock a member of the developmental center teacher's steering committee.

## Free milk in Onondaga

The state's "free special milk policy" for school children whose families are unable to pay the full price of milk is offered at the Onondaga Association for Retarded Citizens, according to Don Boudov, executive director.

Eligibility criteria provides for adjustment for uncontrollable family financial hardships, such as high medical costs, special education expenses, disaster or casualty losses, and economic need based on income and family size.

Applications are available at the OARC and may be submitted at any time during the school year. All application information is confidential and used solely for the purpose of determining eligibility.

## Burgess re-appointed

Karin A. Burgess, Executive Director of Cortland County Chapter, was reappointed by Governor Carey to the Council for Mental Hygiene Planning for a two year term ending in December, 1982. This is her second term of service on the Council.



# Two years of progress

These significant federal laws were enacted during the second session of the 95th Congress (1978) and the first session of the 96th Congress (1979):

— **THE REHABILITATION, COMPREHENSIVE SERVICES AND DEVELOPMENTAL DISABILITIES AMENDMENTS OF 1978 (P.L. 95-602)** extends and amends the Rehabilitation Act of 1973 and the Developmental Disabilities Act of 1975. Title V of the law provides for a three-year extension of developmental disabilities state formula grants as well as funding for state protection and advocacy systems and university affiliated facilities. Title V also redefines the term **developmental disabilities** and requires that states establish "priority service areas."

— **THE HOUSING AND COMMUNITY DEVELOPMENT AMENDMENTS OF 1978 (P.L. 95-357)** provides for a one-year extension of the federal housing assistance programs, authorizes congregate housing services for the elderly and handicapped and allocates \$50-million for Section 202 direct loans to construct housing for nonelderly handicapped persons.

— **THE COMPREHENSIVE EMPLOYMENT AND TRAINING ACT AMENDMENTS OF 1978 (P.L. 95-524)**, reorganizes the original 1973 CETA Act, requires primary sponsors to include the handicapped in their target populations and emphasizes employment and training programs for the handicapped.

— **THE EDUCATION OF THE HANDICAPPED AMENDMENTS OF 1978 (P.L. 95-561)** reorganizes and extends, for five years, the current Elementary and Secondary Education Act (ESEA) programs, including the existing program of aid to state-operated and state-supported schools for handicapped children, as originally authorized by P.L. 89-313.

— **THE DEPARTMENT OF EDUCATION ACT (P.L. 96-88)** establishes a cabinet-level Department of Education. Programs previously under the Bureau of Education for the Handicapped and the Rehabilitation Services Administration are incorporated in the new Department of Education under an assistant secretary for Special Education and Rehabilitative Services.

## Construction begins on Lexington addition

The expansion, to the tune of \$1451,919, to the Lexington Center of our Fulton Co. Chapter is the latest step in the evolution of a program for the mentally retarded that began in an area church basement more than 20 years ago.

This addition will enable Lexington Center to expand its sheltered workshop and provide more suitable space for evaluation. It will also be used by "activity center" clients, the severely disabled who need a less distracting atmosphere than what presently exists.

Federal funding will cover 44 percent of the addition's cost, the state 33 percent, local government 7.7 percent and Lexington Center 15.3 percent.

The facility's share was raised mostly by the Friends of Lexington, a group that sponsors fund raisers like the annual summer fair, auctions, bingo and dances.

Expanding is what Lexington Center has been doing since its beginnings in the mid 1950's. The cornerstone of the program was laid when the Fulton County Chapter of the ARC, primarily parents of retarded youths, started classes in local church basements and at Gloversville's Jewish Community Center.

In 1957, the Gloversville Enlarged School District took over the operation of special education classes formerly operated by the ARC.

When some parents began to realize their children were becoming too old for the school district programs, the ARC purchased Gloversville's vacant Lexington School in 1961.

It began as a crafts and vocational center for the handicapped and slowly evolved into a sheltered workshop.

Paul Nigra, the present Executive Director, succeeded the original executive director, Charles MacVean, in August, 1968 and is now the second longest tenured ARC director in the state. Only Mrs. Helen Kaplan of the Nassau County Chapter has served longer.

The landmark date for the Lexington Center was Dec. 10, 1973, when the county Board of Supervisors, realizing the facility was outgrowing its quarters, bought the former Acme Supermarket.

While the grocery store was being refurbished, a disaster struck. In Aug., 1974, the Lexington Ave. Rehabilitation Center was destroyed by fire, forcing the program to temporarily locate to the former Bishop Burke High School.

Finally, in Feb., 1976, the program moved from the high school to its present location.

The Lexington Center serves nearly 300 persons, 85 percent of them county residents. The clients include not only the retarded, but persons with physical handicaps or emotional disturbance because, in a county that small, it is impossible to support more than one workshop.

In addition, the ARC has three group homes for its clients with plans to build two more homes in the area.

For a program that started out in church basements, its growth over a little more than two decades has been phenomenal.

Nigra credits the glove cities with Lexington's success, "the parents of our clients and staff are very pleased with how well our people have been accepted in the community."

### Albany job freeze

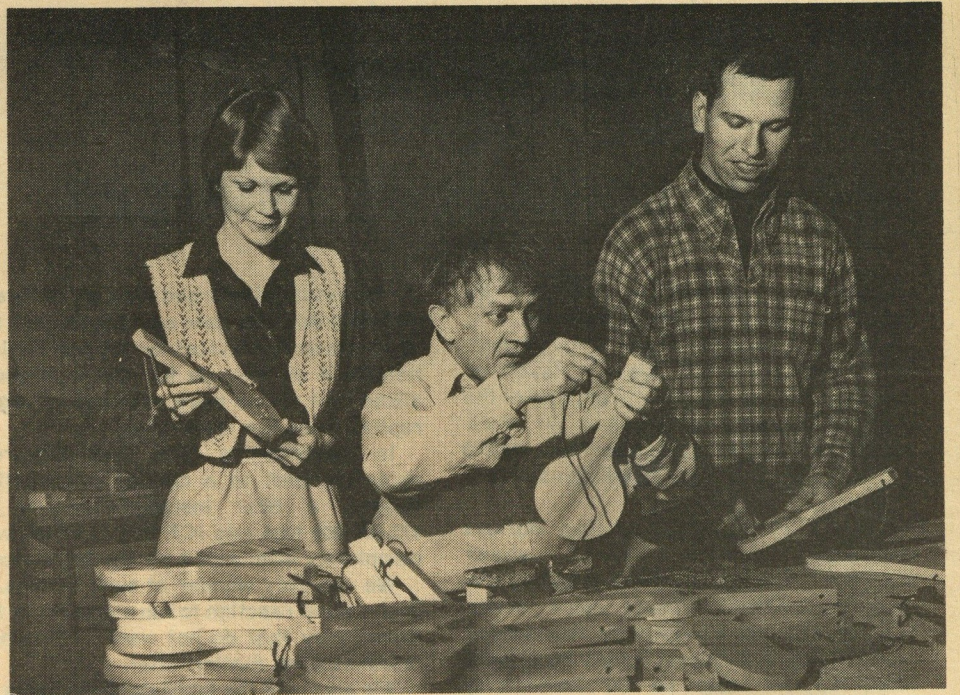
A state job freeze, calling for a total reduction of 3,034 positions in various state departments and agencies, has been ordered in Albany.

The program involves a combination of attrition, a hiring freeze, and job abolitions. It was designed, along with some non-personnel savings cuts, to save the state \$21 million.

The job cuttings were called for in a letter sent out by the state budget division to all departments and agencies. A budget official said discretion was exercised in the manner in which the cuts were ordered. And, a complete job freeze on all new hiring was avoided, he added. It was also said that the program will not require any discharge of employees now on the payroll.

The estimated \$21 million in savings will accrue because money now earmarked for the jobs that won't be filled won't be spent, and the positions that become vacant won't be refilled. It was explained that a flat ban on new hiring in every case was avoided because a few sensitive positions must be filled. The whole thrust, however, is to reduce the state payroll by 3,034 and it is to be accomplished, a state budget official said, with no outright firings.

The job reductions hit hard on the Department of Mental Hygiene where 700 job reductions were involved; Mental Retardation, 400 jobs, and State University of New York, 475 positions.



Debbie Hall, Unity Life Tennis Tournament volunteer, watches as Monarch Industries workers put the finishing touches on key racks given to all players participating in the mixed doubles tournament sponsored by Unity Life for the benefit of the Onondaga Chapter.

## Unity Life sponsors 5th Tennis Tournament

Unity Mutual Life Insurance Company, with its Home Office in Syracuse, sponsored its Fifth Annual Mixed Doubles Tennis Tournament in mid-April for the benefit of the Onondaga Chapter.

As a way of thanking the participants in the tournament for their support, the company contracted with workers at ARC's Monarch Industries workshop for the production of key racks imprinted with the Unity Life logo.

Designed in the shape of a tennis racket, the racks were carved, sanded, stained and imprinted by Monarch Industries

workers.

Over \$9,000 was raised during the three day tournament from player's fees and community contributions.

Scores of Unity Life employees donated their time before and during the tournament, which is now the premier tennis event in the area.

John F. X. Mannion, President and Chairman of the Board of Unity Life, presented a check to Don Boudov, Executive Director of the Onondaga Chapter at the conclusion of the matches.

## Parent group fights for better care

Reacting to what the Parent Group at West Seneca Developmental Center labels a "Crisis situation," because of the cut in staffing and consequent deterioration of programming, the West Seneca Developmental Center Chapter, Toni Parisi, President, placed a half-page ad in the Buffalo Evening News calling the situation to the attention of "The People Of Western New York" under the heading, "How do you like Being Treated As Second Class Citizens?"

The ad pointed out that West Seneca's Developmental Center is the most understaffed developmental center in the entire state. It needs 382 more staff to bring the center up to at least the State average. It called upon the citizens to help them bring this about by writing to their State Assemblymen and Senators.

State Officials said they would consider adding more staff to West Seneca Developmental Center, but that this is tied into population, with the failure of the center to move as many out into the community residences as the State wants.

"We now have about 200 more patients than we can care for in a professionally acceptable manner," said Dr. Louis G. Huzella, the center director.

Under pressure from Mrs. Parisi and state legislators, 50 jobs were restored to West Seneca, but 125-150 more are needed, Dr. Huzella indicated.

The long-range goal, according to Commissioner James Introne, is to move about a third of the West Seneca population into community residences,

"But that's a big if," Mrs. Parisi contended. "What we're talking about is the care being provided yesterday, today and tomorrow, and maintaining staffing as it is now is totally unacceptable."

Mr. Introne said that if the release of patients from West Seneca is delayed, money ear-marked for the community residence programs could be used to provide additional staff for the center, but "We were not able to do that before," he said.

Some of the conditions found during a check by the Buffalo News were:

— Blind children were no longer being trained to find their way around a room or outside on a sidewalk.

— A hospital unit with 30 acutely ill patients has only one employee on the night shift.

— Physically handicapped patients living in a homelike cottage, where they were being trained for placement in the community, have been moved back into general wards.

— The center's ratio of staff to patients is barely above federal guidelines for minimum care.

As a result of these efforts, the report of the Finance Committee directs the Commissioner to "enhance and maintain the direct care staffing levels of West Seneca Developmental Center commensurate with its residential population."

Congratulations to our West Seneca Developmental Center Chapter and to Toni Parisi, their president.



## Fetal alcohol syndrome

Environmental exposure has taken on new meaning as it relates to factors which affect the human fetus while it is still in the mother's uterus. A pregnant woman's personal habits, specifically reflected in her use of drugs, tobacco products and alcohol, have been identified in recent years as factors placing the fetus at risk.

Firming up the data and educating the public about the risks as they pertain to the heavy use of alcohol during pregnancy are two of the objectives which have been singled out by a task force appointed by Gov. Carey which recently issued a report on the phenomenon known as the fetal alcohol syndrome.

While the syndrome, which is characterized in children by several defects, including mental retardation, has been the focus of media scrutiny in recent years, it probably represents only a fraction of the consequences of heavy alcohol consumption during pregnancy, according to Dr. Marcia Russell.

"I think the fetal alcohol syndrome is really only the tip of the iceberg," adds Dr. Russell. "I think alcohol-related birth defects are probably the major problem."

Dr. Russell, an epidemiologist at the Buffalo-based state Research Institute on Alcoholism, was the only Western New York resident on the task force and chaired its research committee.

Using a variety of projections based on other studies, the task force estimated that during 1978 alone, there were approximately 386 babies born in New York with fetal alcohol syndrome and 1,563 other born with alcohol-related birth defects.

Dr. Russell notes that there have been prescriptions against heavy alcohol consumption by pregnant women or those likely to become pregnant mentioned in literature since Greco-Roman times.

Dr. Russell says the fetal alcohol syndrome was "rediscovered" in 1973 by Seattle researchers studying low birth weight infants. Since then, some have even suggested that warnings about drinking during pregnancy be placed on liquor bottles, much in the same way as warnings are now printed on cigarette packs.

Further research has followed and a specific set of defects associated with the syndrome have been pinpointed. It has been established that the syndrome occurs only in some children born to women who are chronic alcoholics who continued their drinking pattern during pregnancy.

Beyond that, however, there are many uncertainties and, Dr. Russell stresses, "there has been no safe level of alcohol use established for pregnant women."

In addition to recommending further research on fetal alcohol syndrome, the task force report stresses the need for further education efforts to inform physicians and the public — particularly women of child-bearing age — of the risks of heavy alcohol consumption during pregnancy.

She suggests that heavy drinking or the occasional binge drinking by women of child-bearing age also be avoided. "Many of these congenital defects probably occur during the first trimester of pregnancy and they may occur before the woman even knows she is pregnant," she adds. "If a woman is coming off of birth control pills or knows she is at risk of becoming pregnant, she ought to be careful and think about what she is drinking."

The caution should continue throughout pregnancy, she adds. "The central nervous system," she explains, "develops throughout pregnancy and presumably may be damaged at any point during the nine months."

## Brain study - a vast frontier

Scientists are finally beginning to penetrate the "ultimate frontier" — the human brain — and the consequences could have major meaning for a whole host of human conditions.

Understanding the brain and the mind it conceals is no mean task, according to Dr. Richard E. Thompson of the University of California at Irvine.

"The human brain is the most remarkable and complex structure in the known universe," he said.

"Composed of more than 12 billion nerve cells, a single human brain has a greater number of possible interconnections among its nerve cells than the total number of atomic particles in the entire universe."

And yet, Thompson noted, it is this three pounds of tissue that "has allowed the human species to dominate the environment, write poetry, compose symphonies, make war and develop a scientific understanding of the world."

Right now — even given the primitive

knowledge of the brain's structure, nerve wiring system and chemical messengers — scientists can to some degree manipulate the brain's functions.

With humans, scientists can correct movement disorders that mark Parkinson's disease, Thompson said.

In addition, researchers at the UC-Irvine campus recently showed they could make old mice swim better than young ones. Other researchers have demonstrated a pathway that explains just how the brain can shut off sudden and acute pain, he said.

And, Thompson indicated, much more is in the offing. It won't happen right away, he stressed, but he predicted that in the next decade or two brain research will find ways to deal with basic motivations, intractable behavior disorders like drug addiction and obesity, problems dealing with learning and memory, and the treatment of major mental states like schizophrenia.

"It must be emphasized that neuroscience is not promising immediate 'cures' for the wide range of neural and behavioral disorders that confront us," Thompson said.

"However," he added, "because of the current rapid growth of knowledge about the brain and nervous system, there is no question but that improved treatments for many disorders will become available in the next few years."

There seem to be no limits to the new possibilities. As Thompson said:

"With this understanding will come treatment for the vast array of baffling disorders that now confront us — psychoses such as schizophrenia and depression, mental retardation, learning disabilities, stroke, blindness, Parkinson's disease, multiple sclerosis, head and spine injuries, drug addiction and, quite possibly, crime and war."

Long-term goals, Thompson admits, but possible.

## Research in retardation

This article was written by Edmund C. Jenkins, Ph. D., program coordinator at the Institute for Basic Research in Mental Retardation for a special series in the Staten Island Advance:

There are millions of retarded children throughout the world and as many as four million more are expected to be born in this country by the year 2000. Research has resulted in the identification of some of the causes and increased understanding of the basic defects in some types of mental retardation. This has led to more effective methods of treatment and habilitation for the mentally retarded child. In addition, better methods for the prevention of the condition of mental retardation have been developed.

Studies aimed at improving diagnosis and better methods of treatment and prevention of mental retardation have been the mission of thirteen centers for research in mental retardation throughout this nation. The centers carry out investigations of mental retardation from many viewpoints. There are very few similar institutions throughout the world.

There is a National Institute for Mental Retardation in Canada and an Institute for Defectology in Moscow. But, in most other countries, research in mental retardation is part of an enterprise concerned with a broader range of human diseases and conditions. It lacks the focus applied in mental retardation research centers here.

The first of the centers to be constructed is the New York State Institute for Ba-

sic Research in Mental Retardation (IBR). The institute was proposed in 1957, authorized in the spring of 1958, and partially completed for initial operation in 1967. Located on 40 acres of central Staten Island, IBR consists of a five-story laboratory tower and three separate wings for in- and outpatient clinics, wards, administration, and an animal colony.

The institute was initially conceived to determine the causes, nature and treatment of mental retardation. Under the leadership of the new Office of Mental Retardation and Developmental Disabilities, IBR has broadened its scope to include research and clinical services in the diagnosis, treatment and counseling of the mentally retarded and their families. This has resulted in making IBR available to the medical community in the state. The institute has not only opened its doors as a referral facility with sophisticated procedures required to accurately diagnose and treat individuals with mental retardation and developmental disabilities, but it is also offering

educational opportunities in the form of lectures, tours and seminars to those parents, students, civic and professional groups interested in learning about ongoing research in mental retardation and developmental disabilities.

Now under the direction of Henry M. Wisniewski, M.D., Ph. D., the institute consists of 31 laboratories in seven departments: biomedical engineering and computer operations, human development and nutrition, human genetics, neurochemistry, pathological neurobiology, psychology and virology.

In addition, a clinical center is being developed which will utilize these departments and clinical staff members for the development of a program to provide state-of-the-art facilities in the diagnosis and prevention of mental retardation and developmental disabilities.

Individuals interested in touring IBR and attending seminars should write to the Director's Office at 1050 Forest Hill Rd., Staten Island, N.Y. 10314.

## Abby on Down's

A portion of a letter from a mother of a child with Down's syndrome, published recently in a Dear Abby column, is reprinted here because of the important message it carries:

What happened to Jimmy was tragic, but the child himself is not a tragedy, and neither is his birth. He is as much a loving member of our family as our other children, so do send a card, a note or a little gift to acknowledge his birth.

Please don't ask if "insanity" runs in the family. Down's Syndrome is a chromosome defect and is rarely hereditary. A Down's child is retarded, which is vastly different from insane.

Don't hesitate to ask how he is getting along. Some people avoid mentioning the child (as though he had died) because they think the situation is too horrible to even discuss.

When the child seems to be progressing, please don't say he seems "normal" and maybe won't be retarded after all! New parents need to face up to the facts about their child before they themselves can accept him as he is. By denying his limitations, you encourage false hopes and convey the message that you don't really accept or love him.

About a third of all Down's children are born with heart defects. We thank God that our Jimmy survived open-heart surgery,

so please don't say it might have been a "blessing" had he died. And don't express surprise that they "would bother" to operate on such a child.

Please believe the parents when they say that their special child is a very worthwhile little person, and they are actually glad to have him. While Down's Syndrome is nothing to wish for, it can be accepted, and is not nearly as catastrophic as it seems the first few weeks.

In the beginning, the parents need to talk about their feelings. Don't argue. Listen. Let them weep, and weep with them. And when they can finally smile about their baby, you smile, too.

Don't refer to the child as "that poor little thing." It hurts me to see people look upon my child with pity and to know that they wish he had never been born. He's not repulsive in the least, and much good has already come from him. Our other children have learned understanding and compassion because of their little brother. We told them the truth immediately, and they have loved him from the day they first saw him.

I cannot imagine life without Jimmy. He is the sunshine of our lives.

People don't mean to be insensitive or cruel — they just don't know how to handle the birth of an exceptional child.

## Woman in wheelchair hired

Mohawk Data Sciences became the first major employer to hire a person from the Herkimer County Training Center, following months of negotiations.

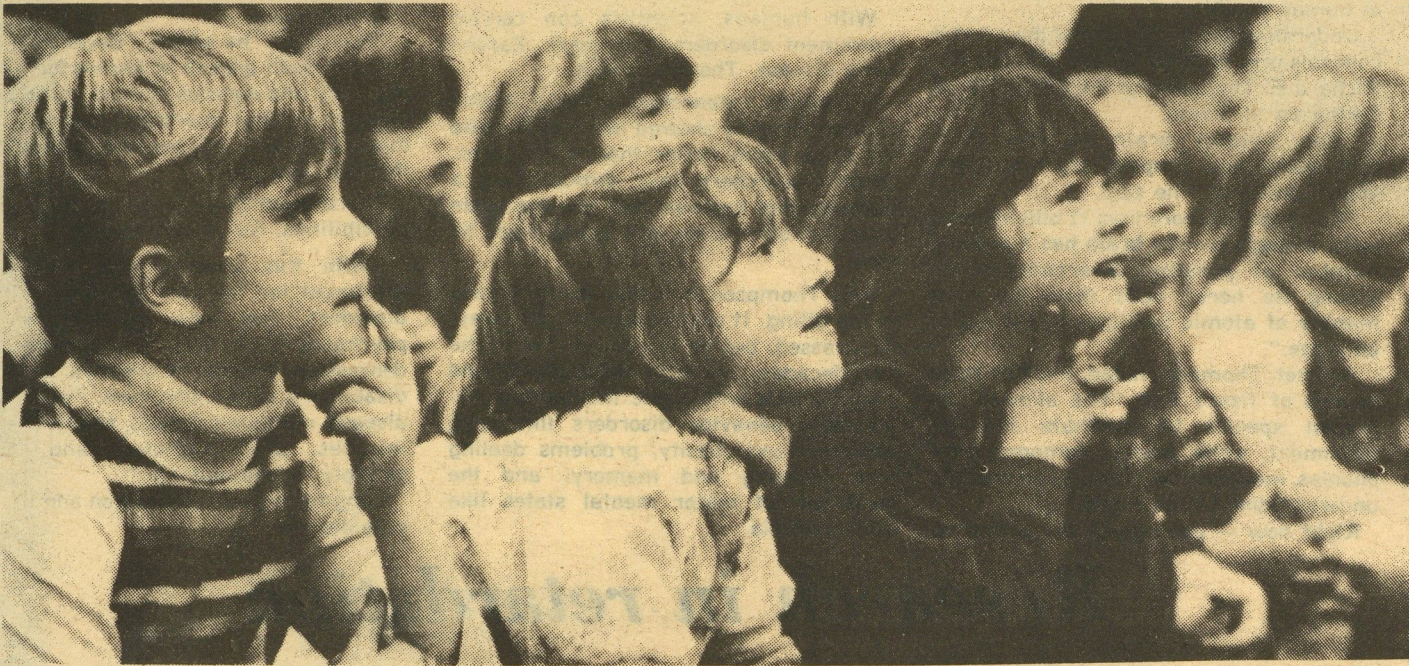
Carolyn Miller, who has multiple disabilities and is confined to a wheelchair, trained for two weeks with Dominick Cirillo, placement specialist for the New York Association for Retarded Children, Inc. before qualifying for the job.

Plant renovations, which Thomas Sprague, executive director of the Herkimer County Chapter of ARC, said were the major problems for MDS in hiring Ms. Miller, were made to accommodate her wheelchair. Those renovations included building of special ramps at entrances, widening aisles and altering restroom facilities.

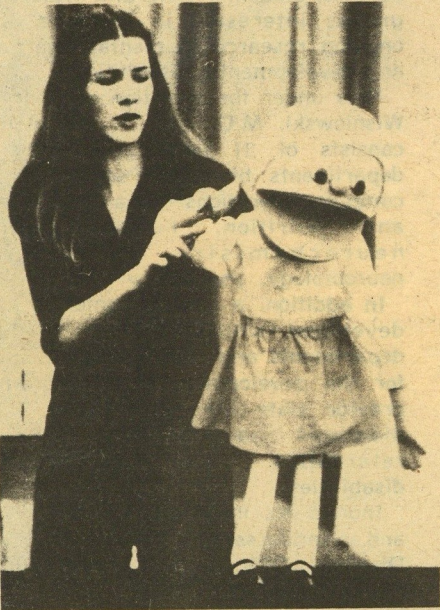
Information on tax credits for these renovations and for sponsoring on-the-job training for Ms. Miller was provided by Ellen Again, from the New York State Department of Education, Office of Vocational Rehabilitation.



## New York's disabled puppets teach youngsters across state



Third graders at the Milton Terrance Elementary School in Ballston Spa watch the puppets in action.



Brenda, one of the non-disabled puppets, registers surprise when she is told that a friend she has just made is mentally retarded. The puppeteer is Lili Loveday.



Renaldo Speaks — OMR-DD's newly inaugurated and innovative 'Kids Project' is helping to bring the message of what it's like to be mentally retarded and developmentally disabled to elementary school children around the state through the use of specially designed disabled puppets. Here puppeteer Beth Byrne and her disabled friend Renaldo answer third graders' questions about blindness during a performance at the Milton Terrance Elementary School in Ballston Spa. Puppeteer Lili Loveday is looking on.

## Football for Onondaga

A National Football League exhibition game will be played in the new Carrier Dome at Syracuse University on August 29, 1981 between the New England Patriots and Philadelphia Eagles. J. Stanley Coyne, a Syracuse industrialist is helping to sponsor the game for the benefit of the Onondaga Association for Retarded Citizens.

Helping to make the announcement were Joe Julian, vice president of Public Affairs at Syracuse University; Jim Gallagher, of the Eagles' front office; Onondaga County Executive John Mulroy, and Frank Kelly, city commissioner of Parks and Recreation (representing Syracuse Mayor Lee Alexander).

It will be the first professional football game in Syracuse in more than 25 years. Also on hand to promote the game were Patriots quarterback Steve Grogan, Eagles defensive back Herman Edwards; Pat Sullivan, son of Patriots owner Billy Sullivan; Don Boudov, executive director of the Onondaga Association for Retarded Citizens and Frank Maloney, SU head football coach.

The Dome, which will seat 50,000 is on schedule for its opening September 20 when Syracuse meets Miami of Ohio.



Pick out the puppeteers! Lollie Abramson and Marian Dwyer of the New York City troupe, surrounded by some of their special friends.

## Workshop Cooperation

An experiment may determine the future of sheltered employment in the Twin Tiers.

The experiment, spearheaded by officials of the Steuben County Association for Retarded Children (ARC), is designed to defuse the threat of competition among workshops and increase their effectiveness.

The new idea, dubbed "consultive coordination", is funded by a one year \$43,000 federal grant channeled through New York state.

It comes at a time when crucial decisions must be made about workshops' future.

"With the number of workshops in the area, the whole idea of synergy should be paramount," said Joan Mayer, executive director of the Steuben ARC.

Synergy — as the word implies — is a synthesis of energy, a cooperative venture. When it works, the total effect of the cooperation is greater than the sum of individual efforts.

That, Mayer said, is what workshops must strive for if they are to satisfy the overall goal of service to the handicapped. "Collectively, we carry more clout," she said.

The proposal affects workshops and other aspects of service to handicapped persons in Chemung, Steuben, Schuyler, Livingston and Wyoming counties.

Allegheny County may be included, Mayer said, once a large number of persons from that county are served in Steuben.

From the beginning, Mayer admits, the problem will be enlisting the various agencies in the project.

"The only way it can work is if all the board help to create the program to begin with," she said.

Assuming that is accomplished within the next few months, the project funding would finance a three person staff in an office centered in the service area.

The coordinator's task would be to stay in communication with all area agencies keeping track of problems and helping to develop more lucrative contracts and work programs.

"If we are able to work together, we are able to deal with larger, more sophisticated work," Mayer said.

She also foresees exchange of ideas — and possibly personnel — to bolster weak points in a workshop's operation.

"It could be our staff could work with their staff or our supervisors could work with their supervisors.

Reaction to the proposal could indicate the direction that area sheltered workshops will take in years to come.

## State increases handicapped workers

The State Legislature acted to amend the Civil Service Law relating to employment of handicapped persons by the state. The amendment increases positions which may be filled by the handicapped to 400 instead of the previous 200. It specifies duties such as can be performed by physically or mentally handicapped persons who are found otherwise qualified to perform satisfactorily the duties of these positions.

Upon such determination, these positions will be classified in the non-competitive class and may be filled only by persons who shall have been certified by the employee health service of the department of civil service as being either physically or mentally handicapped, but capable of performing the duties of such positions. The number of persons appointed shall not exceed four hundred.



# Were pay raises tied to discharges?

Salary increases for several directors of mental institutions statewide, have been held up or denied because too few patients have been discharged to the community from their institutions.

In the past, salaries for the directors of mental hygiene facilities were set up by the state Legislature. Under a new law, however, state commissioners now have the power to set salaries and give pay increases.

In several cases, salary increases have been used to pressure directors to increase the number of patients discharged under the state's deinstitutionalization program.

Dr. Louis G. Huzella, director of the West Seneca Developmental Center, long has been the target of criticism by Albany mental retardation officials for not moving patients out of his institution more quickly.

Although not opposed to the concept of deinstitutionalization, Dr. Huzella has refused to discharge patients unless there were adequate treatment facilities in the community to care for them.

Informed sources say it was made clear to Dr. Huzella that West Seneca's failure to meet community placement goals was responsible for his not receiving his full salary increment.

Although he wouldn't comment on his salary, Dr. Huzella said there has been undue pressure to reduce the population of his facility.

## Pattison is White House delegate

Ellie Pattison, President of the New York State Association for Retarded Children, Inc., was a delegate to the recent White House Conference on Families held in Maryland. She was chosen at a meeting at the Governor's Conference on Families earlier in the year.

When interviewed regarding her participation in the Conference on "the changing family," Mrs. Pattison stated there were all combinations of shapes, sizes, color, ideology, philosophy, knowledge and skills that are today's families.

Since there are so many variations on a theme, it is important that the delegates, themselves, represent different perspectives. Mrs. Pattison felt her experience as a wife and mother of four children, and her 22-years as a citizen advocate for the mentally retarded and the developmentally disabled, enabled her to bring a unique perspective as a delegate.

She stated "experience has taught me that any human problem cannot be viewed in isolation, and that problems must be addressed first within the family unit."

## Unterberg dies

All of us were deeply shocked and saddened by the sudden death of Harold Unterberg, the State's Advocate for the Disabled.

Harold Unterberg brought to his post a rare combination of qualifications.

As a veteran disabled in World War II, he understood the employment, civil rights, housing, architectural, transportation, and attitudinal barriers encountered by the disabled.

As an accomplished attorney, he understood how any legislation or regulation might affect the thousands of persons he represented.

Most of all, it was Harold Unterberg's strength of will, commitment and energy which made him such an effective Advocate for the Disabled.

"We are always constantly reminded that projected figures are absolute and we have to achieve them," he said.

William Knowlton, a spokesman for the Department of Mental Retardation and Development Disabilities, denied that pay increases were withheld because of failure to meet placement goals.

"Directors are rated on a system of evaluation and if you're not up to snuff, raises can be held back or negated," he said. "It's management evaluation. There's no quota."

Meanwhile, State Sen. Dale M. Volker, R-Depew, said he and other members of the Senate's Mental Hygiene Committee have been assured the matter of pay increases for directors will be straightened out.

"If we don't get a thorough explanation we're going to hold hearings and make the whole thing public," Sen. Volker said.

## State hospitals to dump 8000

The State plans to release 8000 patients from mental hospitals in the next five years — accelerating a scandal-marked program.

The Carey Administration goal is to close 10 mental hospitals and eliminate 3000 mental health jobs, mainly by reducing the number of patients in institutions.

An intensive program already has cut the number of mental patients from 70,000 in 1970 to 24,000 today.

Most of the released patients were "dumped" into communities, critics have charged, with little or no arrangements for their treatment or physical care.

The state has not yet announced a "hit list" showing which of the 60 state institutions—including 24 in the Metropolitan Area—will be closed.

An Office of Mental Health spokesman said the state plans to save \$300 million by closing, instead of renovating, some institutions.

But mental health costs have soared

## "Defective babies" right to life supercedes costs

The cost and inconvenience to others of raising a defective infant cannot be grounds for allowing that child to die at birth, State University of Buffalo medical students were told recently.

At least in our society, said Dr. Laurence B. McCullough of Georgetown University's Kennedy Institute for Ethics, we cannot claim our resources are not sufficient to care for the most severely retarded and physically handicapped.

"It's not a question of limited resources, but of competing resources," he told a student questioner in a lecture on ethical issues involving the newborn.

"We waste enormous amounts of money on frivolous things," Dr. McCullough said.

As long as we do, he said "my hard-nosed view is that...we are obligated to spend the money. Otherwise, we are an unjust society."

The same obligation falls on parents when they make the decision to have children, he said.

Mental retardation may seem horrifying to parents of above-average intelligence. But that is the wrong perspective to take, Dr. McCullough said. The value of a life lived under these circumstances must be viewed from the perspective of a child who has never known anything different, he said.

If someone has the capacity to enjoy and place some value on his own life and development of that capacity won't be frustrated by extreme physical suffering, then he is vested with those moral rights that normal humans possess, Dr. Mc-

# Retarded are not psychiatric patients

A State Supreme Court justice ruled that two mentally retarded persons were being kept illegally in the Nassau County Medical Center, and ordered them transferred to a state facility in Melville.

In a lawsuit brought by the State Mental Health Information Service, Justice Vincent Ballella ordered that Michael Payne, 18, of Hewlett, and Mary Jaghab, 40, of West Hempstead, be transferred from a ward for the mentally ill at the medical center to the Suffolk Developmental Center in Melville.

"This establishes a precedent that it is inappropriate for the mentally retarded to be hospitalized," and Alfred Besunder, director of the service, which brought the court action.

The Mental Health Information Service is an arm of the state courts that

represents retarded and mentally ill persons. In the past several years, the service has obtained several court orders to insure that mentally retarded persons are not held in institutions for the mentally ill any longer than is necessary.

In his decision, Ballella chided the service, the medical center and the state for failing to find a solution and avoid court action. "There may not be sufficient facilities for the care of all those mentally retarded... but neither will the court countenance the attitude of all concerned in doing little or nothing to correct the situation."

A spokesman for the medical center said that it had tried to place the two patients, but was told by the state that there was no room for them anywhere.

## L.I. program receives grant

A \$25,000 grant from the State Bureau of Mental Retardation and Developmental Disabilities was awarded to the Town of Oyster Bay for the establishment of an adult handicapped program.

The Town Board approved acceptance of the grant and institution of a program for mentally handicapped adults. The \$25,000 grant was matched by \$10,000 in town funds for the program.

The adult handicapped program, which takes in mentally handicapped adults 25 and older, is administered by the handicapped services division of the town's department of community services, which currently oversees the Group Activities program (GAP) for handicapped youngsters.

Approval for the continuation of a program that hires disabled students to work with the Group Activities program (GAP) for the handicapped was also granted by the Oyster Bay Town Board.

Town Councilman Gregory W. Carman explained that the cooperative program between the town and the Human Resources Center, Albertson, provides part-time employment for specially selected college students. Funding is equally shared by the town and the Office of Vocational Rehabilitation, through the Human Resources Center with a maximum of \$1,800 for the town's share of salaries.

"The concept of having handicapped teens work with handicapped youngsters has proved to be a very solid one," Carman commented. "In addition to providing role models for the youngsters, it provides the college students with valuable job experience."

## Protestants honor Catholic bishop

The Most Rev. Francis John Mugavero, Bishop, Roman Catholic Diocese of Brooklyn, was one of the honorees at the Twentieth Annual Testimonial of the Brooklyn Div. of the Council of Churches of the City of New York, recently held in Flushing Meadows.

The recipient of many honorary degrees and honors, Bishop Mugavero is most known to us as a friend of the retarded, helping us in our efforts to create group homes and facilities in his diocese.

He is the recipient of the Humanitarian Award of the New York City Chapter, Association for Help of Retarded Children and all of us join in honoring him.

Cullough said.

The problem is that physicians can't predict with precision just what the consequences of birth defects will be.

"We can't escape tragic consequences in some instances, but if we must err, we will do so on the side of treatment. The burden of proof falls on those who would withhold treatment," he said.

## City supports recycling project

The City of Oneonta joined a glass recycling program with the Town of Oneonta and the Association for Retarded Children. The city paid for a building on land provided at \$1 a year by the D&H Railroad near Fonda Avenue. The town provided utilities for the building. Together, the city and town set up 12 pick-up sites and equipment for the glass processing center and also each provided a truck for pick-ups for part of the week. The ARC is administering the program.

Alex Shields of the ARC estimated the city could produce 1,400 tons of glass each year if only half the glass discarded by Oneontans is recycled. At \$32 a ton and up, the year's gross sales would be \$45,000. He did not say how much rail transportation will cost.

The state Department of Environmental Conservation will pay half of the equipment cost, an estimated \$4,125, while Susquehanna Manpower Inc. agreed to erect the building.





Ellie Pattison, NYSARC President, disco dances with Peter McManus, AHRC client.

## Orange honors Pattison

Ellie Pattison was an honored guest at the Orange County AHRC Twenty-fifth Anniversary Dance. Ms. Pattison is the President of the NYS Association for Retarded Children. With her charm and exuberance, she mingled with all of the two hundred guests who attended a delightful celebration at the Villa Baglieri in Highland, New York.

According to Executive Director, Pete Young, "These twenty-five years represent a period of intense growth of which the Board can be proud." From meetings held in local churches and schools, Orange County has developed programs in ten locations, two Day Treatment Centers in Middletown and Newburgh house, a program for 150 adults. The Education Program offers Early Intervention classes, a Pre-School Program, school age classes, and summer school. They also provide instruction for children who are physically and mentally handicapped. The clinic gives full evaluations for community clients and those in the program. Six community

residences house about 60 mentally retarded adults. The coordinator of the Recreation Program organizes bowling, swimming, chorus, dances and craft lessons for all mentally retarded people in Orange County.

During the ceremonies, Mr. Bill Volpe, Orange County AHRC President, asked Ms. Patterson to say a few words. She offered,

**In spite of frustrations and incredible odds, your dedication is complete. This is the time to get together and think about the twenty-five years past. But this is also the beginning of a new rededication to the future. Without you and your interest, money, anger, and dedication, we could not do this job. I pledge to you my support to help in the future.**

Everyone was encouraged by the president's words. Her presence at this Orange County function showed those attending that this woman encourages an active dialogue between the State Association and each local chapter.

## Willowbrook Panel seeks to modify decree

A state proposal to double the rate at which handicapped residents are transferred from institutions to community-based group homes has prompted a sharp reaction from the Willowbrook Review Panel.

Commissioner James Introne seeks to reduce the population in Willowbrook to 250 as stated in the decree, by 1981. The Review Panel, through its executive, director, Katherine A. Schwaninger, disputes the ability of the state to do this and still serve the population properly.

According to Ms. Schwaninger, residents transferred from institutions to group homes have averaged 23 a month, with just one highly exceptional month, when 54 transfers were made.

Community placement has been hampered by vociferous opposition from neighborhoods in which group homes were to be created. State officials also have cited red tape for the delays.

Although the review panel has, time and again, disputed the state's statement of

inability to meet the quotas desired, they have now taken the position that what Commr. Introne is trying to do by 1981 should not be done. In fact, one member of the Review Panel said he would be amendable to postponement of the target date for the purpose of "maintaining quality" as residents are phased out of the center.

"Our position was never a numbers game," he said. "We'll accept a few more years or a lot more years, but it has to be done right."

This, of course, according to a spokesman for the NYS Association, agrees with the ARC's position that placements must be made with the best interest of the client and not just for numbers, a position that was not accepted heretofore by the Review Panel.

As a result of this policy by the state, Dr. Jennifer Howse, associate commissioner of the Office of MR-DD and former exec. director of the Review Panel, which was to head up the placement program out of Willowbrook, submitted her resignation.

## Giannini heads new national agency

We are very pleased to announce that Dr. Margaret J. Giannini has been appointed by President Carter to serve as Director of the new National Institute on Handicap Research.

Dr. Giannini headed the first clinic for the mentally retarded in the United States, Flower Fifth Avenue Hospital, at a time when the State Association could afford only \$4,000 to get it started. She served as Professor of Pediatrics at the New York Medical College and also was the Architect of the Mental Retardation Institute at Valhalla.

**We were very pleased, indeed, to receive the announcement of this appointment in this letter from Peg:**

I am very pleased to be able to share with you a very exciting happening in my life. President Carter has appointed me to serve as the Director of the new National Institute on Handicap Research. This new and exciting challenge necessitates my leaving my position at the Mental Retardation Institute of New York Medical College.

Our association goes back over a period of time and I feel that I personally should bring this news to your attention. We have worked together in many situations and strived to attain the same goals for the mentally retarded and developmentally disabled population we serve. We have helped each other, provided each other with encouragement, attended meetings together, and accomplished much of what we set out to achieve. At this turning point in my life and career, I want to let you know how much our relationship has meant to me.

The Directorship of this new national Institute which is under the aegis of the Department of Education, is of tremendous significance, for the Institute deals with people with handicapping conditions of all different types and not only with handicapped persons in our United States, but throughout the world. I look forward to new horizons and trust that in a small way I can contribute to the improvement of life for those less fortunate than we are.

## Landmark decision for retarded parents

The rights of mentally retarded parents received a crucial recognition in a major precedent-setting decision by Judge Kevin C. Fogarty of the New York Family Court. Judge Fogarty ruled that New York State law unconstitutionally abridged the fundamental rights of mentally disabled parents by forcing the adoption of their children, who are in foster homes, and terminating parental rights on the ground that the parents are mentally retarded.

At issue in the case was the State's authority to place children for adoption and to permanently sever the familial bonds between mentally disabled parents and their children. The Court found the relationship between parent and child "one of the most delicate of societal relationships", even when parents are mentally retarded. The Court further stated that "the idea that adoption of such children invariably promotes their welfare and best interests is simply not true."

The parents are represented by Jay Shusterhoff, Esq., an attorney with Protection and Advocacy System for Developmental Disabilities, Inc., a federally funded legal services and advocacy agency for the developmentally disabled. Mr. Shusterhoff described the decision as of **land-mark** significance for the rights of mentally retarded people.

I hope our paths will continue to cross and my warm wishes for your continued success are always with you.

Cordially,  
Margaret J. Giannini, M.D., F.A.A.P.  
Professor of Pediatrics

This is indeed having a friend in court and we look forward to many years of association with Peg and pledge her our complete support in her new and important position.

## Judge orders state aid for home care

A Federal judge in Brooklyn ordered New York State to pay stipends to parents who took their retarded offspring out of the State Island Developmental Center to care for them at home.

Judge John Bartels, stressed that this ruling covered only the people who were part of the so-called Willowbrook class — about 5,000 children and adults who were residents at the S. I. facility in 1972 when lawsuits were begun in an effort to improve conditions there.

But state officials said they feared the ruling would open the door to legal challenges compelling the state to pay stipends to any natural parents who were caring for their retarded children at home. They said this would involve financial burdens the state could not afford. The officials said they would probably appeal the ruling.

In a 24-page decision in Federal District Court, Judge Bartels acknowledged that the payment of stipends to parents to care for their own children — amounting to \$331 a month — "is not explicitly authorized by the consent judgement" under which the state agreed to reduce the population at Willowbrook and improve conditions there.

But he said that, in plans to implement the consent decree, "the importance of the natural home as not only a placement option but a placement goal repeatedly emphasized."

The judge cited figures to show that placement in a natural home was less expensive than either institutionalization, which costs \$30,000 a year, or placement in a community group residence, which costs between \$9,000 and \$12,000 annually.

The state began paying parents stipends to care for children taken from Willowbrook under an administrative decision in 1976. The action was a way of meeting court-mandated quotas to reduce the population there.

It is noteworthy, however, that only about 80 parents have availed themselves of the stipend offer since the state first made it in January 1976. The state, however, halted the practice after a State Supreme Court justice in the Bronx decided that under the equal protection provisions of the U.S. Constitution, the state could not single out one group of parents of retarded children and pay them for care without offering the same kinds of payment to all parents.

That suit, *Sundheimer V. Kolb*, was brought by a group of parents of retarded children who had never been placed in state institutions. It is being appealed by the state.



# Court dismisses award to man taught as retarded pupil

The New York State Court of Appeals dismissed a \$500,000 award to a Queens man who, as a child, had been improperly assigned to classes for the mentally retarded. The attorneys and educators involved said that the case had been the country's only successful malpractice suit.

In a 4-to-3 decision, the state's highest court overturned a lower court ruling that the New York City Board of Education was responsible for its failure to regularly test the man, Daniel Hoffman, who at the age of 6 had been deemed retarded. The man, now 28-years old and a part-time messenger, was found near the end of his schooling in programs for the retarded to have "above-average intellectual potential".

In the majority opinion, Judge Matthew J. Jasen wrote that "the court system is not the proper forum to test the validity" of educational decisions or to "second-guess" such decisions.

The six-page opinion also appeared to shut the door on future educational malpractice suits, a type of litigation that has increased around the country in recent years.

The court said there was an administrative process available through the State Education Law to settle disputes over educational programs. Under the law, parents or guardians can petition the State Education Commissioner to hear appeals on decisions made by local school

districts.

"I don't see a remedy for Daniel Hoffman," said Robert D. Stone, the counsel to the State Education Dept. when told of the decision yesterday, "I do see a forum for addressing and, if necessary, redressing determinations found to be improper as youngsters make their way through the schools."

The arguments in the opinion were similar to those advanced last June when the court dismissed a malpractice case brought by Edward Donohue, a graduate of the Copiague, L.I., schools, who sued the district for \$5 million because he could not read beyond a fourth-grade level. The lawyers in the Hoffman case argued, and the lower courts agreed, that while the Long Island case involved a "failure to educate," the Hoffman case involved "an affirmative act of misfeasance".

The court rejected this distinction and said, "Our decision in Donohue was grounded upon the principle that courts ought not interfere with the professional judgment of those charged by the Constitution and by statute with the responsibility for the administration of the schools in the state".

In a one-paragraph dissent by Judge Bernard S. Meyer, the minority wrote that the case "involves not 'educational malpractice, as the majority in this court suggests, but discernible affirmative negligence on the part of the Board of Education in failing to carry out the

recommendations for re-evaluation."

Mr. Hoffman was assigned to a class for mentally retarded children in 1957 because a test given by a psychologist for the Board of Education showed he had an I.Q. of 74, one point below the minimum necessary for admission to regular classes. The psychologist, however, said the boy's severe speech defect made it difficult to assess his mental ability and suggested he be re-evaluated within a two-year period.

Despite the recommendation, Mr. Hoffman was not given another I.Q. test until May 1969, when he was 18 years old. According to that test, he had an I.Q. of 94 and showed "above - average intellectual potential." A year later, a psychologist said the youth did not know "where he fitted into the world, and even where he fitted into his family."

When his case went to trial a few years ago, another report on Mr. Hoffman noted, "At the age of 26, he had not made any advancement in his vocational life or any particular improvement in his social life."

In 1976, the State Supreme Court awarded Mr. Hoffman \$750,000. Last year, the Appellate Division upheld the verdict, but reduced the award to \$500,000.

Joining Judge Jasen in the majority yesterday, were Chief Judge Lawrence H. Cooke and Judges Domenick L. Gabrielli and Hugh R. Jones. Dissenting with Judge Meyer were Judge Wachtler and Jacob D. Fuchsberg.

## Majority leader on Hospitals

Assembly Republican Leader James Emery demanded that Gov. Carey end the "war of nerves" being conducted against those "among the most unfortunate in our society" — residents of state mental institutions.

Commissioner James Prevost of the State office of Mental Health has repeatedly stated the Carey administration's intention to close as many as 10 of the state's 26 mental health institutions. But, said Mr. Emery, the department has been unable to answer inquiries by the Legislature, the public and the press as to which facilities are marked for closing.

"There has been no comprehensive, credible evaluation of the humane, therapeutic and fiscal impact of the state's deinstitutionalization program," Emery said. "The state's shift to a community-based program may have already gone beyond the population initially targeted and, if a study were undertaken, we might find that more mental hospital beds are needed than are currently available."

"The announced plans to close several institutions is a poor substitute for quality management. A more appropriate approach would be to assure adequate services in the community before embarking on a plan to phase out these facilities."

"Someone needing mental health services cannot wait while the state retools or shifts the emphasis of its programs."

## Coughlin receives Humanitarian Award



Thomas A. Coughlin, III received the twenty-first AHRC Humanitarian Award at the Nassau Assoc. for the Help of Retarded Children's Rose Ball scheduled on June 14th at the Hilton Hotel in New York City. The annual event is a mainstay of the Nassau Chapter's community fund raising program and yearly, the ball, together with its journal and raffle, raises about \$300 thousand.

## Residential program "sabotage"

We reprint a letter written to the Connecticut Association for Retarded Children News, by the parents of a retarded man in Southbury:

Connecticut's traditionally high-quality care facilities for the mentally handicapped ought not to be sabotaged by those short-sighted professionals and misguided parents who propose residential community programs at the expense of phasing out proven facilities such as the Southbury Training School.

Ideally we should have both, specifically for those less disabled who may profit by integration into the community. However, there are those severely and profoundly handicapped who need to be protected from the stresses and upheavals of everyday community life. They need a carefully controlled routine in order to feel secure in a world which is a bewildering puzzle.

What Priscilla Bergethon unfairly labels the "restrictive boredom of institutional living" is indeed the very routine, the order, the special environment and training which are so necessary for our

more seriously handicapped. Her letter oversimplifies the problem and misrepresents the attitude of many parents like us who want to keep and improve Southbury.

Centers like Southbury are as necessary in our society as those other "institutions" — schools, hospitals, and churches. Such centers are not the only answer to a problem which has always plagued mankind BUT we in Connecticut would be very foolish to let such places run down in favor of placing defenseless, vulnerable citizens into hostile neighborhoods where today even those who possess all their faculties unimpaired have a hard time of it.

If our son could have coped with the so-called normal world we would never have made the agonizing decision to place him in the care of strangers. There he is happy, relaxed, part of a community where his needs are understood and provided for.

Our need now in Connecticut is to strengthen and improve existing facilities instead of building new ones based on hypothetical philosophies.

## Parents win plea to bar surgery

California's effort to have the heart defect of a Down's syndrome victim surgically corrected against his parents' wishes failed when the Supreme Court refused to hear the state's appeal from a lower court decision that the parents had the right to refuse the surgery.

The state, arguing that the parents were depriving the child of his "right to life," had sought to have the boy declared a special "dependent of the court" for the purpose of ordering the surgery. The state courts refused the state's petition.

The 13-year-old boy, who is considered "high - functionally mentally retarded" with an I.Q. of 30 to 50, has been in-

stitutionalized since birth. He has a congenital heart defect that, if uncorrected, will lead to death in an estimated 20 years, doctors say. With successful surgery, his life span would be normal, they say.

The parents, urging the Supreme Court to reject California's appeal, told the Justices they were afraid that if their son outlived them, he would "eventually be warehoused in the type of institution in which most older retarded people are forced to live." The case, *Botham v. Warren B.*, No. 79-698, has attracted considerable national attention.

## St. Lawrence wins union contest

In late January, an election was conducted at the St. Lawrence County Chapter by the National Labor Relations Board on behalf of the Truck Drivers and Helpers Local Union 687 affiliated with the International Brotherhood of Teamsters, Chauffeurs, Warehousemen and Helpers

of America as Petitioner and the St. Lawrence County Chapter of the New York State Association for Retarded Children, Inc. as Employer. From an approximate number of eligible voters over half of the votes were AGAINST the participating labor organization.



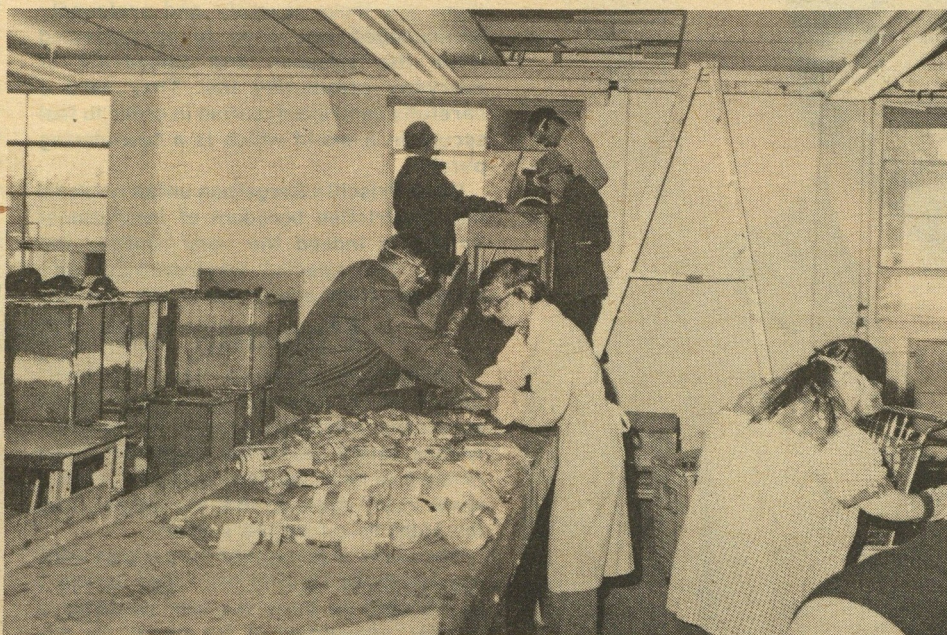
# CHAPTER NEWS *What our chapters*



Kathy Crowley carefully measures weights on the electronic scale as part of the Quality Control Team at Abbey Industries, Ontario County Chapter.

We'll begin this issue of Chapter News with congratulations to **ORANGE COUNTY CHAPTER** on their 25th Anniversary. The occasion was marked with some excellent local publicity and a marvelous dance which was attended by some 200 persons. Congratulations to Orange County on another milestone . . . **COMMUNITY LEAGUE - WASSAIC CHAPTER** writes to say, Community League takes pleasure and pride in announcing that it has opened an office on the grounds of Wassaic Developmental Center. Breaking its tradition, the league has employed Mr. Steven J. Kracht to direct its services from there as its Supervisor - in - Residence. Mr. Kracht has much experience in dealing with the developmentally disabled and will be setting up a program at the Center to facilitate the speed and expertise with which the league can cope with the advocacy and concern for the residents at the Center. The league has received the full cooperation and enthusiastic support of Director Hollis Shaw and his staff in the initiation of the program, thus greatly aiding in guaranteeing its success. Another first for the league is its active pursuit of the formation of a Youth group under the aggressive leadership of Mr. Michael Slansky. **ROME D.C. CHAPTER** is sending out a busy newsletter. The chapter indicates an interest in being a possible host for a future State Association Convention . . . **MONROE COUNTY CHAPTER's** newsletter as usual filled with information about that particularly busy agency. Interesting to note that in their horticulture program, they had a Christmas tree sale and sold 200 trees in nine days. Quite an effort . . . **HERKIMER COUNTY CHAPTER** recently began a mobile unit as a part of its Outreach Program. Working from a mini motor-home base, the mobile unit will carry a daily living skills trainer-counselor, an early education trainer and an outreach coordinator to the clients . . . **MADISON COUNTY CHAPTER** is taking on a large project in trying to acquire a new and larger facility for their programs. This will require some \$80,000 in local money but they are out trying to get it . . . **ULSTER COUNTY CHAPTER** comes to us not only with a new Executive Director, but with a new Banner on their chapter newsletter, The ARC Light. A very interesting renovation, to go along with the new look that Ulster is hoping to provide in all their programs . . . Thanks go out to the students at the Alfred State Agricultural and Technical College who went without a meal recently, contributing the money they would have spent for that meal to the **ALLEGANY COUNTY CHAPTER**. This

worthy endeavor raised \$752 for the chapter for which we thank the students . . . Abbey Industries, the **ONTARIO COUNTY CHAPTER's** sheltered workshop, has received a contract from Sotos International to sort, assemble, bag and seal curlers. It is the largest contract obtained by this workshop and presently involves the assembly and bagging of curlers in large volume. Abbey Industries has obtained several pieces of equipment in order to implement this contract. Among these are four bag sealers and three electronic digital scales used to check weight for a final count after bagging. This requires client workers to learn special skills in order to operate this equipment properly and do the job efficiently . . . **CLINTON COUNTY CHAPTER** with very interesting news in their publication, including the fact that local industry in their area is employing 20 graduates of their workshop program. To note this occasion, they held a Recognition Dinner for those who have obtained and maintained competitive community

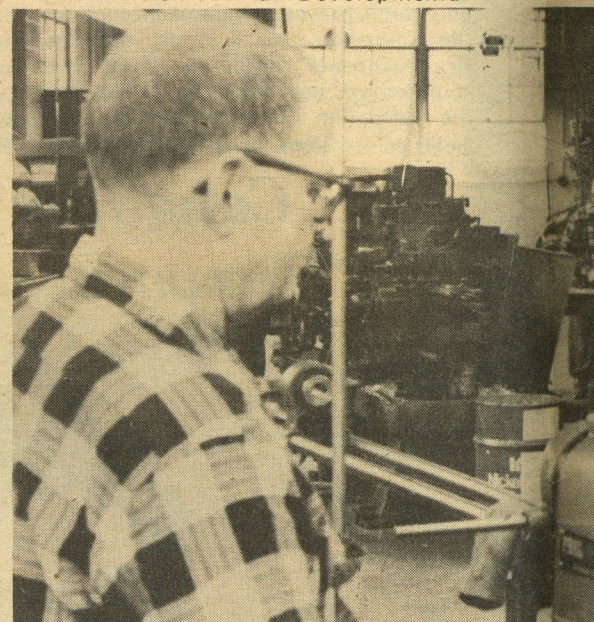


Oneida County ARC workers on the glass crushing line.

employment. Awards were presented to 16 former trainees of the Vocational Rehabilitation program who have obtained and maintained competitive community employment. The function was not only a fine tribute to the workshop clients placed, but also served to motivate current workshop clients to prepare for competitive employment. It was also a tribute to local employers of the handicapped who have well recognized the work potential of these people . . . **YATES COUNTY ARC** very pleased to have

opened a day activities program in September, 1979, to have started contact work in November and to be working toward full OVR workshop certification by mid-1980. That's good news from one of our newer chapters . . . **LEWIS COUNTY** newsletter really quite up-beat considering they are looking at some of the difficulties caused by waiting for state action. Executive Director, Phil McDowell, points out, "As we enter 1980, it is apparent that the wheels of progress are turning, however slowly, for the several projects targeted for Lewis County. In the case of the new state operated community residence, for example, we had hoped for an early 1980 opening. Presently, however, the budget for the Dayan Street Hostel is at the State Division of Budget awaiting approval." . . . It is hard for us at the State Office to believe that **ONEIDA COUNTY CHAPTER** was struggling for existence just a little over a year ago as they now come on strong with new programs and projects. Their glass recycling project is one indication of growth, as reported by Rose Hajdasz. Oneida County Chapter's glass recycling program, has undergone a great expansion since the agency received a Developmental Disabilities grant to purchase trucks and equipment, as well as provide staff salaries. On February 26th, an official dedication ceremony of the new equipment was held at the agency. Among the local officials in attendance were: Oneida Co. Executive Sherwood Boehlert; Mental Health Commissioner Richard Lallier and R.D.C. Acting Director Keith Hoffman. State officials from OVR and the Department of Conservation also attended. The glass recycling program's expansion has created 50 new jobs for agency clients in all phases of the recycling process. . . . Keeping the trend of workshop news, **CHENANGO COUNTY CHAPTER** writes to say that its workshop has installed a well equipped machine shop at its main facility. This equipment includes such machines as turret lathes, milling machines, punch presses, drilling heads, industrial metal saws and others. The machine shop is supervised by one experienced machinist and one tool and die

certificates to provide Day Treatment and Clinic service delivery. Thanks to **CAYUGA COUNTY CHAPTER** not only for their very classy and information filled newsletter, but because we think they are doing as good a job as we have ever seen on encouraging membership . . . **COLUMBIA COUNTY CHAPTER** hosted a workshop on Parents and the Education Laws. Looks like a very well-put together session . . . **NIAGARA COUNTY CHAPTER** inviting people through their newsletter to participate in minor home repairs in their community residences. How you get away with calling wallpapering and paneling, minor, this week-end will never know, but this is up to you . . . Talk about going international, **SCHENECTADY COUNTY CHAPTER** at their February program had a speaker, Alice Lin who spoke on how "China Treats the Mentally Retarded and Developmentally Disabled" We note that Schenectady is regularly getting over 100 persons to their monthly dances for clients. We hope this is some indication of the success of all their programs . . . Bernice Volaski, President of **WELFARE LEAGUE - LETCHWORTH VILLAGE CHAPTER** writes to indicate that Welfare League is very pleased they have received an extension of a Developmental



New machine shop in Chenango County.

Disabilities grant, the purpose of which is to determine the factors involved in the successful transition of residents from the institution to the community. The grant will run until June 1981. Installation ceremonies for this year were held on Sunday, March 23rd at the Mary E. Davidson School on the grounds of the facility. Regional Vice-President Hy Clurfeld and Executive Director J.T. Weingold were present. The Association joins in saluting Dr. Oleh Wolansky, who resigned effective March 6th, 1980 after 30 years of state service . . . **FRANKLIN COUNTY CHAPTER** got the local newspapers to run an interesting story indicating that the chapter and the Tupper Lake Central Schools are beginning an extensive effort to locate and identify preschool children with special needs. That's very good. In addition, clients of Franklin County Chapter got to be right on top the Olympics as indicated in the following bit of information, "A great deal of commotion took place in and around Lake Placid, N.Y. as businesses, athletes and community residents made ready for the XIII Annual Winter Olympic Games. The Franklin Co. ARC was certainly affected by these Olympic preparations as travel became restricted, prices began to rise and excitement among clients and staff rose. Of very special import to the Franklin Co. area were the simultaneous preparations being made for the N.Y.S. Special Olympics. A snow sculpture was erected on the grounds of Sunmount

maker. **CORTLAND COUNTY** sporting an attractive new office for Executive Director Karin Burgess which was made possible by the work for the Diversified Education Class at the Cortland-Madison BOCES. The young people did patching of walls, scraping, painting and carpentry, and Karin is always happy to show anyone the "before" and "after" pictures . . . **PUTNAM COUNTY CHAPTER** is proud and pleased to announce the certification of two vitally - needed programs which are currently made available under operating



# rs are doing and saying for our children and adults

Developmental Center, located in Tupper Lake, and the torch atop it was lit with the torch borne by the Olympic runners who brought it from the site of the original Olympic games in Greece. The Franklin County Chapter is very interested in the full participation of its clients in this year's Special Olympic Games . . . **WAYNE COUNTY CHAPTER** sends the following information about their activities. The Lyons Community Residents, Lyons, N.Y. has recently celebrated its third birthday and the Clyde Community Residence, Clyde, N.Y. will be three years in August, 1980. Our most recent accomplishment has been the Supportive Apartment Program. This is located at the Riverside Apartments in Lyons, N.Y. The Wayne Co. ARC has leased four apartments and serves eight clients. The Wayne County ARC's Vocational Rehabilitation Center has named a new Workshop Director. She is Joyce Rubin, previously director of Vocational Rehabilitation Services. The V.R.C. has become active in many work areas including the assembly and finishing of wood products suitable for household accessories and gift-giving. The Newark DAPT recently enjoyed a delightful daytime concert with the Rochester Philharmonic Orchestra and Sherry Lewis at the Eastman Theater . . . The big news

and one for multiply handicapped children in Lancaster. Both homes are currently under construction and opening dates are set for Spring . . . **RENSELAER COUNTY CHAPTER** is using a number of grants to expand programs. Through a grant from the State Division for Youth, the chapter has been able to initiate a program to integrate handicapped children and adolescents into existing youth-recreation programs operated by municipalities and private agencies. A \$54,000 grant from the Department of Transportation through the 16 (b) 2 program will be used to purchase special adapted vans and station wagons. This is the second year in a row the Rensselaer Chapter has received a 16 (b) 2 grant. Rensselaer is also pursuing purchase and renovation of the building next to their current work center on River Street in Troy. This would allow expansion of the Riverside Enterprises program with 40-70 additional trainees and badly needed storage space. The chapter has also added an interesting dimension to their pre-school program, with the addition of "home training days" to the school calendar. On those days, instead of having the pre-school youngsters come into the ARC's Pinewoods Center, the ARC staff, in teams, goes out to the children's homes. At home, the staff provides information and suggestions for follow-up in the home of the speech, education and physical therapy programs the youngster is involved in at Pinewoods Center. Program Director Michael Daughterty also reports that the home training days have served to expand communication between parents and staff . . . **MONTGOMERY COUNTY CHAPTER** has added a unique dimension to its residential programming — an apartment for two physically and developmentally disabled children, who can now reside and attend school in their own community. Encouraged by the successful placement of adults from the Wilton Developmental Center in 24-hour supervised apartments in their original county of Montgomery, the Association decided to undertake a supervised apartment for children from the developmental center. A two-family house has been transformed into a barrier-free home for 10 year old Jerry and 12 year old Jamilette in an attractive residential neighborhood. The big news in **SULLFOLK COUNTY CHAPTER** is their proposal for expansion of their Bohemia Center. Always a busy place, the Suffolk Chapter apparently wants to make even more room to stay even busier. Thanks to Suffolk, incidentally, for working with the State Association in the 7-11-21 Lottery, which produced funds for a number of our

chapters . . . **NASSAU COUNTY CHAPTER'S**, Nassau News, starts the new year right by pointing out that their 1980 calendar includes a variety of fund raising, social and sale benefit events. We note that their annual Rose Ball which will be held at the Hilton on June 14th will honor an old ARC friend, Tom Coughlin . . . Another new format, in **NEW YORK CITY'S AHRC Chronicle**. A very handsome sheet it is with many interesting stories in it. Particular congratulations to



Glen Hayes diligently applies himself to new contract work at the Yates County ARC facility in Branchport, N.Y.

the chapter on their efforts in connection with the award winning film, "Best Boy" . . . **ROCKLAND COUNTY** also with a new newsletter, have gone to the newspaper approach for the first time. A very attractive sheet and one that will certainly carry news of their many activities throughout the community in a most interesting way. . . . **CHAUTAUQUA COUNTY CHAPTER**, under the direction of its news media specialist, Louis Lombardo, is producing a newsletter with such a fancy new mast head, I can scarcely read the name. However, we know that it is Chautauqua County Chapter and we know that they are very busy, as indicated by the following article, "A spring ground breaking is projected for the \$2.3 million HUD Project—sponsored by the Chautauqua ARC. The complex will include apartment units for 24 handicapped persons, a recreational center and a residential home. The apartments will consist of a two-story structure for 24 persons using a combination of single and double bedrooms. An elevator will also be installed. A live-in manager will be available to assist the residents as well as for maintenance purposes. Plans also call for an Habilitation Specialist to work with residents of the apartments in developing necessary independent living skills (ie. cooking, shopping, housekeeping, etc.) The building should be ready for occupancy by this time next year, according to Executive Director Michael J. Raymond . . . Finally, we are delighted to note that the Saratoga Urban Renewal Agency is helping the **SARATOGA COUNTY CHAPTER** in the acquisition of property for a community residence and we are thankful for this assistance . . .



Activity in the Montgomery County supervised apartment for children.

## Oneida given recycling grant

The Oneida County Chapter of the State Association for Retarded Children (ARC) has been awarded a \$60,000 federal grant to expand its community glass recycling program and create 50 jobs for the handicapped and five new staff positions.

The grant will also enable the agency to purchase equipment and vehicles necessary to make the glass recycling program a major endeavor.

The Federal Developmental Disabilities Grant was obtained through the Office of Mental Retardation and Developmental Disabilities. The ARC had been conducting a glass recycling program with its own funds but the grant would allow considerable expansion of the community service.

The ARC will place drop-off containers for glass at major industries, colleges and hospitals in the Utica area.

Regular door-to-door neighborhood glass pick-ups will be made throughout Utica with advance notice given through telephone canvassing and flyers.

Quantities of glass obtained by these methods will be sorted and crushed at the ARC sheltered workshop at 14 Arnold Avenue, Utica.

Through the grant, two additional conveyor lines and two glass crushers will be added, enabling all three colors of glass — clear, green and brown — to be processed simultaneously. The crushed glass is then sold to glass manufacturers for \$30 a ton.

The program will help train handicapped workers in job skills needed for future competitive employment.

The \$60,000 grant represents 70 percent of the total \$85,700 glass recycling program with the remainder of the funds to be raised by the ARC through special events and private community groups.

## New faces in many places

From time to time, we like to up-date changes in Executive Directors in local chapters. Since last we reported this information to you in OCV, these changes have taken place.

Mr. Leo "Bud" Burdett left Allegany County Chapter in April. He was replaced on an interim basis by Mr. Peter Poulos.

Donald Geist has left the Executive Director's position in the Clinton Chapter. As of this writing, no full-time replacement has been found.

We were pleased to see that James Mroczek, who replaced Mr. John Regan in Monroe County Chapter, as Acting Executive Director, has been named Executive Director for that chapter.

Edward Guthrie, who comes from the State of Maryland, has taken the Executive Director's post vacated by Mr. Wayne Rowe, in Orleans County.

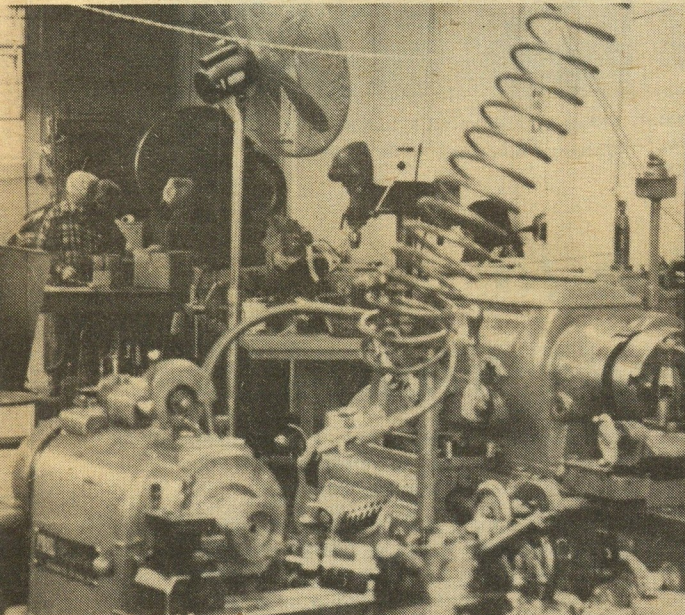
Schoharie County Chapter's first and only Executive Director, Elizabeth Southard, resigned in February. She has been replaced by a current employee of Sullivan County Chapter, Mr. Ira Gellison.

Charles Dailey, a former employee of OMR-DD has joined Seneca County as their first Executive Director.

Another former employee of Sullivan County, Richard Swierat has become the Executive Director in Ulster County Chapter.

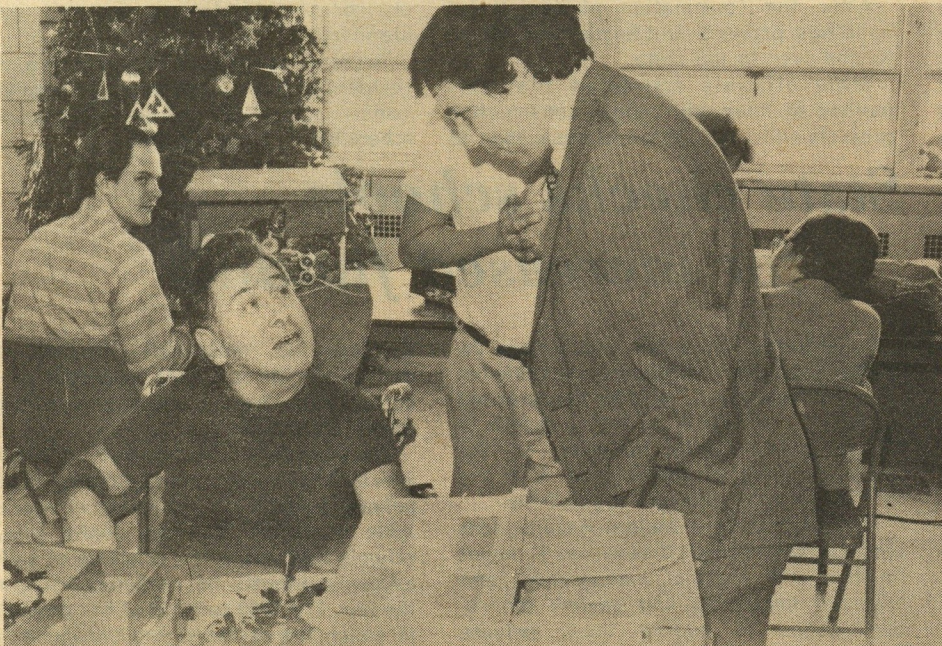
Jean Howard has temporarily taken the position of Executive Director of Warren-Washington Chapter, replacing Linda Kelly.

We welcome all of these new people to their positions.



in Chenango County workshop.

in **ERIE COUNTY** is that they finally opened their first community residence for adults on February 15th in Hamburg, N.Y. A residence in Hamburg was first proposed in October 1978, but local oppositions delayed it until now. The Erie Co. Chapter also operates a group home for children in Orchard Park and plans to open one for adolescents in East Aurora



Commissioner James E. Introne speaks with Melvin Pearl of Chautauqua County's workshop during a recent visit to the chapter's facilities.



# Mother coerced to keep son home

The mother of a severely retarded child charged recently that new laws designed to protect the handicapped actually discriminate against many of them and called the attitudes of social workers toward the mothers of retarded children "unrealistic and sexist."

Writing in the current issue of Redbook magazine, Fern Yasser Kupfer of Ames, Iowa, criticized both state and Federal Governments for not doing enough for the mentally retarded and said that she received more support from other mothers than from professionals whose main goal, she said is to "encourage parents to keep their retarded children at home."

When Zachariah, who will be 4 in April, was diagnosed as "severely brain-damaged," his parents decided they could not continue to care for him at home; but, they wanted a place for him where they could maintain contact and help with his care.

The answer was a residential care facility or developmental center, but Mrs. Kupfer found that getting her child into such a facility was "more difficult than getting a normal child into Harvard Law School." After searching for more than six months, she finally found a facility that would take Zachariah; but, then she had to convince state social workers to approve the placement because the state "foots the bill." The social workers tried to persuade her to keep Zachariah at home, she reported.

"I believe that this philosophy comes from the unrealistic and sexist view that women do not work outside the home — have no life outside their families," declared Mrs. Kupfer who teaches English at Des Moines Area Community College.

"The social workers told us just how expensive Zach's care would be," she reported. "But, we live in a state that has a \$50 million highway fund surplus. We live in a country that spends billions every year for instruments of destruction. Zachariah, who needs therapy and special programming and adaptive equipment, will cost the state \$50 a day . . . (Joe and I read that the state spends over \$15,000 a year to incarcerate a criminal.)"

Emphasizing that her decision was one "reached through great pain, with guilt and sorrow," she said it is a decision that is right for her own life and the rest of her family.

"Choosing to have Zach live away does not mean we do not love and accept him," she declared. After talking with countless other mothers who have kept their retarded children at home "until they couldn't take it anymore," Mrs. Kupfer realized that she needed to find a place for Zach "before I resented him more than I loved him."

Citing a Federal law that mandates education for all children, regardless of the severity of any mental or physical handicaps, Mrs. Kupfer said it has forced institutions to limit the number of children they can care for. "The problem is that for many retarded children there is simply no place," she asserted. "The institutions have closed their doors before the communities have gone about building new residential care facilities."

Describing her son as "a Gerber's baby food original with golden curls, enormous blue eyes and chubby cheeks," Mrs. Kupfer said his development has been "stopped in time as a 3-month-old infant. At 3 years and 9 months, he cannot sit up or keep his head steady; he cannot hold a spoon and he cannot even say 'Mommy'."

Mrs. Kupfer and her husband have one other child, a daughter, Gabi, age 8. Her

article was submitted "blind" to Redbook's monthly "Young Mother's Story" series; but, the editors found it such a moving account of the "pain and frustration" caused by governmental bureaucracy that they decided to give it major treatment.

Zachariah Kupfer is now a resident of Hills and Dales Child Development Center in Dubuque, Iowa, where Mrs. Kupfer reports he is receiving the care he needs to reach his full potential, no matter how limited.

## Hostel complaint

This letter, received in the state office, should be taken very much to heart by those of our chapters who are operating hostels. I am happy to say the situation described here is not at all typical, but even ONE such should not exist.

We have, of course, deleted any reference that might have identified the house:

"Our son's removal from ——— will be the symbol of many things. It is sad, for he really belongs in a good hostel, and we have earned the right to peace and tranquility after 21 years. It is also sad to realize that many of the needs and wants of the other residents will be ignored, until some other person with a conscience, who has the courage of convictions, steps forward to keep a watchful eye over the administration.

Can we blame the administration for not being knowledgeable, for they have nothing to use as a comparison? Can we blame young counselors and aides for not planning and preparing good meals because they've had no real experience or training in this? Can we blame these same counselors for not being good housekeepers, when some of them have never had to perform in this role? Can we blame them for not being good role models (this reeks of Momism, you bet it does!) when they've had no life experiences along this line?

When the basic blueprint is laid before you, it is inconceivable that it can't be followed in some measurable way. Blatant disregard for minimum standards is almost criminal. Perhaps the meaning of minimum standards should be expalined in depth. Serving mini-pizzas for the evening meal, and not replacing the resident housemother on personal leave for 10 days, is certainly short-changing these residents, for they are short of staff as it is. Because we are the only parents making complaints is not a justifiable reason for ignoring them or considering them petty in nature. Every complaint we have made in our opinion, has been reasonable and justifiable.

At this point, I can see no immediate remedy except to erase the slate and start over, but those that will suffer most are the residents; for ——— is a paradise compared to some of the homes they come from. At best, ——— is a rooming and boarding house, and a poor one at that. I think it is a pretty expensive one at that (\$415.60 mo). Hate to put it like that, but realism plays a very important role in my life.

It might be easy to shut my eyes and ears to everything, if I didn't have a son there. Maybe that's why some board and committee members have adopted the "Hear No Evil" "See No Evil" position."

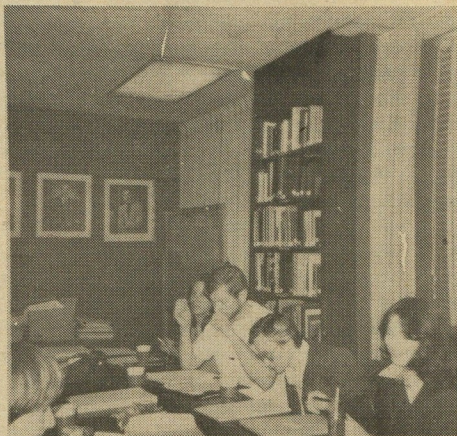
(Name Withheld)

## Some Youth Board activities



AT THE YOUTH BOARD MEETING

Left to right. President Jimmy Cunningham, Diane French, Heather McGar and Paula Lebow.



Left to right, Paula Lebow, Theresa Hynes, Thomas Sprague, Executive Director - Herkimer ARC, Judy Sprague, Members of Stat Ad Hoc Committee on Youth and Mary Kenny.



At the Smithtown Costume Dance, Charles Weidig (Advisor) with Lauren and Tom.

## New approach to Colorado homes

The State of Colorado and representatives of Boettcher and Company, an investment brokerage firm in Denver, have reached an agreement to provide \$16.9 million in capital construction funds to develop community-based residences across the state.

Under the new agreement, funds to build 33 new group residences and 54,000 square feet of additional program space will be raised through the sale of certificates of participation in building leases to private investors.

The Colorado Division of Developmental Disabilities will lease the newly constructed buildings from private investors, who will own the structures until the end of an 18-year lease-purchase agreement.

After the termination of the lease, buildings, property and furnishings will be turned over to the state.

State officials estimated that this method of financing capital construction projects will save Colorado more than \$6

million over the lease period when compared with the cost of building the homes with direct state appropriations.

The program will also enable the state to continue its certification under the federal-state Medicaid program, which contributes roughly \$13-million a year to the operation of the three state institutions.

The 33 new group residences will house a total of 276 developmentally disabled persons, most of whom will be transferred from Pueblo, Grand Junction and Wheat Ridge State Homes and Training Schools.

By reducing the population of these three state operated facilities, the Division of Developmental Disabilities will be able to bring them into compliance with Title 19 environmental, staffing and fire safety standards.

Architectural plans for the community residences are currently being completed, construction of initial homes was scheduled to begin in May.

## State checks schools for increased funding

In January, 1979 a law was passed increasing the court reimbursement rate for private residential schools for the retarded in New York State from \$670 a month to \$900 a month based, however, on the facilities being in compliance with the operating certificate and regulations.

The State office of Mental Retardation and Developmental Disabilities is about finished with a fiscal management and program inspection and review for recertification to qualify these private schools for the increased rate.

The Private School Review was un-

dertaken to determine if they are delivering the services required. If, in compliance, they will receive the \$900 per client per month.

The reason for the passage of this law was that there has been no increase in such private schools for a number of years in spite of rising inflation. Many private schools had made the practice of billing excess to parents, not contemplated under the law. The \$900 consists of SSI payments to which the residents are entitled and a state supplement under the social service law, as for hostels.





## Another supportive apartment

The Nassau County AHRC has opened another supportive living apartment. Residents of the apartment, located in Hempstead, take Nassau AHRC president, Leonard W. Olsen and Mrs. Olsen on a "cook's tour" of the kitchen. At present, Nassau AHRC has four community residences and five supportive living apartments. The organization recently acquired title to two additional homes for community residences and several other sites are in various stages of negotiation. Currently, each community residence accommodates seven to nine residents and two to three are housed in each apartment.

## LETTERS

### Poems from a Parent

Sharon M. Holt of Mechanicville, New York writes:

Being a parent of a handicapped child, I feel a need to express my feeling in some way to the other parents of handicapped children in addition to the many people who have a true interest in the many handicapped children and individuals in this world.

At this time I work in an insurance office, but my true interest is writing. I have so little to offer and through writing maybe I can give a parent of a handicapped child or a handicapped individual the perseverance to never give up.

These are the poems she offers to the readers of OCV:

#### "OH LITTLE ONE"

Oh little one, I will guide when you're lost.  
Oh little one, I will hear your cries and heal your hurt.  
Oh little one, I will see your tears and wipe them dry.  
Oh little one, I will help you reason when you cannot.

Oh little one, I will protect you from those who do not understand.  
Oh little one, whose mind is not as able and healthy as others.  
Oh little one, I will make your world a happy one.  
Oh little one, I will give my life to you.  
Oh little one, God has chosen to spare you so many perils of this world.

SMH

#### BIRTH

We give birth to them.

We mold them.

We build them.

Then why do we destroy them,

With lack of love.  
With lack of praise.  
With lack of time.  
With lack of understanding.

SMH

#### WHY

WHY HIM?

WHY ME?

WHY US?

Why does he not play like the others?

Why does he not learn like the others?

Why does he not speak like the others?

Only one being knows.

SMH

## HEW appreciation

### on Symposium

Robert D. Hankin, Regional Program Specialist Developmental Disabilities, Department of Health, Education and Welfare, writes to Joseph T. Weingold with thanks for the New York State Prevention Symposium held last fall:

Thank you for your report on the New York State Prevention Symposium last November. The New York State Association for Retarded Children is to be congratulated for a highly significant and successful conference. In addition to my own observations, I have already received considerable positive feedback around the state. Of course, the success of the conference will be best judged in light of the activity which will, or should, follow. At this time, a number of such actions are planned.

Again, I want to thank you for your fine efforts and also for the assistance of Geraldine Sherwood whose contributions were essential to the success of the symposium. We look forward to the continued involvement of NYSARC as we proceed to implement the recommendations.

## News and views

# Education Committee

by Betty Pendler

The Education Committee has reprints of articles which could be very useful for any chapter having membership meetings on the subject of the public school-parent-teacher relationship etc. We urge you to send for them and reproduce copies for your meeting. They are valuable tools for any workshop you may be planning — and remember our committee will be delighted to cooperate:

1. Parents-Power and Necessary Allies
2. Positive Attitudes - A Must for Special Education Public School
3. Parent Involvement-by Maynard Reynolds
4. Excerpt from Closer Look-Summer 1978 on Vocational Education
5. Recreation Programming for Developmentally Disabled School Children
6. How to be an Effective Member of a Committee on the Handicapped
7. How to Evaluate a School Program
8. Policies for the Development of a Written Individual Education Program
9. Parent and Professionals - Suggestions for the Professional
10. Parent and Professionals - Suggestions for the Parents
11. Writing to School Officials
12. Do you Know your ABC's
13. What you Need to Know about PL 94-142
14. Psychological Testing - Psychological Assessment
15. Where to Send for Valuable Information
16. A Checklist for an Individualized Education Plan
17. Information Check List for State Education Dept.
18. Mandated Parent Involvement — Reservoir or Swamp
19. Communicating with Parents - It Begins with Listening
20. Parent Professional Partnership - Parents Mishandling of Professionals - Professional Mishandling of Parents
21. How to Move Bureaucracies
22. How to Organize a Self Help Group in Schools
23. The IEP Dilemma - Obstacles to Implementation
24. Psychological Testing Questions and Answers
25. Parent School Conferences - Guidelines and Objectives

Do you have articles of interest that we can use for our booth at the next convention? Please send in any items of interest to our committee at the State Office —

All our literature from the Education Committee regarding parent - school relationships now has a spot on the shelf of the newly established Center for Parent Education, in the State Education Department. They have requested additional pamphlets, articles, interesting programs etc. on this subject to be sent to them for display in this new center. Send to: Ms. Bertha Campbell, Subcommittee on Parent Education, Dept. of Education, Room 365 Annex, Albany, NY 12234 - and, when you are in Albany, be sure to visit this new parent center library.

Does your chapter have an active education committee? Have you submitted the name of your Liaison yet? The Education Committee is working on a mailing list of names to whom we can send directly new information regarding regulations etc. There are some chapters who have not, as yet, given us this information. Won't you please take care of this to help establish a chapter to chapter network.

Columbia County Chapter has new client advocacy program - designed especially to reach those clients not previously served by the Association. Its major emphasis will be to help facilitate the providing of direct services to clients, especially those of school age. Future activities include the use of workshops to help instruct parents in becoming more effective advocates for their own children. Dr. Eugene Keeler, who has recently joined the ARC staff, and who has training in both law and clinical social work, will serve as the client advocate. Lenore Whitbeck of Columbia County has been working closely with Mr. Keeler, and has been distributing lots of material from the Education Committee. We hope other chapters will follow suit.

Herkimer County sees the importance of giving service to parents in dealing with the avalanche of laws, rules and regulations. We are happy to share their philosophy, with the hope that other chapters will follow suit. We feel the philosophical point of view expressed by Thomas Sprague, Executive Director of Herkimer County is the "raison d'être" of any education committee.

Reported by parents — a new book on Down's Syndrome: Parents have told us that they have found most helpful a new book called "The Child with Down's Syndrome — Causes, Characteristics and Acceptance" by Dr. David W. Smith and Ann Asper Wilson, W.B. Saunders Company, West Washington Square, Philadelphia, Penna. 19105 publisher — Price \$6.95.

The Eduletter continues to include items of interest to parents, teachers, administrators and other professionals. If you or anyone else you know would like to receive a free copy, please fill out coupon below. (Chapters... please reproduce this coupon in your own newsletter)

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

Name

Address

County

Te. No.

Chapter Affiliation

Return to:

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

## Pendler attends

### State Ed meeting

At the invitation of Education Commissioner Gordon M. Ambach, a very select group of parent organizations met early this year to discuss the problem of understanding the role of the parent. Betty Pendler, Chairperson of the Education Committee of the New York State Association for Retarded Children attended.

Pendler felt the association received excellent public relations out of this meeting because much of the discussion was focused on the need to change the climate in the public school towards special education — and helping all parents understand the problem.



# Sunmount Audit critical

Deficiencies ranging from improper drug inventory control in the Sunmount Developmental Center Pharmacy, to the lack of fire and theft insurance at the center's Community Store has been uncovered by an audit conducted by the New York State Department of Audit and Control.

According to State Comptroller Edward V. Regan, the field auditors made several major recommendations that include: tighter control of cash procedures, the locking of the pharmacy, which on several occasions field auditors found unlocked and the area unattended; better supervision of the physical count of food items taken monthly by food storeroom personnel; and a count of the linens which are received and distributed from the central storehouse where discrepancies showed a "potential inventory loss problem". Also coming under fire in the audit was the Greenhouse Operation which was to provide training and an opportunity to earn money to a maximum of 14 mentally disabled and handicapped persons including at least four Sunmount patients.

The agreement between the Office of Mental Retardation with the Citizens Advocate, Inc., a non-profit corporation, was to allow the operation of a greenhouse on the Sunmount grounds, with Sunmount paying the utility costs.

When the greenhouse was inspected by auditors, there were no center patients employed there, and there have not been since March 1978, according to the report.

The Tupper Lake facility came under attack in the audit by showing that eight substances including valium, tranxene, and phenobarbital were identified as a six-month plus supply, almost three times the inventory that was recorded as used during the previous 12 months.

The report recommended the pharmacy area be locked at all times and access to the area should be limited to authorized personnel only. They charged that on several occasions, besides finding the dispensing area unlocked and unattended, they found, on two unannounced night visits, that drug storage areas on the wards were behind unlocked doors, although the actual cabinets were locked.

The report also suggested that the keys to the pharmacy be stamped with the phrase "Do Not Duplicate" to preclude unauthorized keys being made.

Also studied by the auditors were the center's payroll where, for the 550 employees, the center's payroll procedures were described as generally "adequate". Funds appropriated for personal services for the 1978-79 fiscal year totalled \$7 million.

James E. Introne, acting commissioner, and other officials of the Office of Mental Retardation and Developmental Disabilities, responded to the review by agreeing with all the recommendations.

## Christmas card program is great success

The 1979 Christmas Card season sold 52,750 cards through our chapters and the State office.

Of these, 36,200 were the 1979 design and 16,550 from prior years. This, of course, is in addition to the commercial stock which was also offered to our chapters.

According to Ed License, chairman of our Scholarship and Awards Committee, one of the most gratifying aspects of the X-Mas card is the satisfaction of those who participate in the design competition and even win an award to two.

Continued from Page 1

strategy meetings held by otherwise dormant neighborhood associations. It means lawsuits to block group homes or simply, though again not cheaply, buying a prospective house before the state can disentangle its checkbook from its own red tape.

Simply put, the hidden war means entrenchment.

No fewer than seven legal actions in Westchester have been initiated in the county against homes in various parts of the county.

One neighbor claimed that the home represents an "institution for the feeble-minded," which local law also prohibits.

Last March, state Supreme Court Judge William Walsh, Jr., ruled that the home does conform to the meaning of the zoning code because the home is intended as a "generic family unit in a single housekeeping unit and is not classifiable as an institution".

Over and over again, the case of the City of White Plains versus Ferraioli, is quoted. Ruling in that case concluded: "An ordinance may restrict a residence to occupancy by stable families occupying single-family homes, but neither by express provision nor construction may it limit the definition of family to exclude a household which, in every way but in a biological sense, is a single family".

In Greenburgh there were five other types of group homes within a mile-radius of a home the state bought for the mentally retarded. The town argued in its lawsuit that such a large number alters the character of the neighborhood in violation of the state law. The Appellate Division ruled "There were no facts which would indicate that substantial alteration of the community would occur". The town is appealing the case.

In another town, the board sought to block a group home three years ago for eight retarded children, complaining that it was too close to a veterans administration hospital and a senior citizen complex. The board dropped its action only after the state agreed the home would be retained only for children and the safety precautions would be met.

When asked if little children should be excluded from living on a street because of traffic, the president of the homeowners association said "To compare young children who are watched by their parents with mature people who are physically disabled and questionably supervised is to mix apples with oranges."

Another increasingly used ploy is to form an 11th hour consortium to get the seller of the house designated for a group home before the state does.

In the face of public uncertainty, group home representatives invariably summarize the positive findings of a 1978 Princeton University study commissioned by the state on property values. This study, based on sample real estate values, included three Yonkers group homes.

Julian Wolpret, the professor who made the Princeton study, concludes in the report: "The proximity to group homes has no significant effect on property values. Properties next door, across the street or a few doors away from a group home have basically the same increase or decrease per month in value as measured by sales prices as properties farther away".

One opponent said at a meeting that he would move if the home was established — the home was established and he still hasn't moved and declines to comment publicly on his plans.

All this opposition has brought an avalanche of proposed legislation to limit the creation and establishment of group homes. One such bill is by Assemblyman William Finneran of Greenburgh, which

calls for as much as 25 percent assessment reduction for those with retarded neighbors. Another state Senate bill 2342, by Senator Rolison, Jr., of North Salem, would create a framework for homeowners to bring their cases for lower assessments before a local review board when a group home or similar facility would be located nearby.

Still other bills want to put the notice time up to 90 days, 6 months, or whatever.

After the establishment of such a group home, many of those who objected become ardent supporters of the program. For example, John Grogan, a New York advertising man, purchased a condominium for his family in Bronxville, never dreaming that a group home would move in next door at Christ's Church. But after a time, he became a firm proponent of the house and volunteers much time to helping the house.

Lest we think this is limited to Westchester, we have article after article in the press concerning other municipalities such as Onondaga which is appealing a state ruling on a group home.

In the Town of Lansing in Tompkins County the neighbors are "fighting hard." In Orange County, Town of Warwick, in Nassau County, lawsuits are now going on. In New York City, Queens, Staten Island, In Dutchess County, the town is fighting hard. In Millbrook and in Rochester.

So, the battle rages, but we are not without friends. For example, in Elmira, there were many who accepted the concept and make positive statements in that direction.



A woman in Yorktown projects the fury typical of the public outcry voiced against some group homes in Westchester. She was speaking out against one of seven proposed sites for group homes presented at a public hearing. A final decision on the location has not been made.

What is most encouraging is that the concept is gaining almost unanimous editorial support around the state. As, for example, an editorial in the Courier Express in Buffalo, "Fighting Fear of the Retarded" citing the need to educate people that their objections are not valid. What it really comes down to is what Joanne Wehling of Medina, New York writes in an attack on the Site Selection law "why are we obliged to warn residents, schedule special meetings, make excuses, apologize, and, in effect, justify what is a basic right?"

"Why are neighbors allowed to judge our people? Why are they allowed to discuss and question the legitimacy of our people's right to live wherever they want to?"

"Why are I. Q. levels a criterion for measuring fitness to live in a neighborhood? (Will 110 be considered undesirable someday? Will blue eyes be frowned upon?)" "And, would anyone, other than our retarded people, have to tolerate this flagrant abuse of constitutional rights?"

In this connection, we should like to quote from the column by Mike Healy of the Courier Express in Buffalo where he describes the experience of a Mr. Fred going to a town board meeting where a hostel or group home would be discussed. What is involved there, he finds out, is the proposed use of a piece of property at 100 Town Lane. The quote from the article is —

Fred sat up straight. That was the address of the house he and Mrs. Fred planned to buy. The head of the Town zoning committee shuffled through a file.

"There's no question that the sale to the proposed individual, one Fred and family, would be a clear violation of the zoning ordinances that apply to that neighborhood," said the zoning man. "The committee suggest we block the sale with a unanimous vote."

"Wait," said Fred jumping to his feet. "I'm the guy who's buying the house. What's the problem? It's a residential area, and that's all we want to do — reside there."

If you must know, said the chairman, 100 Town Lane is in a neighborhood zoned 'Residential - Master's Degree and above'. 'Do you have a Master's degree, sir?'

"Well, No," said Fred, taken aback. "But what does that have to do —"

"In fact, our records show that you had just better than a 'C' average in high school," and it says here your son, Young Fred, very nearly flunked arithmetic last year."

Fred was non-plussed.

"You mean to say we're not smart enough to live in the neighborhood," Fred asked.

"Fred, from our records, it looks like you're just not smart enough to be allowed to live in any neighborhood in the Town," said the chairman.

Finally, Fred is dragged from the meeting by two large sargeant-at-arms, chairman calling after him We have nothing against you or people of your IQ, but we feel the town has done enough for the Freds of the world. You and your family really wouldn't be happy here among the very smart. . ."

Where will this end until we establish the absolute constitutional rights of the retarded to live wherever they will?

## How advocacy works in Buffalo

In answer to your interest in the status of advocacy at the local chapter level: There are no problems in Buffalo. Advocacy is unheard of thanks to an innovative plan instituted by a special education director. The plan — "Systematic Intimidation" — is a sophisticated approach designed specifically for advocacy problems.

The theory for the plan is based on the director's understanding of the parent's psychological frailties. It is believed that parents of handicapped children have deep-seated feelings of guilt which is manifested in variable degrees by their submissiveness in dealing with ordinary problems.

Accordingly, the director classifies each parent on a scale from one to four which measures the varying amounts of submissiveness. Ones are submissive and docile whereas fours are "normal", have an average degree of aggressiveness.

From the director's perspective 'the problem' can be stated as a problem of modifying the behavior of twos, threes, and fours.



# Plea for sanity in M.R. Budget

In a plea for equity, protection of the rights of all retarded, and sanity in budgeting for services for the mentally retarded in the community, Joseph T. Weingold, Executive Director of the Association, made this statement while testifying before the Mental Hygiene and Addiction Control Committee of the Senate, Senator Frank Padavan, Chairman:

First, let me express my thanks to you for this opportunity to present to this committee, the point of view of the New York State Association of Retarded Children with regard to community services for the more than 500,000 mentally retarded in this state, and the budget before you.

With your indulgence, I should like to present to you a scenario for your consideration.

In this fictitious state of Ruritania, there exist 500,000 individuals termed "mentally retarded" who have had the fortune, or as we shall see later, the misfortune, of never having been placed in an institution under the care of the state. In that same state of Ruritania, these are some 14,000 persons who have had the fortune, or misfortune, to be placed in institutions under the care of the state.

Ruritania, in its wisdom, now says that of these 14,000, some 3,000 or 4,000 should not be in the institutions any longer and, having been in the institutions five years or more, should be placed in the community in group homes and with all the back up services they need.

And, to accomplish this purpose, the state has propounded a mechanism whereby the state pays 100 percent for all the services rendered to these persons in the community, whether by the state or by communities through community agencies.

But what of the half-million mentally retarded who have never been in institutions? For them, Ruritania says, "You, because you have never been in an institution, are half-citizens and we will only fund services for you at 50 percent. We don't care where the other 50 percent comes from."

This is what now exists in the state of New York and has existed since the de-institutionalization program, good as it may be, has been instituted.

I suggest to you that you would condemn the state of Ruritania as inhuman, discriminatory, uncivilized and, at the very least, unwise to treat citizens of that state in this manner.

But isn't that exactly what New York State is doing? Aren't you treating the mentally retarded never institutionalized as half-citizens? Doesn't the budget before you show this in a brutal way?

The budget shows some \$20,000,000 for local services for those half million never institutionalized as against \$25,000,000 for the handful under Chapter 620 of the de-institutionalized. Is this equitable? Shouldn't the legislature change this around and make sure that all are treated equally and pass the legislation that has been before you for years to equalize this treatment?

I suggest to you that in common decency, you have a moral and legal obligation to do this and we shall never rest until you do.

Much hullabaloo is being made about the deficiency budget which contains \$11,000,000 for acquisition, etc., for group homes for the mentally retarded. This is being attacked. Why? In this \$11,000,000 are some 50 group homes now in the pipeline that will die on the vine if this appropriation is not made. These are group homes not only for de-institutionalized but for those in the community as well. What is your rationale? Is it the desire of this committee and the legislature to kill all group homes? If not, what is the purpose of this negative approach?

I put it to you, the state and the community agencies, my own agency with a budget of almost \$60,000,000 for this coming year, has made, and is making, an enormous investment in training these individuals to be members of society. How wise is the state in saying we will do all this, but at the point where these individuals no longer have their own home to live in because their parents are too old or dead, we will stop and condemn them for the rest of their lives to a life of destitution, welfare and despair.

The failure to provide group homes means exactly what I have said here; and, I am talking about group homes for all. The budget provides some \$48,000,000 for ICF-MR's which are, as I understand it, group homes primarily for the 3,000 or 4,000 to be taken out of institutions, if that is possible. What of the hundreds of thousands in the community who also need group homes? This item should read "Group Homes" and they may be ICF-MR's or not ICF-MR's, depending on eligibility of the clients and the type of client that needs this kind of service according to regulations.

I want to make it crystal clear that we are not attacking the amount of \$100,000,000 in the local assistance budget.

What we want from this legislature, in fact, demand it as a right as citizens, is that those in the community, waiting for group homes, waiting for services, be treated equally with the several thousand who are to come out of institutions. We say that because a person has never been institutionalized those parents have kept them home at considerable sacrifice, should not be penalized for this social step. We say the legislature should pass the \$11,000,000 in the deficiency appropriation to make good on the promises of the state to the community agencies who have made commitments and even have expanded funds for which they are waiting. We say to this body and to the legislature, pass the bill that has been before you for years to make 100 percent funding for all the retarded, equalizing the treatment of those who have never been institutionalized with those who are institutionalized. We say provide enough funds for the creation of the group homes that we need and without which all the investment we are making will be for naught.

How this is financed, whether out of revenue funds or a bond issue, is up to the legislature. Put whatever restrictions you want on it, but provide the money to do it for all.

If you will permit me a personal digression, my own son, now 37 years of age, who should be leaving his home, has no place to go in Manhattan where he has lived all his life because you have deprived the Facilities Development Corporation of the acquisition funds to get a home for him in Manhattan. Does my son deserve this from you? Do his parents? Do other parents?

Finally, I want to make it clear that it is the position of this Association and of all those who are interested in human rights that mentally retarded persons who are not a danger to themselves or others have a right to live wherever they wish and without the restrictions placed upon them by restrictive laws and restrictive bills, even more restrictive than those in existence, now before the legislature. You would not dare to do this to other minorities. Would you dare to say to blacks that you must give notice to the community where you want to live; that there is too much proliferation of homes for blacks in this or that community?

If this presentation has sounded, and I dare say it has, rather emotional to you, it is because for thirty years, I have been identified with the millions of mentally retarded in this state and in the country. I have been identified on a personal and a professional level with their myriad of problems, too many of them brought about



Staff and residents of the Franklin County ARC pose in front of an Olympic - Special Olympic Snow Sculpture located on the grounds of Sunmount Developmental Center.

## Willowbrook audit

With all the emphasis on de-institutionalization, what is happening to the care of the mentally retarded in the institutions?

We report this editorial from the Staten Island Advance on the subject of Willowbrook:

The Staten Island Developmental Center in Willowbrook appears in recent years to have become almost as lax with administrative controls as it was with patient care standards prior to the issuance of a landmark federal court decree in 1975.

That conclusion can be drawn from a rather shocking audit report released by State Comptroller Edward Regan. Officials of the state Office of Mental Retardation and Developmental Disabilities are so red-faced at the study's documented findings of sloppy bookkeeping and inventory control they've already moved to implement virtually every one of the auditors' recommendations for improvement.

While it's reassuring to know the center's pharmacy no longer will stock drugs that haven't been used in 25 years and that other fiscal and inventory controls will be tightened, a disturbing question remains: How were procedures at the institution allowed to become so sloppy in the first place?

The audit suggests no answer to that question, and state mental health officials make no effort to justify or offer excuses for the sort of carelessness uncovered by Mr. Regan's auditors.

One possible explanation is that the state, under a court-ordered deadline to discharge all but 250 of the center's residents by next year, may have become so involved with the depopulation effort that its day-to-day administrative responsibilities were neglected in some cases.

But that raises another disturbing question: What will become of the thousands of persons moved out of Willowbrook, and other institutions like it, once the state's attentiveness to the crash depopulation program lapses?

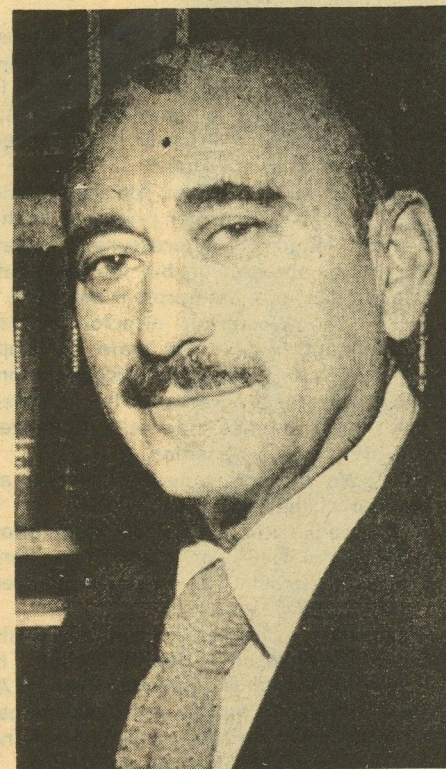
by the half-measures this state has provided for their development, safety, and life.

It seems to me that you have a tremendous opportunity this year to do only what is right. Let not New York State be labeled Ruritania."

That question has been asked with increasing frequency as the state's de-institutionalization program progresses, though there have yet to be any satisfactory answers from the state.

Mr. Regan's audit report, and others like it, have done an exceptional job of telling New Yorkers what's wrong with the Island developmental center. But until it's known why problems develop, and what's going to be done to make sure difficulties don't crop up in the manner in which the retarded and developmentally disabled are cared for undergoes a radical change, common sense suggests the state should not move too hastily to empty institutions.

The sort of problems uncovered at the Island Center can't be dismissed as an isolated bad dream. They recur so frequently that a pattern emerges, and it's one of a lingering nightmare.



WEINGOLD FIGHTS BACK

Joseph T. Weingold, Executive Director of the New York State ARC, was taken aback to see himself referred to in CARC News as a "grand old man" of the mental-retardation movement. He sent along this photo as proof that the News editor may have been overstating things a bit.



# Deinstitutionalization

## questioned by

## Welfare League

The principal advocacy group of retarded residents at Letchworth Village Developmental Center has urged state and federal agencies to reduce lofty goals for community placements and leave more persons institutionalized.

A position paper released by the Board of Directors of the center's Welfare League criticizes the state's five-year plan for trimming institutional populations in a plan not consonant with the needs of the retarded residents.

The critique goes on to say almost 90 percent of the facility's residents can be better served where they are.

League officials, representing parents and relatives of the residents, have taken this stand on previous occasions but they are now seeking to directly pressure the federal agencies which fund the deinstitutionalization program.

Letchworth is slated to lose more than 700 residents in less than 30 months, or one-third its present population.

The dual goals of the five-year plan, as promulgated by the Carey administration, are to save state funds and assure that residents live in the "least restrictive" environment possible. But Welfare League officials aren't sure that least restrictive means better.

In most cases, the position paper states, residents are not prepared for a community setting, cannot be moved to one near their families and are in danger of being transferred from one place to another.

The pressure to meet annual deadlines for deinstitutionalization and shortages of all classes of staff are adversely affecting the care with which residents are selected and prepared for placement, one residence to another as well as of returns to the institution. These are costly both to the resident, in terms of self-image and to the institution, in terms of money and staff morale.

Most of the placements that have been made until now, have met with Welfare League approval but the main concern is that most residents remaining at Letchworth are too retarded or handicapped to thrive "on the outside."

"We're moving too fast, too soon," said Dorothy Gasman, former president of the Welfare League. "The pressure has been to get the numbers out, but the ideal setting for many of these people is not there."

Dr. Oleh Wolansky, director of the Thiells facility and the state Developmental Disabilities Service Organization, which oversees programs for the retarded in all three counties, said he sympathizes with the League's position.

Dr. Wolansky has been replaced as director of the institution.

"Although 85 percent of our population comes from New York City, New York City, for all practical purposes, is not open to us" said Dr. Wolansky.

Another concern comes from the County Community Mental Health Center in Ramapo, through Dr. Bertram Pepper. As the center's director, he wants assurances of continued state funding before relying too heavily on one type of placement.

"One of the concerns" said Dr. Pepper, "is that the residents who are left are extremely handicapped. All of these people require extensive, hard-to-set-up community placements and programs."

In answer to these concerns in a letter to Ms. Bernice Volaski, President of the Welfare League, Commissioner James E. Introne wrote: "the current combined rate

of placement for Letchworth Village Developmental Center and Middletown Mental Retardation Unit approximates only nine per month, far less than the rate required to reduce the population to the targeted goals. This shows, I think, he wrote, our unwillingness to make community placements unless they are sound placements, even if it means not achieving our placement goals. I would also note that the percentage of unsuccessful placements is lower than it has been in past years, further evidence of the soundness of our programs. Yet, we must continue to pursue placements for clients who can benefit from a less-restrictive setting. Our information regarding client needs shows that many more Letchworth Village Developmental Center and Middletown Mental Retardation Unit residents should be in community programs.

I do agree with you that there is a group of residents whose level of care requires continued staffing at the Developmental Center. However, we must seek a more normal environment for these residents at Letchworth Village. This will only be possible with a reduction in population and extensive renovation to the physical plant. Our current plans call for a population of 1500 by 1981."

Commenting on this letter, a spokesman for the Welfare League said that Mr. Introne was begging the question. In fact, better care could be delivered at the Developmental Center if the staffing were properly adjusted instead of keeping the staff low to force deinstitutionalization and bring the population down to 1500.

### Friend to Friend

Protection and Advocacy System for Developmental Disabilities, Inc. has developed a new program called Friend to Friend. This program provides additional services for community and group home residents, including many Willowbrook Class members.

The program's purpose is to assist the developmentally disabled in meeting daily life needs such as marketing, attending a movie, and cooking a meal. Volunteers will be recruited from various agencies, community organizations and service programs to work one to one with disabled persons.

Activities will vary depending on specific personal needs. Volunteers will also share social and leisure time. In fact, PASDD will match volunteers with disabled persons on the basis of personal interests, hobbies and skills.

Based on the success of similar programs in other states, PASDD intends to develop the program throughout New York State. In addition, interested agencies and groups can receive assistance from PASDD in developing their own Friend to Friend programs.

Effective training programs and technical assistance materials have been created and will be available to volunteers and interested groups. The Friend to Friend program will train and supervise volunteers in methods of citizen advocacy.

Presently, PASDD is contracting community residences and service providers to present the Friend to Friend program to disabled persons and staff.

If you are interested in volunteering or want additional information contact Kimm Silverstein at PASDD.



At Welfare League's installation, Hy Clurfeld (1) Southeast Regional Vice President speaks with State Association Executive Director, Joseph Weingold.

## Legislature cuts Panel funds

In an act of frustration at the pressures of the Willowbrook decree, the state legislature removed the entire request of \$342,000 to continue the operations of the review panel.

The Review Panel then went to the federal judge to move that the Governor, the Commissioner of OMR-DD and Comptroller Edward Regan be held in contempt.

The federal judge ordered Governor Carey to ask the legislature for money to continue operations and ordered Regan to sign checks.

Governor Carey said he will not be held in contempt and will ask the Legislature to restore that item.

State Senator Frank Paedavan, chairman of the Senate's Mental Hygiene Committee, disagreed with Judge Bartel and called him "senile."

Senator Padavan said the panel forced the state into some questionable practices, such as placing small group of

"profoundly retarded youngsters" together in their own apartments, at a cost of about \$30,000 - \$60,000 per person.

"It's not the money," Senator Padavan said. "We have spent many times the \$3-million on the mentally retarded, but the panel has forced the state to do something that, in the opinion of experts, is clinically unwise and counterproductive."

He said the Willowbrook expenditures reduced money for programs involving other mentally retarded people.

This Association, a plaintiff in the action, has been opposed to the Composition of the review panel since inception but motions to replace members of the panel coming from other states with experts from New York State have been denied by the judge.

The New York State Association for Retarded Children, Inc., the major agency delivering services to the retarded now in this state, is not represented on the panel.

## High rise facilities for retarded criticized

The ARC, having sparked the move to empty state institutions like the former Willowbrook State School, is now having some second thoughts about the alternative facilities for severely retarded persons.

Joseph T. Weingold, Executive Director, said that profoundly retarded, multi-handicapped residents do not belong in high-rise apartments where, he said, they are being placed at the insistence of a court monitor.

The Association is a plaintiff in a legal action that resulted in a 1975 court decree mandating an end to the "warehousing of the retarded at state institutions".

Under discussion, was the placement of severely retarded with physical handicaps at Flower Fifth Ave. Hospital in apartments to house three residents.

"Unfortunately," said Weingold, "the Willowbrook Review Panel is out of touch with the real needs of the retarded." The housing of three in such apartments is not cost effective at all and certainly does not offer the necessary recreational and therapeutic services these persons need and are entitled to."

The new plan of Commissioner Introne is to reduce the population of Willowbrook to 250 by 1981. This is being resisted however, in spite of the Willowbrook decree, by the members of the Willowbrook Review Panel, who feel this is going too fast and

without proper consideration for the individual needs of the persons concerned.

In effect, are they not agreeing with the ARC at this point?

### Fund raising; a mother's view

This letter appeared in an Albany newspaper. It was written by a parent of a mentally retarded son and provides another view of fund raising for the retarded!

How does a mother of a mentally retarded son say thank you?

This "thank you" is on behalf of my son, Donald, and all the other clients at the Association for Retarded Children.

We recently had a swim-a-thon at the College of St. Rose. It turned out great. How great will be decided by the outcome of the money pledged. Then maybe ARC will get the kind of help that cerebral palsy, muscular dystrophy and multiple sclerosis get, not to mention all the others.

My son is not ready for a hostel yet. When the time comes and I'm no longer around, then I hope he has a home to live in like his own home — no institution.

We are just getting off the ground as you can see — so please, if you made a pledge send in your money.

Mildred Davis of  
Albany





Theater marquee tells success story of movie sponsored by New York City Chapter. Story on page 1.

## Four month old child wins educational funding

A family Court judge in Nassau has ruled that the state and county must pay the cost of educating a Down's Syndrome boy from the time he was four months old.

James Comer of Port Washington is believed to be the youngest handicapped person in the state to benefit from a law that originally was aimed at children three years old and up but gradually was extended to infants by judges around the state.

Family Court Judge William J. Dempsey ordered the state and county to pay \$900 in tuition costs to the boy's parents. The judge said that since the boy was four months old he had benefited from an "infant stimulation" program for children born with Down's syndrome, a genetic birth defect.

"All evidence supports the philosophy and concept that early intervention and efforts to educate a handicapped child of this type are a benefit," Dempsey said in his order.

State and local officials said the decision is in line with a growing trend during the past two years in which Family Court judges have lowered the age of eligibility to early infancy for training for the educationally handicapped. At the same time, costs of such training for the very young have skyrocketed. In New York State, costs have jumped to \$10 million, a

75 percent jump from last year, according to Lawrence Gloeckler, an official in the State Education Department. In Nassau, with 1,000 cases, and Suffolk, with about 700, the price tag went from \$1.8 million in 1977 to a projected cost of \$6 million this year.

Gloeckler said 700 children under three have been awarded tuition costs by Family Courts in the state in the past two years.

State education law requires local school districts to pay for the education of the educationally handicapped from age five to 21. The Family Court Act, however, requires that special-education costs for handicapped children under the age of five be shared equally by the county and the state.

However, some fiscal relief and tighter controls might be coming. State Sen. Kenneth La Valle (R-C-Port Jefferson), chairman of the higher education committee, said legislation soon will be introduced to "take the burden off the counties" and have the state assume the entire cost. The proposed law also would relieve the Family Courts of reviewing the cases. LaValle said a state agency would make decisions with "one eye on the dollar sign. Judges are never conscious of costs."

## College grant to help retarded

Columbia-Greene Community College has received a grant for \$32,000 over a two-year period for a project entitled "The College for Living" which provides community education to mentally retarded and developmentally disabled persons from Columbia and Greene Counties.

The grant, from the U.S. Department of Health, Education and Welfare, HEW, and awarded through the New York State Office of Mental Retardation and Developmental Disabilities, will allow the College for Living at Columbia-Greene to become an integral part of the overall programming for mentally retarded adults in the two counties.

The College for Living has run on a small scale for a little more than a year under the College's Human Services program.

The principal objective of the project will be to provide mentally retarded persons with skills for living and to help those clients make the transition to a less restricted, more independent environment.

# Doing business with the State

Doing business with the State is not an easy thing. This article by Gerald Goldberg appeared in the Buffalo Evening News and clearly demonstrates this. It needs no editorial comment:

Like most of us, William F. Holihan worked hard, paid his bills on time and was reasonably happy. Then he decided to do business with New York State.

After that, a bank went after him for late mortgage payments, utility companies hounded him for non-payment of bills, he couldn't get credit, he lost much time from work and he and his wife went through a tortuous year and a half of worry.

It all started in October 1978, when Mr. Holihan of 230 No. Spruce St., Batavia, moved out of his house at 22 Ross St. in Batavia. He had agreed to lease it to the state for use by the West Seneca Developmental Center as a Community residence for the mentally retarded.

In addition, he borrowed \$47,000 to rehabilitate the house so it would meet state standards for a community residence. The state was to reimburse him for the rehabilitation loan as well as pay him rent for the seven-bedroom, four-bath house.

But the checks never came. For five months, Mr. Holihan was forced to carry loan and mortgage payments of more than \$1,000 a month as well as paying the rent on his North Spruce Street home. Repeated calls to various state agencies didn't help.

"I heard it's coming, it was mailed out last week, all kinds of stuff," Mr. Holihan said. "In the meantime, I was paying late charges at the bank for the Ross Street mortgage, and the utilities were after me."

"I tried to open a couple of charge accounts at stores and couldn't. They have completely demolished my credit in this town."

Finally, in February 1979, five checks came at once. But as quickly as Mr. Holihan pulled even, he fell behind. He didn't see another check until July 19.

This time, he said, he was told he couldn't get his checks because the vouchers he submitted for repayment

didn't have his Social Security number.

"In June, I requested that the state buy the house because I couldn't afford to carry the State of New York anymore," said Mr. Holihan who works for a leather company. "The worries the state caused my wife and me have been devastating."

After many more calls to various agencies in Albany, Mr. Holihan said he was assured several times that the state had agreed to buy his house. The necessary information had been sent to the state Division of the Budget, he was assured.

In a letter to Lt. Gov. Mario M. Cuomo on Jan. 10, Mr. Holihan described the next amazing turn of events.

"In July, 1979, everyone told me it was going to budget," Mr. Holihan said. "You had all the papers. I made sure you (the state) have had everything when you asked for it."

"I kept checking. You kept lying, I finally called Assemblyman R. Stephen Hawley (R-Batavia). He found it sitting on a desk in Albany. It never got to budget. This was two weeks ago."

In the meantime, while still trying to sell his house to the state, Mr. Holihan was missing reimbursement payments for the rehabilitation loan and rent payments.

When he called Albany to find out what was the matter now, he was told his vouchers had been lost.

"Mr. Hawley said state people would contact me, but they haven't," Mr. Holihan said.

"Mr. Holihan said he is not sure who to blame, the Office of Mental Retardation, the State Facilities Development Corp., the Division of the Budget or some other agency. The West Seneca Developmental Center is about the only agency that has gone out of its way to try to help him, he said.

Now, finally, the state has begun to clean up the mess, Mr. Holihan said. Although he still hasn't been paid, he has received a letter from Mr. Cuomo's office saying officials are looking into the matter.

"They've started to make it up," Mr. Holihan said. "But not until I was buried."

## Education malpractice suits ruled out

The state's highest court has ruled that educational malpractice suits may not be allowed because such suits would allow every educational procedure to be brought before the courts.

The Court of Appeals in Albany Monday reversed a lower court decision that had awarded a New York City youth \$500,000 for having been improperly classified as retarded by the city school system.

The suit was filed by Daniel Hoffman, who entered kindergarten in September 1956 and, scoring 74 on an IQ test, was placed in a class for children with retarded mental development.

However, the psychologist recommended that Hoffman be retested within two years, noting that a speech defect made it difficult to assess his mental ability.

Instead, Hoffman continued in the city's program for retarded youths until 1968, when he was transferred to the Queens Occupational Training Center, a shop

training center for retarded youths.

His mother requested a retest and his IQ was determined to be 94, indicating he was not retarded.

A jury trial awarded the youth \$750,000, and the Appellate Division of the state Supreme Court confirmed, but reduced the award to \$500,000 saying the failure to retest Hoffman constituted an act of negligence.

## State grants aid youths

Grants totaling nearly \$1-million have been awarded to community agencies in Buffalo to combat juvenile delinquency, the state Division for Youth announced recently.

The Erie Co. Chapter of the State Association was the recipient of \$30,000 of these grants for a plan to provide comprehensive services for 24 youths who are mentally retarded and thought to be in danger of becoming delinquent.

## Do candidates realize handicapped vote?

Mrs. Carmella Critelli of Utica wondered if candidates are aware of the handicapped vote. She put her thoughts in writing:

It is interesting that the platforms of just about all candidates are sure to include some support for aid to senior citizens. Some of this support I am sure is sincere, and some I am suspicious of, although thankful for. However, I can't help but notice most of these same candidates seem to have overlooked the handicapped, especially the mentally retarded.

Seniors do vote, and some have become very active politically, however, I wonder if the candidates realize that every citizen over the age of 18 has the right to cast his or her vote on election day, no matter what mental ability they may have. The candidates are missing the boat. Every mentally retarded or physically handicapped individual over 18 is a potential vote. I wonder if we will see more programs for this minority now!



# Carey's health message ignores Symposium recommendations

*Ed Committee Booth*

In answer to an invitation from Robert D. Whalen, M.D., vice-president of the NYS Health Planning Commission, for suggestions for inclusion in the Governor's Fifth State of the Health Message, Executive Director Jerry Weingold, wrote the following letter:

"Dear Dr. Whalen:

This letter is in response to yours of December 21, 1979, requesting possible suggestions for inclusion in the Governor's Fifth Annual State of the Health Message.

One of the greatest, if not the greatest, health problem in this state is Mental Retardation and Developmental Disabilities. These include Cerebral Palsy, Epilepsy and Autism. Together, individuals with these disabilities number more than 500,000. They represent an enormous health, social and economic challenge.

All of us are well aware of the great network of services that has been developed in this state, in spite of inadequate funding and lack of community understanding. The essential attack, that of prevention, however, has not yet been mounted in force.

On November 18-20, 1979, the first Symposium on Prevention of Mental Retardation and Developmental Disabilities was held in this state. Sponsored by the New York State Association for Retarded Children, Inc., it was supported by grants from The Department of Health and Office of Mental Retardation and Developmental Disabilities as well as the Department of Health, Education and Welfare. An enormous body of knowledge on prevention was disclosed to the lay leaders and professionals participating. But what was clearly evident was that there is no coordinated plan for prevention of disabilities that cost the state billions over a short period of time and untold hardship and misery that cannot be measured in money only, to the families.

The final session of the Symposium recommended that the Governor create a Temporary Commission on Prevention of MR-DD to develop a plan of action and funding to decrease these disabilities by 50 percent within five years.

Yes, this sounds optimistic, but it is our firm belief it can be done, with the enormous resources and outstanding professionals in this field in this state and the support of the community on all levels.

We speak, for example, of the fetal-alcohol syndrome — the effects of teenage pregnancy — the use of drugs and how they affect the numbers of developmental disabled babies born each year, but it is evident these efforts are sometimes breastbeating, uncoordinated and certainly not action oriented.

If, in addition, we review the instruments now in our hands, such as amniocentesis, etc., our optimism, if such a commission is formed, seems to us, justified.

Sincerely,  
Joseph T. Weingold  
Executive Director

The Governor's State of the Health Message is a historic document ranging across the needs for health, prevention and safety of the most vulnerable parts of our society in this state. Priorities are serving the poor, the frail and the vulnerable in a social statement of the utmost significance.

The legislation the Governor proposes, for example, exempts sheltered workshops, operated or licensed by OVR, from labor law requirements which inhibit their expansion. It maintains protective employment opportunities for the handicapped. It backs a fee-for-service system for providers of community based services. It displays for the working poor, for the children and for all the needs of a population that cannot speak for itself. It is regrettable, however, from all the material that came out of our In-Service Training Program, the only part he chose to emphasize is this statement:

"to protect the particularly vulnerable segment of the infant population, I will propose the establishment of human breast-milk banks. These banks will provide essential nourishment to underweight babies whose mothers are unable to breast-feed and thus protect them from frequently fatal digestive disease associated with the ingestion of artificial food". It may also, as our Symposium brought out, prevent mental retardation through deprivation.

Worthy as this objective is, it is but an infinitesimal part of the many recommendations that came out of our Symposium — the most important of which was the creation of a Temporary Commission on Prevention of MR and DD to reduce the incidence of these disabilities by 50 percent by the year 1985.

We still hope the Governor will do this. That he did not, is unfortunate, especially in light of his important and significant State of the Health Message.

## Dr. Max Dubrow dies

Dr. Max Dubrow, the director of the AHRC workshop in New York City died recently of a heart ailment. He was 83-years old.

For 24 years, Max Dubrow was director of the workshop and the architect of its growth. The AHRC workshop now serves over 300 clients.

In speaking of Max Dubrow, Jerry Weingold, said:

"I remember Max when I first hired him to be the director of the workshop in 1954. At that time, I was the director of the New York City Chapter as well as the State Office. He headed up the research project for the first sheltered workshop for the mentally retarded in the United States. It was funded by a government grant to demonstrate that the mentally retarded can be rehabilitated vocationally.

Together, also, we held seminars at the workshop for people from all over the country about the elements of vocational rehabilitation of the mentally retarded under grants from Columbia University.

Max was a gentle man of enormous ability, working under extremely difficult conditions in the vocational rehabilitation of the mentally retarded with emotional problems. He was the friend of the retarded, a loved and respected person — professionally and as a human being. We miss him deeply."

Dr. Dubrow is survived by his wife, Susan; a son, Dr. Alan Dubrow and a sister, Lillian Simon.



At the Education Committee Booth at Convention. Left to right, Marylin Wessels, Sally Threw, Jon Weingold and Ellie Pattison.

## School district must pay for handicapped treatment

In a far-reaching ruling, the U. S. Office of Civil Rights has charged Connecticut Special Education regulations violated federal law because they don't require local school districts to pay medical and psychiatric treatment costs of handicapped children.

The agency has told the State Dept. of Education in Connecticut it must correct the violation within 90-days or risk the loss of federal funds.

This decision is being resisted by Connecticut's Education Dept.

State Education Commr. Mark R. Sheed has ordered a department review of all the state's special-education statutes and regulations to determine whether they're in compliance with federal law.

"I believe they are," Sheed said. "We have enormous respect for the Office of Civil Rights, but they're not always the last and highest word."

Civil Rights office may recommend to its parent Dept. of Health, Education and Welfare that federal funds be withheld, but it cannot take that action on its own.

The Federal Rehabilitation Act of 1974 requires state and local school districts to offer free, appropriate education and "related services" to the handicapped.

The question is what is the extent of these services?

The civil rights office cited the state's violations after investigating a complaint from the mother of a handicapped child.

The mother claimed her daughter had been denied psychiatric services illegally by the local school board; but the board doesn't believe it should have to pay for psychiatric treatment.

The school district agreed to have the child evaluated by a psychiatrist, but did not agree to fund whatever treatment might be recommended.

## How President's M.R. Committee is appointed

Is the name of Mrs. Janet Allen-Spilka of Utica familiar to you? Well, it should be because a recent press release stated that Mrs. Allen-Spilka was sworn in on January 24th as a member of the President's Committee on Mental Retardation and met President and Mrs. Carter at a White House luncheon that day.

How was she chosen? Well, Mayor Pawling of Utica said that her appointment to the Committee came out of a recommendation he made to President Carter in a telephone conversation last summer.

Now, isn't it wonderful that a citizen like that, of course the parent of a retarded child and even once active in our Oneida County Chapter, could be chosen under the recommendation of the Mayor of her city?

To help you understand this further, you must know that the Committee is charged with the responsibility of evaluating the adequacy of current practices in programs for the retarded and reviewing legislative proposals that affect the mentally retarded. It also coordinates federal agency activities in mental retardation, conducts studies of existing programs, highlights the need for changes, and promotes research. These committee functions are accomplished through task groups composed of committee members, and designated consultants approved by HEW.

Well, in any case, congratulations to Mrs. Janet Allen-Spilka. We dare say she will serve with as much distinction as other members on the Committee.



## Rensselaer runs successful Capital Fund Drive

1979 will be remembered as a significant year for many of our chapters for various reasons. For the Rensselaer ARC, 1979 will be remembered for its successful Capital Fund Drive.

Planning for the fund drive started several years ago, when the Rensselaer Chapter's Board of Directors and Executive Director, Jim Flanigan, realized that a Capital Fund Drive would be needed to finance a portion of the costs involved in the development of the ARC's new River Street Center as well as financing future development projects. In late 1978, approval for the fund drive was received from the local United Way. Planning began in earnest. James Fitzgibbons, retiring President of Hudson Valley Community College and a long-time friend of ARC, agree to take the Chairmanship of the Campaign. A six member steering committee was developed and met almost weekly during the early stages of the campaign. One of the major tasks of this steering committee was to develop a 23 member Advisory Committee, which would be utilized in approaching members of the business community for their support. A consultant, Douglas Alexander of Alexander & Associates, was retained and campaign materials were developed.

The Capital Fund Drive was divided into three sections: internal, external and special events. The internal area involved solicitations from the Board of Directors, members, families, employees and friends. As usual, those connected with the ARC family came through with their support. Over \$14,000 was raised in this area.

The external portion of the campaign involved solicitations from corporations, friends in the business community and foundations. The Steering Committee developed a list of over 100 corporate prospects. Advisory Committee members

selected individuals and corporations from this list that they would approach. Doug Alexander conducted several sessions in which Advisory Committee members became more familiar with the ARC's operations and the structure of the fund drive. As an interesting twist to the usual corporate solicitation process, Advisory Committee members were given the option of inviting a group of prospects to visit the ARC's River Street Center, tour the facility and have lunch prepared by the ARC's food service program. Fred Shenn, ARC Director of Adult Services, noted that this contact, in addition to supporting the fund drive, produced a number of leads for future sub-contract work as well as a higher visibility in the business community. Over \$61,000 has been raised in this area.

The final portion of the Capital Fund Drive, special events, involved a number of activities run for the benefit of the ARC. \$228 was brought in by a spaghetti supper run by a VFW Post in Poestenkill. A dinner-dance, sponsored by the Village Pals of Green Island, raised \$1,300. An old-timers softball game, conducted by the Troy Police Benevolent Association resulted in a \$200 contribution. The Capital District Bowling Council ran a special bowling event that brought in \$437. Finally, the ARC ran a swim-a-thon that raised over \$19,300.

As this issue of OCV goes to press the Rensselaer ARC Capital Fund Drive stands at over \$96,000. With a number of major corporate gifts still to be reported, ARC Executive Director Jim Flanigan expressed optimism that the drive would soon go over the original goal of \$100,000.

Chapters interested in further information on the Rensselaer ARC Capital Fund Drive are invited to contact Jim Flanigan at the Rensselaer ARC; 484 River Street, Troy, NY 12180.

## Rensselaer gets responses from Committees on Handicapped

Like many other ARC Chapters throughout New York State, the Rensselaer County Chapter has found in recent years that the population they serve has shifted from primarily school age children into the Pre-school and Adult Services areas. However, this Chapter has not forgotten completely the school age population, which can derive a great deal of benefit from the efforts of an ARC Chapter.

In addition to providing a primary emphasis on the school age population and their families in both the recreation program offerings and general membership meeting programs, which are held on a regular basis by the Rensselaer Chapter, the Chapter has also made an effort to establish ties with the members of the various Committees on the Handicapped throughout Rensselaer County.

One excellent vehicle for providing information to members of Committees on the Handicapped was a training session conducted for COH members by the Columbia Rensselaer Greene BOCES. James Flanigan, ARC Executive Director, was invited to speak as part of a panel at this training session.

In addition to explaining the reasons why the ARC no longer provided classes to elementary school age children, Flanigan also provided a great deal of information

regarding the Pre-school and Advocacy programs of the ARC and offered Committee on the Handicapped members an opportunity to be placed on the mailing list for the State ARC's Edu-Letter, which is written by the State ARC Education Committee. By providing slips which Committee on the Handicapped members could use to sign up for this publication and by pointing out that the price was right (FREE), virtually every member of a COH present at the training session signed up. A number of members even took along extra slips which they then gave to other COH members from their home district who were unable to attend the training session.

In commenting on this bit of advice, Jim Flanigan noted: "our Chapter feels that the Edu-Letter is a varying well written publication which, in addition to providing valuable information to parents, can also make educators sensitive to issues and perspectives of importance to parents. We would strongly recommend that other Chapters try a similar approach in getting more Committee on the Handicapped members on the mailing list for this fine publication. In cases where the local BOCES may not be conducting any specific training sessions for COH members, Chapters can still obtain listings of these members through the BOCES offices."



From left at Annual dinner dance, Rensselaer Chapter. . . Russell McGrath, President; Jim Flanigan, Executive Director; David Wilkie, former president; Ellie Pattison, state president and Ara Baligian, Unified Services Commissioner.



Seen at General membership meeting in Rensselaer from left, Bonnie Westendorf, Richard Newton, Sue Bonner, Carol Mason, State President Ellie Pattison and Margaret McEntee.



Present Rensselaer ARC work center (white building with clock) and DAV building (arrow) to be acquired.

## Tips on making committees work

Gary R. Morrow, Ph.D., a professor at the University of Rochester, reveals the results of his vital work in committee meeting studies. "The present paper," he writes, "represents a major methodological advance in our attempt to pioneer the breakthrough results" of his research. Here is a sampling of Professor Morrow's findings:

The raw data clotted into clear factors, centroids, clumps and-or elements:

The Number of Players: The maximum number of participants at any committee meeting at which a decision is made is one.

Morrow's First Measure: It takes two days multiplied by the number of committee members to find a mutually agreeable meeting time for the number of

committee members.

Morrow's Second Measure: The complexity of any problem decided by the committee is the inverse of the number of meetings devoted to it.

The prime mission of a committee member is to slough as much responsibility and work as possible while retaining as much authority as he can muster.

In masterly committee member fashion, Professor Morrow concludes his report: More research on this issue is needed. It's not clear exactly why, except that all articles end saying that more research is needed. Perhaps more research is needed on why more research seems always needed."



# From One Father.....

Almost 25 years ago in 1956 Joseph T. Weingold, Executive Director, wrote an article for *Children Limited*, the official newspaper of the then National Association for Retarded Children. In a letter sent with the article, he wrote:

By all means, let the women speak, but let the fathers also have a voice to air their point of view, their frustrations, their hopes, their approach, and in general give them a sense of belonging in the family scheme of things.

Too often have I seen guidance fail because the father is not involved; too often have I seen plans defeated because of the non-cooperation of the father; and often it is the father who shoulders the major portion of this burden to which mothers give such clear and continuous voice.

The entire article is reprinted here because what was true then is true now:

## FROM ONE FATHER

In order to allay all fears that another columnist is making his debut in *Children Limited*, let me say at the outset, this is not to be a regular column by "one" father. It would be presumptuous of me to speak for or to all fathers, but I am grateful for the opportunity to raise my voice this time on behalf of fathers of the mentally retarded.

Doing some research recently, I went through all the copies of *Children Limited* since it began and was struck by a rather odd phenomenon. All columns, except Editors Notes (and editors are notoriously anonymous when writing their views) were written by women, and, with the exception of our teenage friend, mothers of retarded children. Why, I wondered, weren't fathers impelled to write for CL. Or, perhaps they had never been invited. So I wrote a note to the Editor asking him about this.

"The columns of *Children Limited*," I wrote, "are replete with articles by mothers of retarded children, sisters of retarded children, etc. It has struck me, as I am sure it may have struck other readers, that nowhere is a regular column open to the father of a retarded child."

"Knowing me as you do, I am sure you will agree that I am not a misogynist. By all means let the women speak, but let the fathers also have a voice to air their point of view, their frustrations, their hopes, their approach, and in general give them a sense of belonging in the family scheme of things."

"Too often have I seen guidance fail because the father is not involved; too often have I seen plans defeated because of the non-cooperation of the father; and often it is the father who shoulders the major portion of this burden to which mothers give such clear and continuous voice."

Eric Sandahl promptly asked me to write the first column — sort of put up or shut up kind of thing (much more politely put). And here I am, for this column, at any rate.

This isn't a matter of black or white. It isn't the mother or the father. In different families the major role may be played by one or the other, but it is wrong to assume that because one is more vocal or even ostensibly shoulders the greater share of the problem, that the other is not deeply involved, feels most strongly, suffers as much, takes as great pride in the successes of the child and weeps the bitter tears of love and pity.

But to-day I speak for the fathers, for the fathers who reject their retarded children, for the fathers who accept, for the fathers whose ego has been deeply hurt, for the fathers whose tears the mores of our times channels into bitter privacy, for the fathers who feel doubly, for the child and the mother. It is important that fathers speak out, that they join actively in all the work that's being done, because without them the child has only half a hope. It is important to show all the seemingly disinterested fathers that there are those who have cast off despair as an unworthy garment. I suppose it is too much to hope that the father who aggressively rejects his mongoloid child for years and ends up by proudly coming to a father and son cub scout breakfast will write a column. But then, we don't get a column from the mother who beats her twenty year old retarded daughter for doing cleaning chores in our Workshop.

In my work I have seen and talked literally with several thousand parents. Mostly, because it is during the day the mothers come with the children, but frequently it is the father, and many times both the father and the mother. In almost every instance, the best and most enduring results in planning and counseling have been achieved when both parents are actively involved.

I get a feeling that, by and large, a stereotype of a father has been created that is only partially true, and that part must be hedged with innumerable qualifications. How many believe that the father's role is easier because he can shed the problem by escaping to the world of work; that he uses the work of the next day as an excuse not to get involved when he comes home at night. Have I set up a straw man? Correct me, please. From my experience this concept of the father does not jibe with the facts. This is something he carries with him always, even as the mother, and it lies even more heavily upon him whose duty it is to provide for the now and the future. It is he who wakes up in the middle of the night asking: have I enough insurance? What will happen to them when I am gone?

Well, I forgot that I can speak for one father only, myself, and those I have known personally. There are hundreds of examples I could give, and some would show fathers in a good light and some in a bad, but all will show that they are deeply involved in their child's handicap and are important in meeting its myriad problems.

Which brings me back to the reason for this column. Fathers must be asked to express themselves on a regular basis, as have the mothers. And so, with the Editor's permission, a call to fathers: talk to us and each other here in this column. Aren't you involved in guiding your adolescent retarded son in his sex education, in planning for his future, in deciding on institutionalization, in community work? And if not, why not. Here is the opportunity to let all know that you fellows are necessary, have something important to contribute as fathers (not as members of the Parent Group, or officers or committee chairmen or members) a something indispensable if we are to do what we have set ourselves to: make a better life for the mentally retarded.

## New Voc Rehab rules issued

The Rehabilitation Services Administration recently issued final regulations governing special procedures for designating a substitute agency to administer a state's vocational rehabilitation program when the federal government has withheld all funds from the previously designated state agency. The rules implement Section 102(b) of the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978 (P.L. 95-602).

Under the new regulations, published in the *Federal Register* on September 28, any public or nonprofit private subdivision of a state may apply to serve as the substitute agency. The federal Commissioner of Rehabilitation Services will then designate a substitute agency on the basis of a "competitive review" of proposals submitted by the applicants. After the selection process, the designated alternative agency will submit a substitute state VR plan which may be approved for either a three year period or the period of time remaining under the previous state plan.

In a preamble to the final rules, HEW said that it preferred administration of the state VR program by a sole state agency. The regulations, therefore, provide a mechanism by which the previously designated state agency may be redesignated. However, no automatic reconsideration period is established.

## Article Prompts Letter

An article on Deinstitutionalization, appearing in the *Syracuse Post Standard*, prompted this letter from Executive Director Joseph T. Weingold:

I fear that your article of December 13, 1979, "Deinstitutionalization" by Patricia Cappon, leaves a very erroneous impression that persons born retarded are completely neglected.

For example, the statement "The retarded have never had a home", says Gunnar Dybwad, a noted authority on mental retardation and a professor at Brandeis University, is a colossal insult to the parents of 98 percent of the mentally retarded born in this country and who live with their families with tender loving care.

Even at the height of the eugenic alarm of the Twentieth Century and the warehousing of people in institutions, even then, at least 95 percent of the mentally retarded lived at home.

What is wrong with our programs today is that heavy investment is made on bringing the retarded out of institutions (less than two percent of the retarded population) without a commensurate effort to provide continuing living arrangements for the retarded who spent all of their lives in the community but whose parents are too old or gone and cannot provide the home.

In New York State, there are now probably less than 15,000 in the institutions with a budget of about \$400,000,000 against more than 500,000 in the community with a budget of less than 10 percent of this amount spent by the state.

The point I am making is that the tail is wagging the dog and those who are supposed to be authorities should be careful of what they say.

## Priorities in placement

In a Summary of Project Placements for 1980-81 fiscal year, the state projects the following:

Out of the 3,835 placements they contemplate, 3,208 will be coming from developmental centers, Karl D. Warner and Flower Fifth Avenue.

Only 500 of this total will be direct community admissions.

But of these 3,835, about 1,800 will go into voluntary operated community residences or ICF-MR's.

Note, therefore, that the community will not even be given half the places for direct community admissions. Can anyone point out what is wrong with this picture?

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

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**Our Children's Voice**  
For Retarded Children and Their Families

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