

Our Children's Voice

Retarded Children Can Be Helped

Vol. XXX No. 2

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

June 1978

Carey budget short for community services

Commissioner for Mental Retardation Thomas A. Coughlin sharply criticized Governor Carey's budget for mandating massive resident transfers from Willowbrook Developmental Center and other large institutions for the retarded without adequately funding community-based programs.

Although lauding the plan to phase out the large centers by placing their residents in community facilities such as hostels, halfway houses and day care workshops, he said the proposed 1978 budget does not provide enough money for these community alternatives. There is a need to both absorb the additional clients and take care of mentally retarded persons now living at home and awaiting admission into small scale programs.

The New York State Association for Retarded Children, meanwhile, has also charged that the plan lacks adequate funding. Speaking on behalf of the Association which represents 58 Chapters in the State and 600,000 mentally retarded persons, Joseph T. Weingold, Executive Director, testified before the Senate Standing Committee on Finance and the Assembly Standing Committee on Ways and Means, early this year. These are some highlights from that statement:

The budget document states (P. 391) "The goal of the Office of Mental Retardation and Developmental Disabilities is a comprehensive system for the delivery of all services to the mentally retarded and developmentally disabled. To move toward this end, the new office will plan,

develop, coordinate, conduct and evaluate programs of prevention, care, rehabilitation, training and research for the benefit of the mentally retarded and developmentally disabled."

On the same page the statement is made, "They (the budget recommendations) represent a continuation of existing state program and fiscal policies aimed at increasing the emphasis on community-based programs and services and partially financing residential population."

Both of these statements are belied by what follows.

NUMBERS WITHOUT REASON

All we see in this budget are numbers thrown around without any backing or justification, such as 1350 people will be placed in the community out of the institutions during the year 1978-1979, with a total emphasis on "deinstitutionalization",

(whatever that may happen to mean, a slogan) with an almost total, if not immoral, disregard of the mentally retarded and developmentally disabled in this state who have never been in an institution.

Let us examine some of the figures that are being offered to us in this budget.

\$5,425,000 is recommended for the implementation of Sub-Chapter C (Medicaid reimbursement). This is a day treatment program for severely and profoundly retarded individuals representing a very small fraction of the totality of mental retardation.

\$3,015,000 for the purchase-of-service program. This is a fund almost entirely for those who are in institutions to prepare them for deinstitutionalization.

\$8,101,000 for family care program also for those who have been in institutions and are placed in the community.

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The Greenlawn hostel, before and after

Burned hostel not lost

A hostel for the mentally retarded, bitterly opposed by residents and destroyed by a suspicious fire is here to stay. Thomas Coughlin, the State Mental Hygiene Department's commissioner for the retarded, promised.

The house, in Greenlawn, Suffolk County, has been the focus of controversy since it was learned that it was to open as a hostel for about 10 retarded persons, most of whom are now living at the Kings Park Psychiatric Center. The house was to be operated by a couple under the direction of the Association for the Help of Retarded Children. The fire occurred after a number of threats were made to the couple, who had been living in the house but were away at the time of the fire.

Huntington Supervisor Kenneth Butterfield has said he will ask the town to sue the state in an effort to prevent that home and three others from being converted into hostels for the mentally retarded. Angry residents forced the cancellation of plans for a fifth hostel in Huntington. About 300 persons met at a local junior high school, and many said they feared the presence of the hostels would reduce the value of their homes.

Coughlin has blamed the Huntington town board for fostering an anti-hostel attitude among town residents, but Butterfield angrily charged Coughlin had not adequately informed residents of the state's plans and that they had turned to town officials for help.

While the officials argued, Joseph Ruocco, a psychologist whose 20 year old son, Jeff, is retarded, sat in his home at 6 White Deer Court, a block from the burned house, and shook his head in disbelief. "It's not a rational act," he said. He said the blaze, if deliberately set, was the work of "obviously disturbed people." His wife, Marilyn, had attended the meeting. "I didn't realize there was so much hostility" to the plans for the house, she said. "I was amazed."

Lionel Goulet, an elementary school principal said he also was shocked over the incident. "It's just a shame that people in this day and age would do a thing like that," he said.

Coughlin said the state will not abandon its plans to open a hostel in the house — on an acre of land and worth about \$100,000 — which was once the home of Gene Goodman, brother of musician Benny Goodman, and of philosopher John Dewey. "We own the land and it's a very nice piece of property," Coughlin said. He said he told the architect to see if it can be rebuilt. If not, he said, another house will be built on the site.

The state is attempting to open hostels throughout New York in order to reduce the number of retarded persons living in state institutions. The state plans to open two or three hostels in Nassau and six or seven in Suffolk by early this year.

Residence battles rage

Although the New York State Mental Hygiene Department's deinstitutionalization policy calls for a growing number of community residences for the mentally retarded, it has been rough going throughout the state. As the number of sites grows, so does the vehement, vocal and hostile reaction of prospective neighbors. Early this year, a suspicious fire in Greenlawn, Suffolk County, Long Island totally destroyed a house that had become a center of controversy since it was learned it was to open in February as a hostel for the mentally retarded. On the other side, many voices have been raised to protest the ignorance and violence in defending the residences and their purpose.

NEWARK RESIDENTS OPPOSE HOME

In the Finger Lakes community of Newark, more than 200 persons jammed a school gymnasium to hear Dr. Margerette Rogler, Director of Newark Developmental Center, explain the community centers' function. Another Center representative said, "Our philosophy is that every individual has the right to live in an environment that is the least restrictive possible." Many of the objections raised by residents expressed a fear for the safety of neighborhood children. Some expressed a feeling that the village is being forced to shoulder more than its fair share of dealing with the mentally disabled. "Why should Newark take all the responsibility of all the retarded of New York State?", a village policeman said.

"You could say, 'don't go into the pool', to one of the children and he wouldn't understand", said one resident living near a proposed hostel site in Orchard Park, near Buffalo. A year ago the ARC at-

tempted to establish a home nearby in Kings Court, but the town zoning board ruled ARC couldn't do it because Kings Court was in a residential zone of single family houses and that a house filled with more than five unrelated persons was not considered a single family house. The Deputy Town Attorney in Orchard Park cited this case, and suggested that, on that basis, the site presently under discussion would not be permissible. If the ARC continued, he said, the town board would resort to court proceedings to evict the ARC.

STORY REPEATED THROUGHOUT N.Y.S.

Throughout the state, the story is repeated. The characters may be different; the dialogue is essentially the same. In Crugers, Westchester County, the town board moved to seek a temporary restraining order to keep eight children from placement in group homes, with the step following being a permanent restraining order. Astoria residents came out en masse with angry demonstrations protesting the turning of a former apartment house into a group home. "We'll picket as long as we have to," said one member of the group, adding that the site is next to a church. Valley Stream in Nassau County has joined Hempstead and Freeport in confronting the Nassau County AHRC with 40 complaints against a residential hostel for 9 adults. A Flushing Civic Group said their community is "under siege" upon voting against a group home for retarded adults from Willowbrook. In Fishkill, a zoning board of appeals denied, by a three to two vote, an application for a lease to Dutchess County ARC.

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About Billy Conklin from About New York

(Reprinted from N.Y. Times)

At age 37, Billy Conklin has the kind of honest child's presence that could interrupt the Pope, as he did once.

Everybody was supposed to be reverentially quiet as John XXIII came into a Vatican room for an audience. Billy Conklin, hardly retarded socially, went over and said, "Hello John." The Pope, who stood about as tall as Billy, embraced him and said, "Questo il regno die cieli" — of such is the kingdom of heaven.

Years later, Billy Conklin's kingdom remains the earth, and it is not bad as he roams it. He was one of the first retarded persons in the city to be taught systematically to ride the subways and buses alone — a special virtue of the city that is widely used now by the moderately retarded.

His mother, Jessie, saw his resources when others didn't, back in the days when people tended to generalize pessimistically about the "mongoloid" retarded even more than they do now. She shopped around carefully and got Billy a job in an eyeglass shop on Nassau Street as a messenger.

She stayed on the job with him one week while he put his firm memory to work getting down the twists and turns of his job and its neighborhood. Then he was left on his own each work day and for the last 14 years he has made the trip back and forth from the Conklin home in Bay Ridge, Brooklyn. Abe Schwartz, his employer at Crystal Opticians, says there is no one like Billy. He says he is always helpful and on time and once when he was late he somehow managed to get a note from the subway conductor explaining the train was delayed.

Billy's father also says there is no one like Billy, that he'll always surprise you. He taught Billy to ride a bike in the dark, when there were not so many people on the streets to watch. That was years ago and the whole Conklin family has since become far less defensive, to put it mildly, about Billy. The father remembers when Billy's I.Q. was measured at 46 and he sees now it is measured at 71, so he is not that interested in the prescriptions of experts.

Billy gives a very plain and direct interview, walking on his lunch hour down Nassau Street and over to another eyeglass shop on Broadway run by his friend, Artie Gustafson. Billy stops and points to a visitor's pad. "Artie needs more business," he says. "Take that down, Times".

Billy stops to buy some hot-dogs, take-out, and carries them up to Artie's place of lenses and little boxes and polishing machinery. Artie, a gray-haired fatherly man, is busy and laughs at Billy's generous idea of promoting more business. Artie chats with Billy and does a little work, like every lunch hour. He helps Billy do lengthy crossword puzzles, nonsensically but happily. He gets Billy onto one of his favorite subjects, the Mets.

"The Mets," Billy says. "The Mets should get rid of Koosman," he says flatly of a hard-luck pitcher. "Take that down Times." He watches as you do.

Last week Billy had to go to Surrogate Court, and it was like the Vatican all over again because he suddenly decided to speak up to the judge. At Artie's place, Billy remembers word for word what he said: "I love my folks; I have a good home. That's the story of my life."

Artie likes that and Billy nods a little in proud emphasis, showing the retarded person's special unguarded smile.

The Surrogate Court can boggle the most sophisticated mind, and Billy's father found it annoying to be there at all. It seems there is something in the law that

requires the parents of a retarded person to go before the surrogate and be declared legal guardians of their offspring after the 18th birthday.

It was a formality of five minutes, the father said, but if overlooked, as often happens, it can prove costly later in estate management. A lawyer, of course, was required for the brief mission through the court, and a typical fee for this runs up to \$400.

After this experience it is only natural that Billy's father should have introduced a bill in the State Senate to change this, proposing that the burden be reversed with an affidavit procedure — and no lawyer's fee that continues the parents' as guardians unless someone successfully challenges this natural right in court. Billy's father is State Senator William T. Conklin, a non-lawyer who got into politics years ago in large part because of Billy, when the Conklins realized there was no great public awareness of the problem.

The Conklins helped organize the Guild for Exceptional Children in their local neighborhood and Mr. Conklin went on as a legislative lobbyist for the retarded and finally got elected to the Senate on this second try. He is the legislative expert in this field, serving now as deputy leader to the Republican majority. While he can be as foxy and partisan as any politician on some issues, he is feisty on retardation, making sure the Legislature has more than 40 retarded persons working in the capital as messengers and clerks, and pushing for the pioneer legislation requiring birth tests for PKU, the brain-damage disease.

The Senator's only regret about Billy seems to be that for the first four years the family took the traditional closet approach, wanting to believe the broken-hearted relatives' advice that of course he was normal, he just needed extra carrots or milk or something. Billy's first subway mission alone was a day of intense anxiety for the Conklins, but the recollection years later by the Senator is in terms of a great moment in the life of everyone.

Billy has never missed a transfer. "I take 'M' to DeKalb and take 'N' — no more Sea Beach — to 59th Street. RR to 77th Street and I walk home." Billy turns suddenly to Artie. "I met Artie's sister on the train. Artie, what's her name?"

"Mildred," Artie says.

Mildred," Billy says. "Take that down."

Advisory Council for Disabled named

Governor Hugh L. Carey has announced the appointment of 14 persons to the newly created Advisory Council on the Disabled which will work with the Advocate for the Disabled and state and local government agencies in dealing with the problems of the handicapped.

The council will study policies and programs that affect disabled persons assist the state in solving problems for the disabled, examine and coordinate governmental programs for the disabled, and assure compliance with programs to prohibit discrimination.

"This important council will work with Harold Unterberg, the state advocate for the disabled in eliminating obstacles to dignity and achievement that the disabled may face as a result of a government and society unaware of their needs," Governor Carey said. "They will help in the development of policies to meet the needs of the disabled and assure that services for the disabled are provided." The positions are unsalaried.



Groundbreaking for new construction

ARC President Elmer Muench and Executive Director, Michael J. Raymond really "put a lot of foot into it" as they break ground for construction of the new residential facility on Willard and Pardee Avenue in Jamestown, New York. It is expected to be occupied in about three months. From left: Board members John Real, Leslie Stanford, Mary Cogliano, Virginia Rugg (foreground), Eva Pryde, Marlayne Bergman; County Executive Joseph Gerace; Mrs. Elmer Muench (hidden); Lucy Alpaugh, Housing Director with Jamestown's Department of Development. Anthony Ingrao, on Hostel Committee; and Board Member, Fred Hitchcock.

Charles McAllister dies in Florida

Charles I. McAllister, 66, of Delmar, New York, retired Assistant Commissioner for Mental Retardation with the New York State Department of Mental Hygiene, died recently in Deland, Florida.

Born in the Bronx, New York, Mr. McAllister was educated at New York University. He started teaching the mentally retarded in 1936 in New York City. In 1947, he became supervisor of classes for retarded children of some 50 schools in Queens and Richmond counties.

In 1954, Mr. McAllister came to Albany to direct educational services for the retarded for the New York State Department of Mental Hygiene. In 1966, he was appointed assistant commissioner.

In 1956, along with Dean George J. Spears, he organized the graduate program for teachers of the mentally retarded at Russell Sage College. These courses have proved to be very popular and the enrollment has continuously been heavy since 1956.

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NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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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Continuing trend

Courts support group homes in residential neighborhoods

Though opposition to locating community residences for the mentally disabled in areas zoned for "single family use" has spawned much litigation, group homes have prevailed in four out of five recent cases challenging the establishment of group homes in residential areas.

Two superior court cases in Massachusetts have upheld the right of group homes to remain in residential neighborhoods under Massachusetts statute which prohibits municipalities from restricting, through zoning, the use of land for educational purposes. *Dynamic Action Residence Enterprises, Inc. v. Board of Appeals, Town of Mashpee*, and *Schonnings v. People's Church Home, Inc.*

The Massachusetts Courts have broadly defined "educational purposes" to include the activities of group homes. "Education is a broad and comprehensive term. It has been defined as the 'the process of developing and training the powers and capabilities of human beings.'" An institution which attempts to prepare its "clients for life and to assist them to solve the difficulties in adjusting to their parents" may be classified as an educational institution. It is interesting to note that, in upholding the plaintiff's right in the *Dynamic Action* case for a special zoning permit for its group-settlement home, the court found a permit could not be denied to the home because of its ineffectiveness in helping the residents. The quality of a program is to be monitored by the state licensing agent and is not the concern of zoning statutes.

The group home program involved in the *Schonnings* case was also held to have an educational purpose. These were emotionally disturbed adolescents with social and behavioral problems transferred from the Worcester State Hospital.

Two other cases upheld the location of group homes in districts permitting only single family dwellings under their local zoning ordinances . . . *Hessling et al vs.*

City of Broomfield et al, Colorado and Village of Freeport v. Association for the Help of Retarded Children, Nassau County Supreme Court. Both courts utilized the functional view of the family in order to accommodate the placement of group homes in single family areas.

The Supreme Court of Colorado, in upholding the proposed residence to be a family under the ordinance, emphasized that the important consideration is not a genetic or marital relationship among the persons residing in one dwelling, but whether the home is structured as a single housekeeping unit which is, "to all outward appearances a relatively normal, stable, and permanent family unit." They quote the *City of White Plains* against *Ferraioli*, a New York State case, 1974.

Contrary to the foregoing decisions, a federal district court in Florida has refused to permit a group home for the mentally retarded to operate within a "single family use" area. (*Palm Beach Hospital, Inc. v. City of West Palm Beach*, 1977.)

The plaintiff's group home housed ten retarded males, under the supervision of two sets of house parents. The city of West Palm Beach has an ordinance which prohibits more than five unrelated persons residing together in a single family dwelling. Plaintiff sued to enjoin the application of the single family zoning ordinance, arguing that the ordinance, on its face, and as applied to the plaintiff was violating the equal protection clause of the Fourteenth Amendment to the United States Constitution.

The court in this case rejected the plaintiff's contention, relying on the United States Supreme Court decision in *Village of Belle Terre v. Boraas*, 1973, where it was held that a zoning ordinance restricting living patterns in a village to single family residences was not arbitrary and unconstitutional as long as the ordinance was rationally related to a permissible state objective.

It is interesting to note that the Florida decision does not mention the Florida Statute, Section 393.15, which establishes a group-living home trust fund to stimulate the establishment of community-based group living homes for retarded, autistic and other developmentally disabled persons. Although specifying that loans from the trust fund will be made only to group homes which comply with local zoning regulations, the statute provides: "The Legislature finds and declares that the development of community-based treatment facilities for the retarded, autistic, or other developmentally disabled is desirable and recommended and should be encouraged and fostered by the state."

Efforts to get a bill passed in the New York State Legislature prohibiting the passage or implementation of zoning laws prohibiting the use of any residence for group homes for the mentally disabled have been unavailing. Senator Frank Padavan of Queens, the Chairman of the Mental Hygiene Committee of the Senate has opposed such legislation. In contrast, he has favored legislation which permits the local community to at least 40 days to find alternate sites where one is proposed for a group home for the mentally disabled.

It is interesting to note that the 1974 legislation introduced by Senator Flynn of Westchester, passed and signed, amends the Human Rights Law to prohibit discrimination in housing of any kind against a mentally or physically handicapped person.

Residence Battles

Continued from Page 1

NEWSPAPERS PRINT OTHER SIDE

As anti-hostel activity quickens, so do many voices in editorials, letters to newspapers, and feature articles:

"It's not OK. They have just as much right as anyone else to enjoy life. To get them out of institutions and into small, private family homes, the public has to be informed and educated about them. So for the sake of your fellow man, (even if he happens to be retarded), why don't you visit a local school for retarded children and see how these people really are. Why don't you give it a try? There are none so blind as those who will not see and in this area you are very blind."

In an open letter to the East Fishkill Zoning Board of Appeals, Charles Weatherford, Executive Director of the Dutchess County Association for Retarded Children wrote:

My concern is for the retarded citizens of Dutchess County. They are, as it were, being treated as "strangers in a strange land". I feel we must speak out for them as they are not capable of speaking out for themselves.

The retarded need group homes where they can carry on their lives in a normal way not permitted by institutionalization. The East Fishkill Zoning Board decision denies the right of the retarded to form family groups around professionally trained parents under professional supervision.

Laws should always be tempered with understanding and mercy and in this light I ask the three members of the East Fishkill Zoning Board who voted against these retarded citizens to remember the words of the master: "Even as you have done it unto the least of these my brethren, you have done it unto me."

Grumet states his goals

In response to a question from Mrs. Betty Pendler, Chairperson, Education Committee, New York State Association for Retarded Children, regarding his goals and objectives, Lou Grumet, newly appointed Assistant Commissioner for Education of Children with Handicapping Conditions wrote this in a letter to Mrs. Pendler:

You asked a most important question about my goals and objectives. I view the major assignment that I have been given as trying to make sure the worthwhile goals and objectives which were contained in 94-142 and Chapter 853 of the Laws of New York of 1976, as amended, are implemented. We have had a great deal of legislation and regulations during the past two to three years. We must now turn to making sure they work. The battlefield is shifting from the Congress and the Legislature to the individual schools, both public and private. We must make sure that the success of the individual education plans and the committees on the handicapped becomes reality and not just stated objectives. In order to do that, I think that my office should reach out to work with parents, educators, special educators, school administrators, finance administrators, unions and community groups to try to clear up the misunderstandings as to what the intent of the Law is and to make sure the interests of the children are paramount.

Chapters eligible for funds

In accordance with revised guidelines published in the October 25, 1977 and March 1, 1978 issues of the Federal Register, a new eligible activity for use of Community Development Funds is "Centers for the Handicapped".

According to the Federal Register, the term "Center for the Handicapped" means any single or multi-purpose facility which seeks to assist persons with physical, mental, and/or emotional impairments to become more functional members of the Community by providing programs or services which may include, but are not limited to, recreation, education, health care, social development, independent living, physical rehabilitation and vocational rehabilitation; but excluding any facility whose primary function is to provide residential care on a 24 hour a day basis "such as a group home or half-way house".

One Chapter that has already been able to take advantage of this new provision is the Rensselaer County ARC, which will be receiving \$1,500 in Community Development Funds from the City of Troy for its new River Street Adult Training Center. The process involved in obtaining these funds is somewhat elaborate, involving Public Hearings and a great deal of Community input. However, James Flanigan, Executive Director of the Rensselaer County ARC, noted that the neighborhood organization in which the new Work Center will be located worked very closely with this Chapter in development of the application.

Additional information on Community Development Funds should be available from either your City or County Planning Office or the Home Office of your Representative in Congress.

Bus Start



BUS START

These five new buses will be serving the Chautauqua County Association for Retarded Children. Michael J. Raymond, Executive Director of the ARC, and Louis Lombardo, Director of Education services took a look at the new vehicles. The buses will hold 20 passengers. They are being paid for as a part of a \$94,424 grant through the Urban Mass Transportation Administration and the state Department of Transportation. They will be used to transport clients to and from the Association's three Achievement Centers in Westfield, Dunkirk and Jamestown. Two of the buses are equipped with wheelchair lifts to accommodate the physically handicapped.

Weingold testifies

Governor designates Coughlin

The New York State Senate has confirmed the nomination of Thomas A. Coughlin, III, to head the new office of Mental Retardation and Developmental Disabilities. Governor Hugh L. Carey made the post effective April 1st, to coincide with the effective date of the law reorganizing the department and creating the office.

Coughlin joined the Department in October of 1975. Since that time he served as Chief Administrator of Programs for the mentally retarded and developmentally disabled in the state. Governor Carey especially praised his "effective leadership in implementing the Willowbrook Consent Decree and expanding community programs for the mentally retarded and developmentally disabled."

Before accepting his position with the state, Coughlin was Executive Director of the Jefferson County Association for Retarded Children Programs in Watertown. His reputation as a creator and innovative leader in developing programs for the mentally retarded was established there.

He has established an objective for the division of mental retardation which is successfully bringing great numbers of mentally retarded residents of the state's developmental centers, through a system of solid preparation, to eventual placement in a variety of community residential programs. He has also implemented a program to greatly upgrade the state's residential facilities. His model approach has gained approval and national recognition from the Federal government.

In his statement at the hearing on the confirmation of Tom Coughlin, Joseph Weingold, Executive Director of the New York State Association for Retarded Children, spoke of his long association with Mr. Coughlin. This is a portion of his statement at the hearing:

What we need in this position is a man with all of Tom Coughlin's qualifications, but also with the fortitude, guts if you will, to stand up to the system, to the Governor's advisor, to Budget, yes, even the Legislature and say, "This is the right thing to do! I am supported in this by the people who are concerned, the parents, and this is what must be done without further considerations."

These are the questions that we must still ask and they are not yet answered.

Are we going to continue to finance services for less than 2 per cent of the population at 100 per cent with almost \$400 million for the institutions and "deinstitutionalization" program, with only 50 per cent for the 98 per cent who are in the community, or are we going to redress this imbalance and finance all at the same level?

Willowbrook name change

A tongue in cheek communication to all chapters was sent by Joseph Weingold, Executive Director:

I cannot resist telling all of you that the Legislature passed, and the Governor signed, earthshaking legislation. It is Chapter 923, Laws of 1978, the first dealing with mental retardation. It changes the name of Willowbrook Developmental Center to Staten Island Developmental Center. Congratulations all!

The rose has been transformed.

Are we going to accept blindly the "least restrictive environment" principle or are we going to say that this means the least restrictive environment in terms of the needs of the client?

Are we going to say that a family care home, where a man is tied to a chair and beaten with a lead pipe is the least restrictive environment in relation to the institution from which he came? Or, are we going to determine this on the basis of the needs of the person and try to make wherever he should be, in or out of the institution, the best and least restrictive environment?

Are we to continue in a headstrong rush for "deinstitutionalization" as last demonstrated in Suffolk County, or are there going to be stricter controls over the local employees of the Department to prevent what happened there? Is mental retardation going to be tarred with the brush of mental illness where some 60,000 were dumped into the community without services and the state, ex post facto, is beginning to think of service managers, or are we going to prevent this be a reasoned approach and well funded back up programs in advance?

Are we, indeed, going to find out what the unmet needs are in this state and provide the funds to create the day services necessary if we are to place people into the community, or are we just going to hope and leave it to the almost bankrupt voluntary agencies to carry this immense

burden with little help? In other words, whoever the commissioner is, what we need is a man ready to answer these questions, not as an individual, but as a commissioner. And the answers must include, not only, "Yes, of course" — but how.

I cannot put the blame entirely on the executive branch of government, because the legislative branch has a co-equal responsibility in many ways with regard to appropriations and oversight. The appropriation process is not what it should be. The Legislature could control many of these things that I have mentioned here through its hold on the purse strings. In my opinion, they have not done so.

So, what we are engaged in here is not a simple process of saying Tom Coughlin is a good man, he can do a good job, and should be confirmed. I firmly believe no one better than Tom Coughlin could have been designated for this immense challenging task; that really is not the question.

What we should be doing here is having a hearing on the confirmation of the Governor and his advisor as to their commitments for doing this, and their ability to carry out what we think is needed. And that is what I hope this committee will do. As for Tom, I endorse him. I don't think I am doing him any favors. We shall dog his footsteps every inch of the way along this arduous, perhaps impossible, path.

Facilities, space needed, Voc Rehab survey shows

A recent survey of the anticipated space requirements to service those on the waiting lists and projected client increases both from the developmental centers and the communities by the chapters of the Association revealed there is a need for 400,000 more square feet of space for the year 1978-1979. A survey was conducted by Geraldine Sherwood under the direction of Evald Gasstrom, Chairman of the Vocational Rehabilitation Committee.

These figures are on the basis of 37 chapters who responded to the survey (14 chapters thought it was non-applicable, 9 chapters did not respond). The current waiting list of the 37 chapters is 866

mentally retarded adults. The projected client increase in the community for '78-'79 is 1177, and discharges from the developmental centers, 1200 or a total of 3,143 additional clients.

The absolute minimum space requirement is 125 square feet per client, hence with a 400,000 square foot estimate the Governor's budget of \$1,200,000 for capital construction is inadequate.

It is the contention of the Governor's office that this need for space can be met by way of lease, remodeling, etc. rather than construction. We look forward to this if, indeed, we are to have the back-up services for the retarded adults both in the community and from the institutions.

Tennis exhibit for retarded

A clinic and an exhibition match featuring Arthur Ashe and Dick Stockton was held at the Olean Racquet Club recently and was sponsored by and for the Association for Retarded Children. Tickets sold for \$25 each.

The afternoon event, including clinic, match and social hours ran 5 to 6 hours.

A crowd of almost 1500 viewed the exhibition and filled the bleachers around the indoor tennis court.

Ashe is well known for participating in benefit matches for charity. Stockton defeated Jimmy Connors in the U.S. Pro Indoor Tournament and has 20 national junior titles, more than any player in history.

Not only did the event help develop tennis in the area, it was a great and inventive fund raiser for the Cattaraugus County ARC.

Service purchase contract revised

The purchase of service contracts have been revised to afford the greatest possible service to the clients and, at the same time, minimize the financial dangers to the chapters of the Association entering into such contracts.

Under purchase of service contracts, the ARC chapters agree to serve in day programs a certain number of clients residing in institutions plus a certain number who are in the community and "at risk" of institutionalization. Under this the Department of Mental Hygiene pays the full cost. The objective, of course, is to make clients ready for placement in the community and transfer them from the purchase of service to 620 funding.

Under the old contract, the budgets were broken down into a per diem basis. The danger of this was that if the referring agency (the developmental center) for some reason or other did not send clients or if the clients were absent for any period of time due to conditions not under the control of anyone, the Audit and Control could come in at the end of the period and charge back to the agency days when clients were not present. This was a disastrous course.

In addition, the method of payment was such that the agencies had to borrow money or have money in the till to finance the state.

After a lengthy negotiation with Tom Coughlin, it was agreed that the contract would prefer a guarantee of the number of referrals to be sent by the sending agency and that the ARC or the contracting agency would be paid whether or not referrals are made.

With regard to absences, it was agreed that there would be an unexplained 20 per cent allowance for absences.

It was also agreed that, where there is a dispute between the sending agency and the ARC as to the appropriateness of a referral, this would be decided by the Commissioner or his designee.

Satisfactory arrangements were also reached on the method of payment and the inclusion of some part of some interest in the budget where the agency has to borrow money in order to finance the operation, pending the processing of vouchers.

This was an excellent example of cooperation between the ARC and the Dept. of Mental Hygiene, Office of Mental Retardation, but it does not solve the basic problem of community support where we still feel very strongly that the state should be putting up at least 75 per cent instead of the present 50 per cent. Until this is done, it is the opinion of your executive director, that we will be picking up band-aids to help a basic situation of under-funding by the state.

Retarded to fill defense contract

The money attained from two grants will be used to develop job potential among the handicapped in Chautauqua County.

More than 40,000 tent pins will be manufactured for the U.S. Defense Department at the Jamestown Achievement Center after machinery is purchased with a \$55,000 Gebbie Foundation Grant. This is the first attempt by the Association for Retarded Children (ARC) at federal subcontracting and the pins will be made by handicapped employees.

The machinery will mean employment for 40-50 handicapped workers and 20-25 non-handicapped employees.

Executive Director of the ARC Michael Raymond said, "I am extremely pleased

with the Gebbie Foundation decision to grant this money to the ARC. The purchase of the machinery is one of the final hurdles to be negotiated in fulfilling the requirements for this federal contract. I would like to express my appreciation and that of the entire board of directors for this generous grant."

The ARC will also accept a grant of \$12,334 from the New York State Education Department's Office of Vocational Rehabilitation. Equipment will be purchased that will evaluate areas of job exploration and job potential. Raymond said, "This will give the ARC the ability to do the most thorough vocational evaluation of any agency in Western New York."

Minority report disagrees

Natl. task force re-defines D.D.

A national task force, consisting of representation of consumer, provider and professional groups as well as state agency officials, recently completed a year-long study of the definition of the term developmental disabilities. The purpose of this independent study, mandated under Section 301 (b) of the Developmental Disabled Assistance and Bill of Rights Act of 1975 (P.L. 94-103) was to advise Congress on the types of disabled individuals who should be considered eligible for assistance under the federal-state Developmental Disabilities program.

Ever since the Developmental Disabilities Act was initially enacted in 1970, the question of how the central term should be defined has been an issue of considerable controversy. The definition in the original act specifically referenced mental retardation, cerebral palsy and epilepsy, but also gave the Secretary of Health, Education and Welfare discretion to declare persons with other neurological conditions "closely related to mental retardation", or requiring similar treatment, services eligible to share in the benefits of the Act. After considerable attempts, HEW officials decided there were no clear grounds for defining any etiological syndrome as a developmental disability other than those associated with mental retardation, cerebral palsy and epilepsy. Thus, neurological categories as such were eliminated.

In the 1975 amendments to the Act, Congress added autism and dyslexia to the list of covered conditions (but the latter only when it was associated with MR, CP, epilepsy or autism) and dropped the reference to "other neurological conditions".

ABT Associates, a non-profit social research firm based in Cambridge, Massachusetts, was selected by HEW's Developmental Disabilities Office to conduct the definition study.

The 47 member National Task Force on this definition included no representatives for mental retardation from the State of New York that anyone connected with mental retardation could recognize.

Based on three two day meetings held over an eight month period, the Task Force, with the assistance of ABT staff, finally arrived at recommended definitions which in fact eliminated all categories which said "is attributable to a mental or physical impairment or combination of mental or physical impairment". This approach of the majority of the Task Force for a purely functional approach in definition was contradicted by a minority report, however, on behalf of approximately one-third of the Task Force members who accepted the definition except for the opening section "attributable to mental or physical impairment". The minority said that the program cannot be successfully administered without identifiable categories of disabilities and recommended "is attributable to mental retardation, cerebral palsy, epilepsy, or autism: or is attributable to any other condition of a person similar to mental retardation, cerebral palsy, epilepsy or autism because such condition results in similar impairment of general intellectual functioning or adaptive behavior and requires treatment and services similar to those required for such persons."

Various pieces of legislation have been introduced in Congress, the most likely to

succeed being the one that continues developmental disabilities with no change in the definition.

According to a spokesman of the New York State Association for Retarded Children, to broaden the definition to include all categories of mental and physical handicap would be to dilute this system which is already diluted from the original legislation passed under President Kennedy which dealt with mental retardation only. Furthermore, said the spokesman, the mentally retarded and emotionally disturbed are not being included under the laws providing assistance to the physically handicapped.

It is unfortunate that this study was made without real input from agencies such as the ARC dealing with this problem on a day-to-day basis and year after year, and long before the D.D. Act was passed.

Jacqueline Fenn Client of Year

Jacqueline Fenn a client at the Dutchess County ARC, has been named client of the year by the Mid-Hudson National Rehabilitation Association.

Jacqueline is 31 years old, severely disabled and is confined to a wheelchair. After two referrals to the office of vocational rehabilitation, Jacqueline was finally placed at the Dutchess County ARC. At that time, architectural barriers did not permit the ARC to take the clients in wheelchairs. They also realized they would have a major task in trying to find transportation for her for the 25 mile ride to the workshop. It appeared there would be little the chapter could do for her.

Finally, she was accepted in early 1976. After medical examinations, the doctors report included this statement: "I personally do not feel that further gains could be obtained. . . I wonder how much, if anything, she can do in a workshop".

He did make a recommendation that she be evaluated at Sunnyfield but stated he felt her potential was very "minimal". But the ARC gave her a chance and she began her program in early 1976. She was transported in a wheelchair van.

Although the evaluation indicated that she would not be able to use an electric chair because of poor perceptual motor skills, the Dutchess County Chapter of the American Cancer Society loaned Jackie an electric chair with which she practiced in the workshop. Within a very short time, she could manage an electric chair adequately and the office of vocational rehabilitation ordered an electric wheelchair for her to use at the workshop.

Through the cooperation of many agencies and her own determination, Jacqueline Fenn has been able to move from being at home with nothing to do but watch television, to become a quite successful sheltered worker. She has learned to master her electric wheelchair so well she sometimes now serves as a messenger at the ARC and she now sees herself as a "worker".

In spite of her many difficulties, she is always happy and smiling. Her achievement is a most significant one and we congratulate Jacqueline Fenn on being named Client of the Year.



Padavan honored by Letchworth

State Senator Frank Padavan, center, chairman of the Senate Committee on Mental Hygiene, is honored during recent ceremonies at the annual luncheon of the Letchworth Developmental Center Welfare League, a chapter of the State Association for Retarded Children. At left, George Hirsch, president of the State Association, joined by Dorothy W. Gasman, right, president of the League, in citing the Senator's efforts to improve programs for the mentally handicapped.

Legislation proposes to transfer voc rehab from education to executive

Reacting to the almost universal accusation that the State Department of Education has been treating vocational rehabilitation as a stepchild over the years, Senator Donovan and Assemblyman Kremer have introduced legislation (S.8864; A. 12162) removing vocational rehabilitation from the Department of Education and creating a vocational rehabilitation board in the Executive Department. In a statement issued by Assemblyman Perry Duryea, he said "Vocational Rehabilitation has been the stepchild of the State's efforts to provide employment services to handicapped individuals and to assist communities in the development of critically-needed rehabilitation resources. Currently these programs are operated in a fragmented fashion by at least six state agencies, the federal government, local rehabilitation facilities and community services and health agencies.

"The new era of advocacy for the handicapped requires a visible and accessible focal point for the needs of clients, providers and communities.

"The magnitude and potential of these rehabilitative services require creation of a single agency which would directly reflect the priority and needs of our physically-mentally-handicapped to the Governor and Legislature," Mr. Duryea

said. "It is unreasonable to expect these needs to be adequately communicated when they must compete with educational programs in the State Education Department, which administers the services through a series of agreements and arrangements with Departments of Mental Hygiene, Correctional Services, Social Services, Labor and other state agencies."

The Office of Vocational Rehabilitation is moving in the direction of aiding the agencies delivering services by increasing fees for long term employment of the handicapped (SEP) which has received no increase since its inception 6 years ago.

Furthermore, the Office of Vocational Rehabilitation recently set up an order of priorities concentrating on the severely handicapped to the exclusion of others because they said they lacked \$8 million to complete the year. Suddenly, when the Coalition of Rehabilitation Agencies issued a strong protest on behalf of all the rehabilitation agencies, in fact at one point almost threatening to cut off services, the Education Department found the funds to serve all the handicapped as required by State law.

This Association backs the move to remove Vocational Rehabilitation from the Education Department which has shown its inability to cope with the problem in a responsible fiscal manner.

Grumet appointed

The appointment of Mr. Louis Grumet, of Albany, to the position of Assistant Commissioner for Education of Children with Handicapping Conditions, was announced November 18, 1977, by Commissioner Gordon Ambach, effective December 1, 1977. In announcing the appointment, Commissioner Ambach stated: "He will bring to our Department strong experience in developing interagency relationships for the administration of State programs. This is particularly important to handle the new State statutes authorizing Education Department

supervision of education programs in administering field services and programs as complex as services for children with handicapping conditions."

Mr. Grumet has had broad experience in State government in the administration of programs, including the organization of the Advocate Office for Disabled Individuals, the Council for Disabled Individuals, and was responsible for preparing the State's position for the White House Conference on Handicapped Individuals.

Pipe beating of retarded man prompts need for reassessment

On Jan. 18th and 19th, 1978, articles appeared in a Syracuse newspaper to the effect that a retarded man was found, tied, and beaten with a lead pipe. The article went on to say that the retarded man had at one time been a resident of Rome Developmental Center and that his records were being hunted by the D.A.'s office who was investigating and he couldn't, up to this point, find the records. Cornelius Walsh, director of Rome Developmental Center said that his office had had no contact with the former resident since he was "terminated from our roles in November 1973."

He escaped from Rome in May 1973 but was picked up by the State Police later that month and returned to the Rome facility from which he was released when an investigation showed the care he was receiving as a resident in the community was adequate. When deputies in the sheriff's office arrived at a rural house in the southwestern corner of Onondaga County to investigate a report of family disturbance, they found a retarded man, 31 years of age, tied to a chair in the kitchen. He was bleeding from his right ear and had numerous bruises about his face and head.

In another room deputies said they found a home owner's live-in housekeeper apparently passed out on the floor. She had a steel pipe in her hand, the deputies reported. Around here there were numerous sickly-looking dogs, cats and chickens were running about."

The home owner — legal guardian of the retarded man, apparently, was away from the house during the investigation.

The deputies aroused the woman and questioned her and the retarded man. They learned that 10 cats, 2 dogs, 4 chickens and a pig were allowed in the house during the Winter — but the retarded man was not. It was reported that he slept in a junked station wagon, one of some one hundred cars in the yard around the house. It was also reported that the "guardian" beat his charge about once a day, and sometimes twice "when he was in a bad mood".

The retarded man was removed and placed with a family in Syracuse later that week. It was in reaction to this that Mr. Weingold wrote to Senator Frank Padavan enclosing the articles, stating "I feel at this point the preparation has been sketchy to say the least, in preparing facilities for the deinstitutionalization of the mentally retarded. This may also be true for the mentally ill."

The letter also mentioned that about nine months ago Mr. Weingold had suggested a moratorium on such placements in order to see what is being done in the community for these people before they are placed. At the end of the letter Mr. Weingold said, "This matter should be followed up very strongly. Perhaps it would be well to have a public hearing on this issue soon."

This letter was not answered by Senator Padavan, or Assemblywoman Connelly, to whom it was addressed. The letter, however, found its way into the S.I. Advance and elicited a sharp comment from Dr. James Clements, Chairman of the Willowbrook Review Panel. His letter follows: "Dear Mr. Weingold: The Willowbrook Review Panel has read with shocked amazement your letter dated January 23, 1978 to Senator Frank Padavan calling for a moratorium on community placements. It is our belief that your call for and support of a moratorium on community placements can only be destructive to the goals we all work

so hard to achieve, the establishment and maintenance of a quality community based system of services for the mentally retarded. It would also, of course, result in a violation of the Willowbrook Consent Judgment and the Court's Order of March 10, 1977.

"Our monitoring activities have clearly established that overall, community placements under the Consent Judgment have been of good quality. As you are a named plaintiff in the Willowbrook case, you and your counsel are routinely provided with our reports in this connection. Further, we have had no complaints from your organization to date, serious enough to support a moratorium.

"We would appreciate receiving any documentation you may have of your complaints so that we may further evaluate your position and take appropriate action within our jurisdiction. Sincerely, James Clements M.D."

In reply to this Mr. Weingold answered Dr. Clements:

"The shock and amazement of the Willowbrook Review Panel regarding my letter to Senator Padavan calling for a moratorium on community placements is misdirected. Your shock, if not amazement, should be directed towards situations such as the one reported in the Syracuse newspapers on the beating with a lead pipe of a mentally retarded 31 year old male, a former resident of Rome Developmental Center by his, what seems to be, family care provider; your shock and amazement, if you are keeping abreast of developments in the state, should be directed towards the forceable rape, both by a father and a son, of a mentally retarded woman placed in family care. Your shock and amazement should be directed to a situation where a young woman was forced to eat the feces of a child in a family care home.

"I call to your attention, if you do not yet know it, that the New York State Association for Retarded Children represents 58 chapters in New York State and is concerned with a total situation in New York State, not only Willowbrook. Our being a plaintiff in the Willowbrook case is only one activity. We have been a plaintiff against Wassaic as well. We have defended parents in various actions brought by the state and have acted for parents against the state in situations other than Willowbrook. The calling for a moratorium, therefore, in order to assess what is going on in the state is not directed against Willowbrook placements. Your shock and amazement should be with the State of New York buying or leasing, some for its own operation, 9 hostels in Suffolk and Nassau Counties, 5 of them in one Township, Huntington, and one on the same block where our Suffolk County Chapter was about to open a hostel on lease from the state, March 1, 1978. The resulting reaction from the community could have been foretold. As a matter of fact, the hostel our Suffolk County Chapter was about to open was burned down, probably by arsonists. It is doubtful whether the state will be able to effectively place in community residences any of the Willowbrook or other classes in Suffolk County in the foreseeable future.

"I am not questioning the placements under the Willowbrook Consent Judgment and the Court's Order, although I think the panel should be much more alert to placement outside the jurisdiction of the Metropolitan Placement Unit; that is, in upstate placements and what is happening to them. In brief, the body of the state cannot be waved by the Willowbrook tail, worthy as that tail is.

"Parenthetically, I have read very carefully the reports of your panel and I am sure you will agree that they reflect a very slow, snail-like pace in the improvements of services within the walls of Willowbrook. I gather also, you are not too happy with other aspects of the recent stipulation.

"To summarize, therefore, any judgments or calls for action that come from this Association are on the basis of a statewide program, and not just Willowbrook and the Metropolitan area. Some of this may be under your jurisdiction, (is Kings Park?) but most of it I think is not.

"We are not resting with the call for a moratorium, but are drafting a statement on what we consider a program for placement in the best interests of the retarded persons."

Dr. Clements has not replied.

86 year old collects bottles for ARC

Recycling glass for the benefit of the Herkimer County Chapter of the Association for Retarded Children is keeping an 86 year old former Watertown resident active and "young."

Howard Robinson, retired finishing department foreman - supervisor at a Brownville paper mill, and a resident of Folts Home, Herkimer, has collected 38,694 glass bottles of all shapes which had been discarded at the home.

The bottles are stored in a garage behind the retirement home and are picked up every two weeks for delivery to the Community Recycling Center, Herkimer, which benefits the Herkimer County ARC.

He began collecting bottles for something to do (keeping active is the secret of staying young at any age, he says) and to help the ARC.

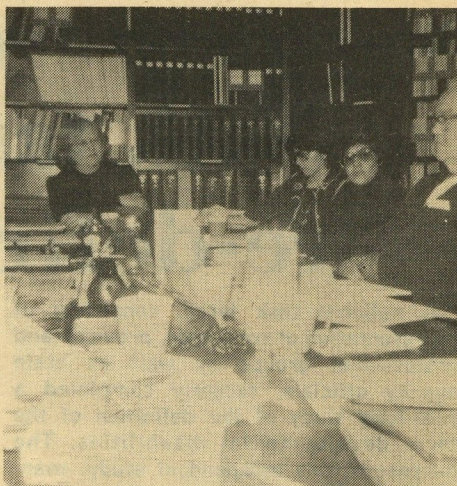
He keeps a daily account of the number of bottles collected so no one can dispute that he has collected a total of 38,694 discarded glass containers, his wife, Blanche, notes.

\$750,000 award against N.Y.C.

A trial by jury resulted in the award of \$750,000, plus court costs, to the plaintiff in Hoffman v. Board of Ed., N.Y.C., on October 21, 1976, for educational malpractice by the defendant.

The complaint charged that Daniel Hoffman was wrongly evaluated as mentally retarded when he entered school at age six. The defendant was charged with violating its statutory duty to provide educational services; specifically, negligence in providing evaluations, re-evaluations, and educational support services, and failure to hire and supervise competent personnel, resulting in the plaintiff being deprived of his right to an education consistent with his true capacity.

Daniel Hoffman was placed in classes for the educable mentally retarded for all of his 12 school years, and did not learn that he had a normal level of intelligence until he was re-evaluated by the Queens Occupational Training Center in 1969. The complaint charges that throughout his school years Daniel Hoffman possessed a



Left to right: Karin Burgess, Chairperson, Institutions Committee, with Ann Marie Vodney, Ellen Maroun and Edward Licence.

Institutions Committee meets

Karin Burgess, newly appointed Chairperson of the Institutions Committee, convened a meeting at N.Y.S.A.R.C. State Office on March 18th. The full committee in attendance comprised of Karin Burgess, Chairperson, Mary Andrews, William Eberhardt, Edward Licence, Ellen Maroun, Toni Parisi, Anthony Pinto, Frances Reville and Michael Styler. Also in attendance were Commissioner Thomas Coughlin, and members of the OMR-DD Technical Assistance Unit, Ed Jennings and Ann Marie Vodney.

Priorities for the year were articulated and discussion centered primarily around the Institutions Budget, the status of the deinstitutionalization process, and the role of the newly formed Developmental Disabilities Services Office. Committee support was unanimous for the Senior Companion Program, an adult version of the Foster Grandparent Program and the MHIS proposal to legislature for needed safeguards of rights of residents involved in incidents of abuse and mistreatment.

severe speech defect for which he was not given adequate therapy.

The 1969 re-evaluation found that Daniel "has above average intellectual potential and a good personality structure (but that) due to his being almost immobilized in the speech area, as well as considering his extremely defective academic background, he would find it difficult, if not impossible to function in a regular high school."

Daniel's mother was also named as plaintiff, charging that the defendant caused her to expend funds for unnecessary programs and services. She also claimed that they may be required to expend additional sums for the retraining and further treatment of her son, and that she has been caused severe financial loss due to the lost earning capacity of her son. While the complaint sought \$1,500,000 in damages for Daniel and \$500,000 damages for Mrs. Hoffman, the jury awarded damages only to Daniel Hoffman.

The defendant has filed an appeal in the case.

ARC testimony on sterilization

Early this year, HEW Secretary Joseph Califano announced a proposed rulemaking that would revise "informed consent" standards for performing sterilizations on persons who reside in mental institutions and other facilities and for persons who are mentally incompetent.

The proposed regulations, designed to eliminate federal support for coerced or uninformed sterilizations, would limit HEW funding to sterilizations which the patient had voluntarily requested with full understanding of the irreversible consequences. Federal funding for sterilization of persons in mental institutions and other facilities would be available if the patient had voluntarily signed a consent form he or she could understand and the doctor performing the sterilization had certified in writing that the patient received full information. Further requirements include a minimum of 30 days must elapse between the date of informed consent and date of the sterilization, the individual must be at least 21 years old, a review committee must certify that consent procedures had been followed and a court must further find the committee's judgment to be in order.

Comments on the proposed restrictions applicable to sterilizations funded by the Department of Health, Education and Welfare were made by Joseph T. Weingold, Executive Director, on behalf of the N.Y.S. Association for Retarded Children:

First let me compliment the Department on its very able and soul-searching discussion on this matter. In fact, after reading the discussion of these proposed regulations with regard to the denial of funding for so-called individuals who have been declared incompetent or who are in fact incompetent, we find that the Department has reached a tortured conclusion against such funding in spite of its own very cogent arguments in favor, with the safeguards suggested.

In the first place, the phrase "who is in fact mentally incompetent under Federal or State Law", is so imprecise as to be without meaning.

There is no such thing as a person being, "in fact incompetent", without a court decision to this effect. All persons are presumed to be competent unless declared otherwise by a court of competent jurisdiction. The proposed regulations, therefore, would have some legal meaning if they were limited to persons who have been declared mentally incompetent by a court. They have absolutely no meaning with regard to persons "who are in fact incompetent."

On a broad basis, we feel that if such a regulation were enacted it would be discriminatory under the equal protection amendment to the constitution, especially where there is a court appointed guardian.

We are not talking about "natural guardians", although I think that that argument could well be made for them as well, but certainly court appointed guardians of the person have broad, if not entire authority, over the persons of the ward and the Federal government cannot substitute itself for the State courts.

A duly constituted guardian of the person may decide where that person may reside; a guardian may decide whether or not the person shall be operated on and give consent; the guardian may have complete control of the finances; in other words act as and for that person in all matters.

It is interesting to note that in some states, such as New York State, guardians may be appointed by the Surrogate Court without a declaration of incompetence, but a declaration of mental retardation duly attested to by a physician and a psychologist and if the person is in need of a substitute judgement in matters concerning his or her life. (Article 17A, New York State, Surrogates Court Procedure Act).

If we add to the proposed prohibition against aid for sterilization, the prohibition against aid for abortion, except for special circumstances, including that or rape or incest, then we have indeed a Catch 22 situation.

Let me give you some examples. Recently, the mother, a duly court appointed guardian, of a severely retarded adult woman, asked the Supreme Court in New York State to sign an order permitting sterilization. The retarded woman was good looking and gregarious, but did not have the capacity to make social judgements. The Court appointed a social worker, who happened to be a nun, to advise it as to whether or not this person should be sterilized. The advice came in that she should be sterilized. Nevertheless, the judge refused such an order because he might eventually be liable for damages.

What happened then? The girl became pregnant. It is doubtful, since she was "incompetent" that she consented to the act. It was, therefore, if not actual, statutory rape. Could the person who made her pregnant be prosecuted? No. Because there was no corroborating evidence. Furthermore, the girl could not give "competent" evidence of such a rape.

The guardian would then like to have an abortion performed. Can this girl have an abortion? Only if there was a rape that was reported etc., etc. How could she report a rape when she was incompetent to testify that there was a rape? Therefore, no abortion.

What happens to this woman, her child, the guardian, society?

All this could have been prevented if under the proper safeguards, the guardian could have given consent to such sterilization.

The proposed regulations contravene every legal power of guardianship, legally constituted guardianship.

We are now witnessing the swing of the pendulum from the genetic alarm of the early 20th century where state after state passed statutory mandated sterilization of the mentally retarded, to the other extreme, there can be no sterilization because of the "rights" of the retarded individual which are invaded. On the one hand, we say that the person is incompetent, on the other hand we say that they have inalienable rights that cannot be in any way invaded by the courts, guardian or anyone else. This contradiction must be resolved in favor of a humane policy that permits such sterilization under the safeguards as outlined for persons who are "normal."

We are not proposing that there be payment for such sterilization merely on the application of the guardian. We are in favor of all the safeguards proposed by the regulations. We are in favor of a committee. We are in favor of a guardian ad litem or a lawyer to present the case to the court. We are in favor of a court declaration.

In the first place, I did not know that regulations of this kind are promulgated for the convenience of the Department's "ease of application". Furthermore, we know of no attempt on the part of the Department to get evidence that this has prevented sterilization, without the law, and without federal aid. Nor do we see any hard data to support the statement that there has been no significant hardship traceable to the moratorium.

These are self-serving declarations. If the Department means the State and Federal Governments have saved money by this moratorium, we probably agree, but everything else in the statement is unprofessional and unworthy to be included as an argument. In fact, the arguments to the contrary are overwhelming. The unwanted pregnancies and statutory rapes in and out of institutions should move the Federal Government to act appropriately.

Let us see what a most highly respected authority in the field of mental retardation

has to say about this. Dr. Harry H. Gordon, currently of the National Association for Retarded Citizens, Grover S. Powers Professor of Pediatrics at the Albert Einstein College of Medicine at the Yeshiva University, New York City, was formerly Dean of the Albert Einstein College of Medicine, the Director of the Rose F. Kennedy Center for Research and Mental Retardation and Human Development, and Co-Director of the Yeshiva University Affiliated Facility for Training Personnel on the care of the retarded. In addition to his other duties, he has been chairman of the Public Policy Committee, United States, Children's Bureau. He is the present coordinator of the Teaching Program, Bioethics at the Albert Einstein College of Medicine.

He states that the denial of privilege of sterilization of the "mentally incompetent", under appropriate safeguards is as much a denial of civil rights as is compulsory sterilization.

Many retarded citizens can enjoy sexuality and some of them can marry and enjoy family life. They should not be denied the right to have children, if that is their wish, nor the right not to have them, if that is their wish. With the decrease of child mortality as a result of vaccinations and antibiotics, retarded children can look forward to a normal life span. They may grow up and develop many of the medical conditions as a result of which continued child bearing effects health adversely, as in the case of normal persons which woman of normal intelligence will request sterilization. For example, multiparity, repeated caesarian sections, kidney disease, heart disease, hypertension, diabetes mellitus.

Approximately 50 per cent of the children born to women with Down's Syndrome (mongolism) are themselves mongoloid. A woman with Down's Syndrome who is to be married or otherwise exposed to pregnancy should have the right to choose sterilization as a contraceptive method and that right should be exercised, where the woman cannot give completely informed consent only through a duly constituted guardian.

Not to give this woman with Down's Syndrome the right to sterilization under any circumstances is to deny a person already disadvantaged by an incurable chromosomal aberration for which she is not responsible the rights of persons who have normal cognitive development and can give so-called consent.

Some retarded citizens are repeatedly impregnated against their will in and out of institutional settings. Such persons are severely retarded persons and find pregnancy and child bearing painful experiences without any compensating pleasures or values. There is absolutely no reasons for such persons to undergo medical risks and suffering upon pregnancy and child birth. Furthermore, a doctor should not be required nor should anyone else be required to make the statutory judgement of "in fact incompetent" at his peril.

If parents or legal guardians believe that they cannot protect her from becoming pregnant, sterilization should be available provided that there are proper safeguards and a proper judicial procedure.

Legislation in this area should be directed at creating such a procedure, not absolutely to deny the right of sterilization to these disadvantaged citizens who may need it, in the end, the most.

North Country Catholic prints series on MR

North Country Catholic, the diocesan newspaper of the Ogdensburg Diocese, printed a series of three extensive articles on Mental Retardation and Services.

The first article explored the causes and detection of mental retardation. In the second, a history and description of ARC

Sterilization

Judge Immune

The Supreme Court ruled that a state judge who approved the sterilization of a 15 year old girl is completely immune from her subsequent damage suit, even though there was no authorization for his action in any state law or court decision.

In a 5-to-3 vote, the majority held that immunity for judges was so broad as to cover "grave procedural errors," such as signing a mother's petition for sterilization without any discernible authority, despite "unfairness to litigants that sometimes results."

"A judge will not be deprived of immunity because the action he took was in error, was done maliciously or was in excess of his authority," Associate Justice Byron R. White wrote. "Rather, he will be subject to liability only when he has acted in the 'clear' absence of all jurisdiction."

Justice White's decision, in which he quoted from an earlier ruling in the case, means that only in the most extreme circumstances, when there was no vestige of legal authority for a judge to act, could such a damage suit be allowed.

The minority contended that the judge's approval of the sterilization petition — without a hearing, notice to the child or any legal representation for her — was "beyond the pale of anything that could sensibly be called a judicial act" and thus not immune from a civil rights action.

What the Indiana Judge did in 1971, Associate Justice Potter Stewart declared for the minority, "was in no way an act normally performed by a judge." Indeed there is no reason to believe that such an act has ever been performed by any other Indiana judge, before or since," Justice Stewart said.

The Judge involved, Harold D. Stump, is still on the bench in Indiana, having been re-elected, since the case arose, to a six-year term that ends in 1983.

The legal director of the American Civil Liberties Union, Bruce Ennis, charged that the ruling meant that "judges can violate citizens' constitutional rights and get away with it" and "can ignore the law with impunity." He said that the civil liberties group would ask Congress to approve legislation reversing the decision.

The Supreme Court decided in 1872 that judges were immune from damage suits "for judicial acts" and ruled in 1967 that this doctrine applied to civil rights cases. Today's ruling thus hinged primarily on whether signing the uncontested sterilization paper would be considered a "judicial act."

The case (Stump v Sparkman, No. 76-1750) arose when Ora Spitler McFarlin had her lawyer draft a "petition" asking the DeKalb County Circuit Court to approve the sterilization operation on her daughter, Linda Kay Spitler. Judge Stump of that court signed the paper, and six days later the operation was performed. The girl was told it was for appendicitis.

Two years later in 1973, Miss Spitler married, discovered she could not become pregnant, and ultimately learned of the operation. She and her husband sued her mother, her mother's attorney, the judge, the doctors and the hospital, alleging a half-dozen constitutional violations.

programs spanning the years from birth to adulthood were described. The series ended with an article about the Church reaching the mentally handicapped with its sacraments. A letter praising the articles was written by the President of the St. Lawrence County Association for Retarded Children.

ARC protests phase out of aid to handicapped

On March 16th, the House Subcommittee on Elementary, Secondary and Vocational Education approved an amendment, introduced by representative Albert H. Quie (R-Minnesota), which would gradually phase out, over a five year period, Title I, Aid to the States on behalf of children in State operated and supported schools for the handicapped. In effect it would fold the handicapped portion of the so-called 89-313 program into the basic federal grant authority for educating handicapped children under 94-142, the Education of All Handicapped Children Act of 1975.

Under 89-313, programs operated by voluntary agencies for preschool children and others not in public school were funded through grants from the Federal government through the State Department of Education. The rationale underlying P.L. 89-313 was that children in state institutions and other publicly financed education programs outside the local public schools should be entitled to Federal assistance parallelly to general Title I aid.

In Fiscal year 1978, the states received \$111.4 million in assistance under this program. This amount will increase to \$133.8 million next fiscal year. Of this total, approximately 56 percent has been used to educate mentally retarded youngsters in recent years.

The theory behind the gradual phase-out is that the children in institutions and state supported schools would be eligible for support under 94-142 and would be counted for the fiscal year 1979 and subsequent years.

In addition, the Quie amendment would repeal a Section 121, subdivision (d) of the current Act, which authorizes 313 support to follow the child from an institutional setting back into the local public schools.

In letters addressed to Congressman Mario Biaggi, Ted S. Weiss and Leo C. Zeferetti, members of the House Committee on Education and Labor, our executive director protested this move. The letter that he wrote follows:

"I have read with dismay that the House Subcommittee on Elementary, Secondary and Vocational Education approved an amendment introduced by Albert E. Quie, which would gradually phase out over a five-year period, Title I, aid to the states on behalf of children in state operated and supported schools for the handicapped (89-313 program). The rationale that it would be folded into 94-142 does not impress me at all. The Title I program has been an enormous help in this state in supporting programs for the education of preschool children and children not admitted to public schools, who are in programs operated by voluntary agencies.

Our own Association, as well as United Cerebral Palsy and the Autism Society, are educating about 4000 children a year with funds from 89-313. We doubt very much that these funds will be available under 94-142.

Percoff retires

In a letter to Joseph H. Percoff, retiring associate counsel in the department of mental hygiene, Joseph Weingold, New York State ARC Executive Director, expressed the appreciation of the Association, its Chapters, and its thousands of members for the help of Mr. Percoff in developing services for the mentally retarded in this state.

Weingold wrote, that "although we did not always have the answer, you have always been ready to explore with us positive approaches to difficult problems."

To us, this appears to be an attempt to use the \$133.8 million of 89-313 funds to support the 94-142 program, which does not include preschool children.

We urge you, therefore, as a member of the House Committee on Education and Labor to reject this amendment and keep Title I of the 89-313 program in place.

I cannot for the life of me understand how we can do this in the name of consolidation and reorganization.

All of my chapters are extremely concerned about this, as well as the parents of the children in such programs. Under 89-313, for example, we received a grant for the last seven years for an in-service training program for teachers of the developmentally disabled, in programs operated by the non-profit agencies. This year we are not getting that grant. It is a pity, and an indication of what is going to happen.

With many thanks for listening to me."

County officials support ARC stand on budget

Joseph Gerace, County Executive of Chautauqua County, was one of several county officials who wrote to Governor Hugh L. Carey in support of the ARC stand on the Governor's budget. In his letter, he referred to a financial breakdown of the proposal by the N.Y.S. Association for amendments to the budget:

The proposed budget doesn't seem to be client or cost effective. There seems to be over-emphasis on the "deinstitutionalization" program. The total institutional population represents about 2 per cent of all of the mentally retarded in the State. The 620 and other services represent a fraction of that 2 per cent. Thus, it appears that your budget proposal including over \$300 million for the institutions will be serving about 3 to 4 per cent of the total mental retardation population in the State and only \$19 million for the other 96 to 97 per cent of the mentally retarded in the communities.

The financial proposal I have enclosed would seem to redirect more money for a greater majority of the mentally retarded without increasing the total amount of your budget.

Your budget proposes to place 1300 people into additional beds in the community in the next fiscal year in addition to the 1200 clients who have been placed in community residence since 1966. If you were to reduce this from 1300 to 600, it would result in a saving of over \$4 million.

Until there is a program for the parents who have struggled to keep their children in their home for many, many years at full personal expense, the \$2.25 million proposed in your budget as an incentive for parents to take their children home would appear to discriminate against those who could have placed their children in institutions but did not. Redirecting that money to the community will benefit a much larger number, a number which will include the parents who struggled without any aid whatsoever.

The savings suggested could be utilized for construction or implementation of sheltered workshops as backup services for the 600 which you would propose be placed in the community as well as those who have never been in institutions but need such workshops.

In summary, the proposed changes would redirect a substantial part of your proposed budget toward a majority of the mentally retarded.



First workshop for retarded in U. S.

Workers at the first workshop for the retarded in the United States, 1953. It was initiated by our executive director, then executive director of the New York City Chapter in a walk-up on Nostrand Avenue in Brooklyn. The first job was finishing belts for Morton Sobel, one of our first members.

Sheridan blasts CSEA campaign

A recent issue of the Albany Chapters Newsletter carried this message from its President:

"Have you seen the latest CSEA ad on 'deinstitutionalization'?"

What can I say? We and humanity are in trouble. In the past twenty years the entire world has come to the moral realization that the community is the ultimate institution, that is, that all people including the disabled should live together with each group expanding its horizons by understanding the aspirations, limitations and fragilities of each other. (The entire world but not CSEA.)

We thought we were fighting the good fight, we thought we were fighting ignorance, fear and lack of understanding of who the retarded are. Could it be all this time the real enemy was CSEA?

The ad and CSEA gives credibility to a concept you and I have given a lifetime to reverse, that is, the concept of subverting people less capable than ourselves who have not committed any crimes, nor done anything wrong; to incarceration institutions, away from their community, away from their families, away from society, and away from allowing them as citizens to grow as we do in our normal environment.

We could say it is immoral on the part of the newspaper to print such an ad, we could say it is immoral on the part of CSEA to place such an ad but we know that's not true. Very few of us are intentionally immoral. To me this ad is an indictment of all of us. Maybe we're more at fault than CSEA for not being more alert advocates and for giving credibility for so many years to incarceration in institutions.

As I mentioned, ignorance, fear, and lack of understanding of the disabled are our real enemies. Therefore, we should question not how this gross attitude starts, but what can be done about it. We know the CSEA cannot be that insensitive to the needs of society and the winds of change. We know that the newspapers cannot be that much in need of bucks that they will print anything, even if it means setting society back 100 years. Therefore, it is up to us to educate and keep stating and restating that past experiences have demonstrated that community environments work, and that the community can do everything that the state institution does.

Above all it brings us one step closer in our relationship with our fellow man.

I would also urge that you review the vocational rehabilitation budget. Not only is the budget inadequate for the vocational education effort but the incredible rules and regulations often frustrate the objectives of the statute.

I know that you can't personally become involved in the day to day operations nor familiar with the day to day effect on the retarded. I do know from personal experience how thoroughly you reviewed the cost effectiveness of budget proposals and therefore ask that you intensely review this particular budget item and the recommendations of those who deal every single day with the problems of the mentally retarded. It makes good budget sense. It makes good program sense.

Please review page 179 of your budget. The State Education Department asks for nearly half a million dollars to reorganize the administrative structure of the Central Office. There is an additional \$243,000 to reorganize three major local offices. We respectfully suggest that you might consider whether vocational rehabilitation belongs in education at all since it is in fact a stepchild of that department. It would be well to consider whether vocational rehabilitation should remain in education or placed in an appropriate executive governmental office.

I urge you to reconsider your budget appropriations for the retarded.

Praise for Advocates Guide to Ed Laws

James T. Raymondjack, Chief of Service for the Southeast Quadrant of Monroe County's Developmental Services, is responsible for Case Managers and Advocates for mentally retarded school aged youngsters.

Recently, he reviewed The Revised Advocates Guide to New York State Education Laws for the Mentally Retarded and Other Developmentally Disabled, and felt that the publication should be the handbook for his staff involved as advocates for school aged youngsters.

Jerry Weingold, New York State ARC Executive Director, commented in a letter to Mr. Raymondjack that although these publications have been in print for some time, this was the first such order from any developmental service.



Left to right, Roger Sibley, New York State Child Find Associate, and Thomas J. Goodman, Child Find Coordinator, admiring the Child Find Poster.

Follow up on Child Find

Over 1,000 telephone and mail information inquiries from the public have been reported for September through November by New York State "Child Find", according to Thomas J. Goodman, the project's State Coordinator.

Launched officially in September, Child Find is the name given to the local and state effort to spotlight federal legislation, The Education For All Handicapped Children Act of 1975. The purpose of this legislation is to insure the right to a free appropriate public education for all children with handicaps.

Child Find is now in the midst of a statewide public awareness campaign to inform parents, schools and the public about the new law and its sweeping implications. Articles, posters, public service announcements and other materials designed to capture the public's attention are promoting a toll-free number 1-800-342-3814, to take inquiries from all interested citizens. To handle the expected volume, the interviewers are bilingual in Spanish and English and have an education background. A special teletype has also been installed to take inquiries from persons who are deaf.

Said Goodman, "The figures on the first three months demonstrate the initial success of the awareness campaign. Ninety percent of the callers were parents; their questions were answered, and many were sent information packets and the proper forms for followup service in their home school districts." Goodman added, "We must continue to make every effort through the news media to make parents aware of their handicapped children's educational rights. The more they hear, the more likely they are to pick up the phone, as hundreds of others have already done. We're very pleased with the efforts in New York State to date, and expect the statistics on calls to be even more impressive as we move towards our completion date for Child Find, the end of June.

The law defines handicapped children as those who are between the ages of birth and 21 years of age who are mentally retarded, hard of hearing or deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired or have specific learning disabilities.

Voc. Rehab. starved

SEP funding bill introduced

Reacting to the fact that the Department of Education has not increased funding of long-range employment of handicapped clients (SEP) for the last six years, legislation has been introduced to remedy this situation.

The first bill is a bill to increase reimbursement for long-term sheltered employment from \$1000 to a mandated \$1500 (at present it is a permissive \$1500 which has never been observed by the Department of Education). The bill is S. 7486A Donovan; A. 7931 M. Murphy.

The Coalition of Rehabilitation Agencies have asked Commissioner Ambach to request these \$1500 from the Legislature, but the highest he would go was \$1100, a "pittance" in the opinion of the Coalition members.

In addition to this meager funding, the regulations of the Commissioner of Education required that the clients to be eligible for SEP services must wait at least a year after the end of their sponsorship by OVR on the theory that during that year perhaps they could be found to be eligible or even placeable in industry. This concept was knocked into a cocked hat over the last six years, but it was impossible to get the Department of Education to change this regulation. Legislation was, therefore, introduced to eliminate the waiting period to make clients eligible for SEP services immediately upon the termination of OVR sponsorship (S. 8106 Levy; A. 10530 Amatucci). At this writing, the bills are still in committee.

Workshop budgets cannot support necessary programs

A nationwide sheltered workshop study, on sheltered workshops and the employment of handicapped individuals, conducted by the U.S. Department of Labor found that the size of the operating budget from any workshop, especially those serving mentally retarded clients, seems inadequate to support necessary programs.

It is especially noted that the fee income was generally restricted to rehabilitation services and could not be used to support long term employees.

The study gathered data from more than three-fourths of all known sheltered workshops. A total of 2,530 workshop programs (regular program workshops, work activity centers, and training and/or evaluation programs) operating in 1,786 establishments reported data on operations, policy, etc. It is the most comprehensive analysis of sheltered workshops ever undertaken.

The report was issued by the U.S. Dept. of Labor, Employment Standards Administration, Employment and Training Administration, June 1977. It showed the following:

A. Client earnings increased very little in the five year period since the last wage study. Wages of regular clients increased by 9 percent, work activities center clients wages by 6 percent, and training evaluation client wages by 11 percent in the period '68-'73. By way of comparison, average hourly earnings of production or non-supervisory workers on private non-agricultural payrolls increased by 38 percent in the same period.

B. The separation of work activities center clients from regular program workshop clients did not produce significant changes of services, productivity or programs provided.

C. The workshops were substantially under-utilized. About one-half the workshops reported unused capacity, although this was not true of all states, New York State being an exception.

D. Most of the workshops provided some degree of training, education, and/or therapeutic services to their clients, but annual expenditure reports reflected a relatively small amount for professional and technical staff salaries for this purpose.

E. Very few workshops were serving clients referred by federal manpower programs. Most of such clients were served in regular program workshops, but the rate of successful completion of training and competitive job placement for clients referred by manpower development training programs was higher than for non-federal program clients (this may have been due to the selection process in referral).

As an aside, it was noted that, because of the non-production orientation and the generally low productivity level of the clients, work activity centers did not seem to hold the promise and potential for serving non-handicapped persons. (Editorial comment. Why should non-handicapped persons be served under the Vocational Rehabilitation Act.?)

F. Clients were moved from sheltered workshop into competitive employment and community jobs at the rate of 12 percent of the total served annually, but less than 15 percent of the clients placed in competitive employment had to return to the workshop for further training or other services.

G. The type of work provided in workshops influenced training and wage

earnings, although the client disability seemed to be a factor as well.

The most common job in the workshops was bench assembly work, possibly because it required the least investment in equipment and engineering. It is also likely it is the most suitable work which was available to the workshops for the mentally retarded worker who had very limited skills and potential.

Lack of work was a major problem in the regular program workshop, as well as in the activity center.

H. The size of the client group in the workshop seemed to influence services, wage earnings of clients and other benefits. Average daily attendance of nearly one-third of the workshops was fewer than 20 clients. Three-fourths of the workshops' programs had fewer than 40 clients in average daily attendance. The small size made it economically impractical to provide comprehensive services and limited the size of the sub-contract jobs which the workshop could undertake.

I. Very few workshops appeared to have the capability to manufacture commodities to sell to the federal government under the Wagner-O'Day Program, but more than one-half of the workshops provided training in services which might be provided to the Federal government on a service contract. Workshops for the blind dominated the manufacture of commodities, something to be expected. Over less than 4 percent of the workshop clients were involved in rendering services such as janitorial, custodial and building and grounds maintenance at the time of the study, a more recent report on workshops involved in the Wagner-O'Day program (Committee for Purchase from the Blind and other Handicapped, Procurement List 1976, General Services Administration) shows that workshops serving other than blind clients have increased success in developing contracts to provide these types of services from the federal government. The limited size of funding of the average workshop makes the involvement in service contracts more practical than manufacturing because of the development of services requires a substantially smaller investment.

J. Finally, most of the clients in the workshops did not receive the fringe benefits usually provided to employees in competitive labor market.

Copies of this report may be received from the U.S. Government Printing Office under the following number, L9770-732-166-136.

Mid-Hudson hostel progress

Do you remember when the State Association was going to build 10 hostels in the Mid-Hudson Region with a grant of almost \$½ million from HEW, and the rest to come from the State and mortgages? Do you also remember how this fell through because Housing Finance Agency went down the drain at that time?

Well, this was about two years ago. The state took over the project.

This was not entirely abandoned and at this point we understand that four sites have been selected, two in Middletown, one in Monticello, and one in Ulster and construction will begin on one of the Middletown sites in the near future. The Middletown site is a double site and construction is beginning on both of them.

So you see that where is life, there is hope.

CHAPTER NEWS *What our chapters a*

ALLEGANY COUNTY CHAPTER very pleased with the closeness of the opening of their first hostel . . . **CAYUGA COUNTY CHAPTER** has recently begun marketing a new product called "Bowl-At-Home." This miniature bowling alley is a perfect, engineered-to-scale reproduction of a conventional big alley. Anthony J. Terranova, Jr., Executive Director of the **CAYUGA CHAPTER**, states that "Bowl-At-Home" is an ideal item for use in hostels, nursing homes, hospitals, and schools. Made of solid red Philippine Mahogany lumbercore and plywood, "Bowl-At-Home" is offered to A.R.C.'s at a retail cost of \$300.00 plus shipping . . . In response to the poignant plea of Louis Lombardo, Editor of the **CHAUTAUQUA COUNTY CHAPTER** Newsletter, we certainly don't want to let the month go by without mentioning **CHAUTAUQUA COUNTY CHAPTER**. Louis, one of the problems is that your newsletter is really good and filled with information which is very interesting, but requires more space than we can normally give it in Chapter News, so why don't we just say that the Chapter has five new buses, for 20 passengers each, part of a \$94,424 grant, to help them transport their clients within **CHAUTAUQUA COUNTY** and as of January 1978, their three workshops had 366 clients receiving services . . . **CHENANGO COUNTY** proudly sends along the following report: During 1977 the Community Workshop successfully bid on and received over fifty Sub-Assembly Contracts and so far this year has required thirty more sub-assemblies . . . Recent articles from **CLINTON COUNTY CHAPTER** have indicated their activity both in the area of pre-school programs and community residences. Twenty infants are presently being served by the Early Infant Intervention Program. We all wish a speedy recovery to Executive Director, Donald Geist, who fractured his ankle very badly while cross country skiing . . . Dorothy Fixler, our Public Relations Chairman at **COMMUNITY LEAGUE, WASSAIC CHAPTER**, sent the following information on their volunteer program: Ms. Jackie Coughlin, one of the fine volunteers who visit Wassaic, recently completed 258 hours of service to the residents of Taft Hall . . . Perhaps by the time you read this article, **CORTLAND COUNTY CHAPTER** will be in its first community residence. They have certainly been working hard toward that . . . **ERIE COUNTY CHAPTER'S** February newsletter reported what has got to be an ARC first. It indicated that Board President, Stan Searl, had taken a leave from his duties for a three month period. This was "paternity leave" to assist in the care of Stephen Andrew, a new son born to Mr. and Mrs. Searl on January 24th. . . Although it has been in existence for several months, we have not previously had the opportunity to report that **GENESEE COUNTY CHAPTER** has started a parental assistance committee. Following the lead of several other Chapters, **GENESEE** has begun offering services to parents right at hospitals where necessary and having parent to parent support of families who are having difficulty accepting a child's handicap . . . **HERKIMER COUNTY** took a page from the book of Livingston - Wyoming Chapter, and sponsored a contest for the naming of their newsletter. Apparently the name decided upon was Aglow Ready Capable. We do not find who the winner was, but maybe I am just not reading carefully enough . . . **HERKIMER COUNTY CHAPTER** continuing their very large recycling program, and expanding it at all times. Couldn't help but notice a brief article indicating that they raised \$10,000 in their Swim-a-thon, which we think is



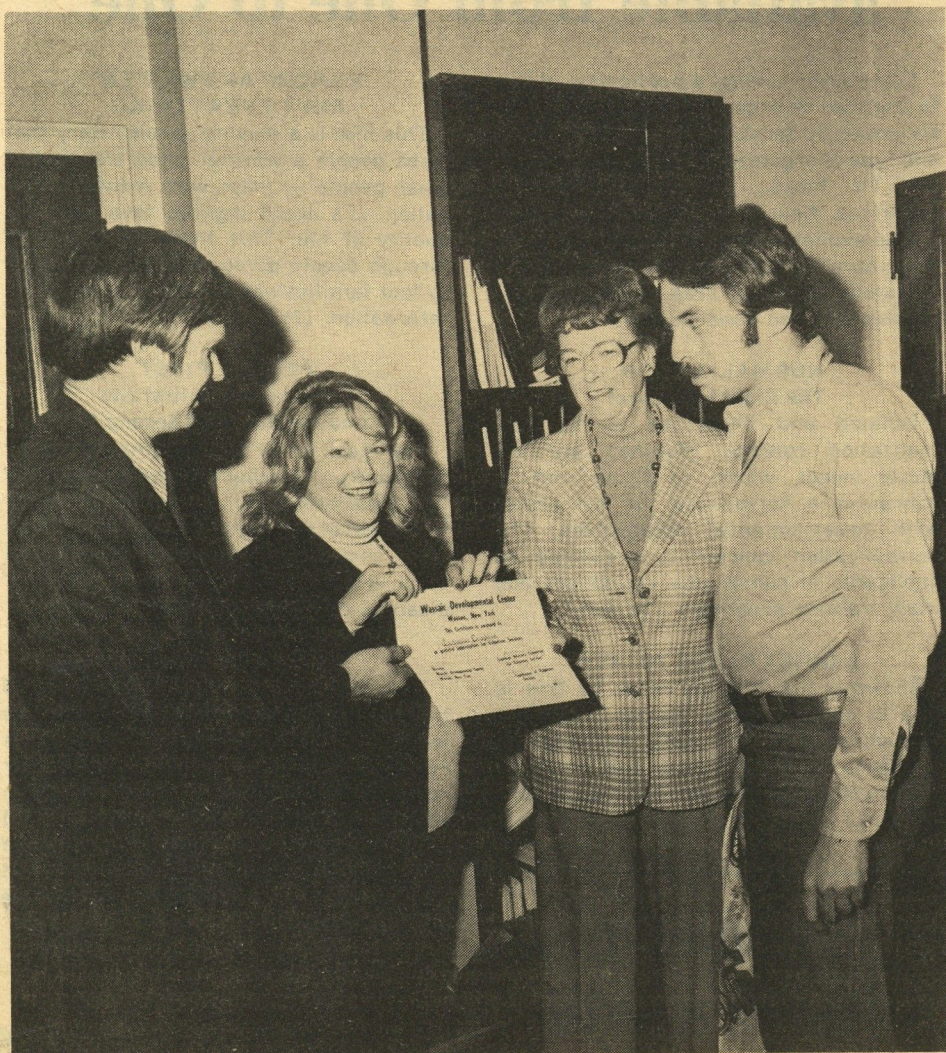
Nassau Group starts on sightseeing.

wonderful. Where will we find that on the assessment form? . . . **LEWIS COUNTY** quite excited about the movement of their workshop from Greig, New York to the former administrative offices of the South Lewis Central School in Turin, New York. Glad that we are able to see such expansion in the far North . . . In addition to their recent pace-setting newsletter naming contest, **LIVINGSTON - WYOMING CHAPTER** appears to be acquiring equipment by saving Campbell's Soup labels. Just think how many labels they could get if all 33,000 of our readers would save all their Campbell's Soup labels and send them to **LIVINGSTON - WYOMING CHAPTER**. Let's try it and see how it works . . . By the time you receive this newsletter, **MADISON COUNTY CHAPTER** will have held its 10th Anniversary festivities. Continually impressed with **MADISON COUNTY'S** willingness to scratch around to find a dollar. They need \$20,000 a year for matching their Mental Health Board Contract, it is hard money to find in their County, but here is a Chapter that is willing to try anything to go out and do it. Beautiful . . . Just got to see an article from the Rochester newspapers telling us about **MONROE COUNTY CHAPTER'S** interesting recreational program. Together with the Rochester Rehabilitation Center, they have young adults going off on cross country skiing programs. We hope they had better luck than Don Geist (see the Clinton County blurb). **MONROE COUNTY** working hard getting ready for the State Convention this Fall. If the activity of the Committee is any indication, this is going to be one of the greatest Conventions ever . . . Lots of news this time from **NASSAU COUNTY CHAPTER**. Good news for many **NASSAU** residents is that the Day Camp is now planning a new summer session at Brookville. This program will be approximately 350 youngsters . . . Perhaps equally exciting is an event that has already taken place. One hundred seventy-eight men and women from the various **NASSAU AHRC** programs, together with chaperons, went on an overnight trip to the Pennsylvania Dutch Country. This was the first overnight and the second special event in the new leisure time program which was started last spring. A most interesting article back in the November '77 issue of their newsletter, which we didn't get to report to you until now, showing Executive Director, Helen Kaplan, Mrs. Mary Smith and Mrs. Smith's son, Steven, cutting the Chapter's 28th birthday cake. Steven was 6 years old when he was a part of the first group to attend a program at the Chapter and today is living in a Chapter hostel and working in its workshop . . . April 14, 15 and 16 were the dates of the 3rd Annual Mixed Doubles Tennis Tournament sponsored by Unity Mutual Life Insurance Company as a benefit for **ONONDAGA COUNTY ARC**. There were 160 players in the Tournament this year. Last year the Tournament raised about \$4,500 for the Chapter . . . Very pleased with the article in the

ONEIDA COUNTY CHAPTER newsletter, indicating that their program in Rome, New York has about doubled in space. For many years in **ONEIDA COUNTY**, there was a great rivalry between Utica and Rome, with Rome seeming to get the short end of the stick. We are really delighted to see the total County approach being taken . . . **ONTARIO COUNTY CHAPTER** newsletter filled with activities each month, but perhaps most interesting the fact that effective March 20th the Chapter was going to take over the maintenance of the New York State Electric and Gas Buildings in Waterloo, New York, as a part of their workshop training program. Bet they will have the nicest looking grounds around . . . Thanks to the members of the National Junior Honor Society in Circleville, New York, who share the efforts of their recycling programs with our **ORANGE COUNTY CHAPTER** . . . Well, she has finally done it. Working hard and largely on her own, Marti Smith, President of **ORLEANS COUNTY CHAPTER** has been notified that the Chapter is going to receive a \$106,000 contract from Orleans County Board of Supervisors to get a workshop off the ground this year. Marti is starting job interviews right now, in the hope of seeing this service in **ORLEANS COUNTY CHAPTER** before the end of this year . . . **OTSEGO COUNTY CHAPTER'S** newsletter indicates the start-up of a Mother's Sharing Group, the purpose being the coming together of parents who wish to share successes, problems and ideas with helping their handicapped teenagers or those approaching the teens, through these difficult years . . . From **RENSELAER COUNTY CHAPTER** comes the following news: After approximately four years of frustrations, negotiations, delays, and red tape the **RENSELAER COUNTY CHAPTER**, Association for Retarded Children purchased the former Amalgamated Clothing Workers Union Building on River Street in Troy for use as an adult training center. At the present time, the **RENSELAER A.R.C.** operates Adult Service Programs at three locations. The Oakwood Avenue Presbyterian Church in Troy houses the longest operating adult training program run by a Chapter. The program has been in operation for twelve years and at present serves 18 adults. The Co-operative Crafts Shop on Broadway in Troy involves a retail outlet for the sale of crafts items as well as production areas for various crafts and areas for some industrial sewing work. This program was initially started by Eleanor Roosevelt Developmental Services and became par' of the **RENSELAER A.R.C.** Adult Program in 1976. It presently provides day programming for twenty-three retarded adults. The third Adult Services Program location of the **RENSELAER A.R.C.** is in a converted furniture store on Second Street in South Troy. Included in this program are a Wood Shop, Greenwares production area, and Table Contract areas. Staffing at both the Second Street and Crafts Shop locations involves some shared staff from Eleanor

Roosevelt Developmental Services as well as **RENSELAER A.R.C.** staff members . . . The very helpful **ROCKLAND COUNTY** Auxiliary puts out a very interesting monthly newsletter. They are the first whose newsletter I have seen that contains ads. Another interesting fund-raiser in **ROCKLAND COUNTY** . . . **ST. LAWRENCE COUNTY CHAPTER** wrote to say, "Jim Munice, Member of the Chapter Board and Finance Committee, was featured in Alcoa's article "WE CAN'T WAIT FOR TOMORROW." Jim has been most influential in assisting the Chapter as an active Board Member and Member of the Finance Committee, further he was influential in gaining sub-contract work for the Chapter relating to significant employment in our Sheltered Workshop. This directly lead to Alcoa Massena Operations being nominated Employer of the Year in 1976" . . . **SARATOGA COUNTY CHAPTER** helps itself and rescues a building. The Chapter had been really squeezed in their quarters on the old Verazano College Campus in Saratoga Springs and they have been looking for a long time for a building in which they could invest Building Fund monies they had received over the years. They found such a facility in the former Andy's Glass Company in Ballston Spa and anticipate moving in quite soon . . . **SCHENECTADY COUNTY CHAPTER'S** been tugging at our heart strings each month with a picture of some past service or activity of the Chapter under the caption, "Do You Remember" . . . **SCHOHARIE COUNTY CHAPTER** struggling through the difficulty of getting their building, which has been a problem for them right from the beginning, finally settled showing the fact that their spirits are high on their cheerful newsletter, which has also come out with a new name, The Valley Voice . . . **SUFFOLK COUNTY CHAPTER** is suffering through a very difficult time as the Department of Mental Hygiene tries jamming a number of community residences into the County. The Chapter has expressed its opposition to efforts of the Department of Mental Hygiene to establish five community residences in the Town of Huntington alone, as well as four others closeby in Suffolk . . . One of the residences planned in Huntington was even on the same street, as an existing ARC residence. It appears that someone is perhaps finally listening to the voice of reason, but isn't it strange that we should have to go through fights with those we are supposed to be helping in service . . . **TOMPKINS COUNTY** digging hard for their first community residence. We'll certainly be pleased if they can get it off the ground after the year's frustration that Chapter has suffered with an unfriendly community . . . A second residence to be open soon by **WARREN - WASHINGTON CHAPTER** at 79 Broadway in Hudson Falls . . . **WELFARE LEAGUE'S** very successful 38th Annual Luncheon was being held about the time the last issue of OCV was being prepared for press. We didn't have an opportunity to bring any news of that successful affair, at which Senator Frank Padavan was presented with an award by **WELFARE LEAGUE** . . . The **WESTCHESTER COUNTY CHAPTER** recently opened its third training center in Mt. Kisco, New York. This facility now provides programs for 80 residents of Wassaic Developmental Center, Wingdale Unit and serves approximately 175 retarded adults in the northern Westchester area. The program has been moving aggressively and is now opening two community residences in Bedford and one in Rye, providing a home setting for approximately 21 retarded adults. WARC operates nine other community residence programs.

are doing and saying for our children and adults



Ms. Jackie Coughlin receiving volunteer award for service at Wassaic.

Montgomery Purchase of Service - "it works"

Early this year, the Montgomery County Chapter implemented one of the first Purchase of Service programs in upstate New York. After several months of negotiating, it was finally able to breach the bureaucratic road blocks and the program became a reality.

The obstacles were to be expected since this funding mechanism was new in upstate New York, and there had been no experience rate. The planning principle, however, was sound, one hundred per cent funding for transitional programming that would lead to 620 and medicaid budgets in the future.

The Montgomery County Chapter is presently busing 33 residents of Wilton Developmental Center daily to its new Day Training Center in the Village of Tribes Hill. It is also accepting 17 community clients into the program as well with full funding. The staffing pattern is rich by our traditional workshop standards, four to one, and the training modules include — Remedial Education — Activities in Daily Living Training — Pre-Vocational and Occupational Therapy — Physical Education. Workshops are forced to have a predominate vocational focus because of the nature of their funding, this is often true whether or not the individual served have their first needs in this area. Purchase of Service programs allow for a great deal more diversification of programming with the focus to be put on education and self help skill training which are the primary concern with the more severely multiple handicapped.

Montgomery County Chapter is optimistic about the future of this program. The separate building leased for this purchase will remain a permanent component of the Chapter's programs

even when the new training center under construction will be completed in December. It will also be aided in transitionalizing the institutional residents by the HUD Housing Loan it recently received.

L.A.R.C. active in membership

Columbia Chapter's YOUTH-ARC group lent its energy and support to an aggressive membership effort coordinated by Mrs. Betty Young, Membership Chairman.

Prospective members were mailed the Chapter's most recent newsletter, an application blank and a letter explaining the progress that had been made by the local chapter. L.A.R.C. (Love Association for Retarded Children), the Association's YOUTH group proved to be a most valuable partner in the drive. A complete multi-media campaign was organized. A series of 60 and 30 second radio commercials made by adults and YOUTH members were broadcast by the areas two radio stations, WHUC and WCKL, as well as guest appearances on area radio talk shows. Area newspapers published frequent articles submitted to them by the ARC. The Hudson Register Star, a long-time supporter and advocate of the Chapter, provided feature articles on the community workshop as well as the community residence program.

A highlight of the membership drive for L.A.R.C. occurred when Herbert Merritt, principal of Hudson High School, was enrolled as one of the first residents of the county to join Columbia ARC.

Rensselaer pays off mortgage Pinewoods featured nationally

Pinewoods Center, Home of the Pre-school Program operated by the Rensselaer County Chapter ARC, was featured on both the cover and in an article in the December issue of *ARISE*. *ARISE* is a new magazine published by the American Research Institute in Special Education.

The article described the work of Ann Marie Truppi, a dance therapist with Eleanor Roosevelt Developmental Services, who works on a shared Staff basis with the Rensselaer ARC. The article described how Ms. Truppi is teaching the handicapped youngsters in the Program "a new feeling for their bodies and ability to coordinate, express themselves and experience joy in relating to others".

Recently, at the Troy Elks Club, the Rensselaer ARC held its annual dinner dance. Highlight of the evening, for over 120 guests, was the ceremony in which the Chapter "Burned the mortgage" on their Pinewoods Center facility. The building loan for Pinewoods Center, which was approximately 10 years old, was issued to the Rensselaer ARC by the Union National

Bank in Troy, New York. During a brief presentation at the dinner dance, Chapter President David Wilkie described the hard work of many ARC members to purchase the land, construct Pinewoods Center and eventually pay off the cost involved in this major project.

Over the years, Pinewoods Center has seen a number of dramatic changes. A major portion of the facility was used originally to provide classes for children excluded from public instruction. After many years of effort on the part of ARC members across the state, the public school systems began taking responsibility for school age children, eliminating the need for classes for excluded children. An adult training program, which had its start at Pinewoods Center, has grown dramatically in recent years and will soon be moving into a new facility on River Street in Troy.

Today Pinewoods Center is used primarily for the Pre-School Program operated by the Rensselaer ARC.

NYS ARC welcomes 3 new executive directors

NYS ARC welcomes 3 new Executive Directors in our Erie, Onondaga and Rensselaer County Chapters.

Georgeann Redman, employed in our Erie County Chapter since 1974, recently served as Acting Director since the resignation of Michael Trowbridge and has now been chosen as the new Executive Director.

Don Boudov, former consultant with the National Association for Retarded Citizens and the Director of a school and work activities center for the retarded in Illinois, has accepted the position of

Executive Director with our Onondaga Chapter. **James Flanagan**, former Director of Community Residences at Rensselaer ARC, and President of the New York State Association of Community Residences Administrators is the choice of his Chapter's Search Committee which recently announced his appointment as Executive Director.

We welcome our new Executive Directors to our statewide Association and wish them well in their endeavors for quality services and programs for the retarded in their respective counties.

Chautauqua receives highest ranking

The Office of Vocational Rehabilitation has announced that the Chautauqua County Chapter of the New York State Association for Retarded Children has received the highest of all category designations.

The category designations are determined by the different kinds of services made available and by the size of professional make-up of the staff.

In a letter to the A.R.C., Mr. Howard Berger, Director of the Division of Vocational Rehabilitation Operation stated:

"It has been determined that staff and services justify an upgrading of the

category for the Jamestown Facility. Consequently, effective October 3, 1977, the fee category for the Jamestown facility, (Jamestown Achievement Center), will be changed to IV."

Jamestown Achievement Center had just received category III designation last year. The Chautauqua County A.R.C. provides the following services in Jamestown, Dunkirk, and Westfield:

1. Vocational Evaluation.
2. Personal Adjustment Training
3. Vocational Rehabilitation
4. Work Readiness Training
5. Counseling
6. Job Placement

Schuyler is newest chapter

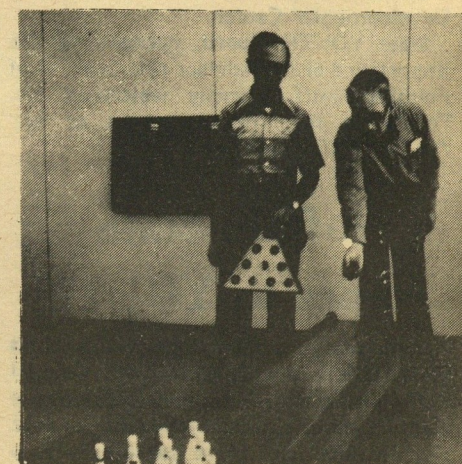
In November of 1977, the latest Chapter of the State Association was organized, under the leadership of Joyce Palmatier and Mrs. Kit Palmatier, formerly of Dutchess County Chapter.

It lists a membership of approximately 30 residents, and is already embarked on a program of services for the retarded of Schuyler County.

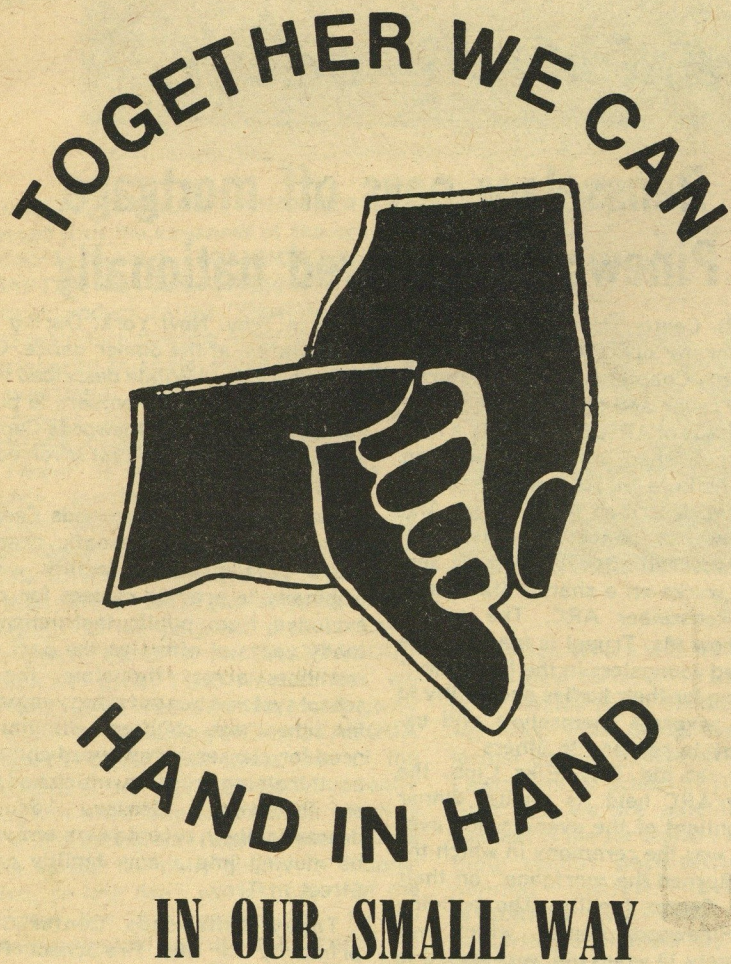
It has already received a charter membership (\$100.00) from Sullivan Vending Inc. of Montour Falls.

With the advent of this Chapter, the number is now up to 60 for the State of New York.

Congratulations to Schuyler and welcome.



Cayuga Chapter ARC demonstrates "Bowl-At-Home".



We have a special job to do,
and we'll need some cooperation from you.
Our goal is not that simple. . .
we want for the handicapped what is rightly due.
We are the adults of tomorrow,
but more important, we are the teens of today.
Just this once while we do the work,
let it get done in our small way.
We may not do it the way you like and
we're bound to make mistakes. . .
We only ask for a little of your patience,
you'll find that's all it takes.
So lend an ear and try to hear some of
the things we're trying to say.
Someday, when our mission is through,
you'll look back and be proud that we did it all,
in our small way!

(Submitted by Cathy Adams of the Smithtown Junior Auxiliary dedicated to the Smithtown Juniors.)

West Seneca

YOUTH ARC conducts a morning of Swim and Gym for residents of Cottage 40. The gym program is under the direction of Bill Monahan; Deb Felix directs the pool activities; Lynn Schroeder handles refreshments.

Welcome MS. Perner

Shirley Reynolds, co-founder and first advisor to West Seneca Developmental Center informs us that she now shares advisor responsibility with Ms. Darlene Perner. Ms. Perner is a member of the Education Department of West Seneca Developmental Center.

State YOUTH Board, recognizing the importance of the Advisor role in all local member units, warmly welcomes Ms. Perner to the growing ranks of our YOUTH-ARC Advisors.

Buffalo State comes to YOUTH

Members of the Mental Retardation and Physically Handicapped Students Council of Buffalo State College recently joined the West Seneca Developmental Center YOUTH-ARC unit. State Board extends a warm welcome to: Kathy Nixon, Robinne Axelrod, Deb Felix, Bill Monahan, Jack Dempsey, Ann Manzick, Debbie Rohrer and Sue Weisler.

Suffolk Youth stops traffic

Walkers in AHRC's Y.O.U.T.H. Walk-a-thon periodically stopped traffic along Veterans High way enroute to AHRC's Bohemia center.

One hundred and fifty young people participated in this year's walk, following one of two ten mile routes.

Walkers began at 10 a.m. and were escorted by the Suffolk County Police throughout the day. As time went on, two questions were repeated with increasing regularity. "Where's the next stop?" and "How much further?" The long lines of young people moved steadily along the

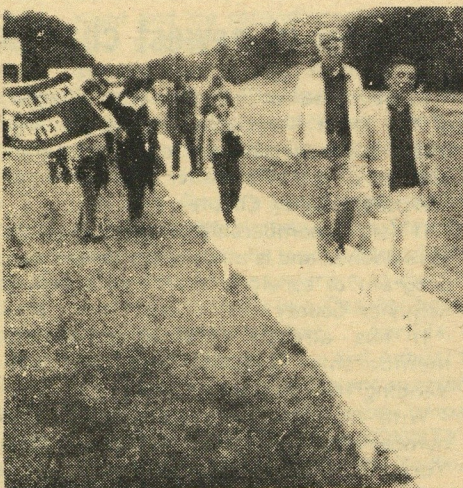
highway, stopping briefly for juice, cookies and fruit at designated check points.

Spirits were high throughout the walk, boosted by periodic horn bursts of approval from passing cars.

Approximately four hours later, the walkers reached Bohemia, the final check-point.

Following rest and refreshments, AHRC President Joe Dempsey presented each walker with a certificate of appreciation.

The total in pledges for the day was \$6,000.00.



Executive Director, Bob Sansone, Suffolk, leading the youth marchers.



Any costume will do for walking.

Public education resources available from One to One

Community Living, a publication of One to One, can be ordered for \$7.50 a year for six issues by sending your name, address and type of organization to One to One, c-o ABC-TV News, 1330 Avenue of the Americas, New York, New York 10019.

Also available from the Resource Center are a number of films, each one designed to handle a special area of the joys and problems of the handicapped.

NORMALIZATION: The Right to Respect

Defined and illustrated is the normalization concept. Outlined are the major needs which must be met to guarantee a normalized life for people with developmental disabilities. The normalization concept is presented as applicable to community residences and work training programs. (20 min.)

A QUIET PLACE TO LIVE

Shown is the progress made by One to One in opening group homes. This film concentrates on the daily activities of residents in these homes and covers a variety of age groups and living situations. (15 min.)

READIN' AND WRITEN' AIN'T EVERYTHING

This film is a moving documentary that gives people a warmer understanding of other people — those with mental retardation. It's about dignity, love, and the quality of life. This theme is conveyed through deeply personal experiences told by four families who live daily with mental retardation. (26 min.)

PEOPLE FIRST

"We are people first and
And Handicapped Second."

The most ambitious documentary ever produced on the subject of equal rights for the developmentally disabled — over 25,000 feet of film was shot to document the lives and political activities of People First, a self-political advocacy group of disabled citizens. (34 min.)

COMING HOME

This film depicts the adjustment and training of a girl in her late teens who leaves a state institution to live in a residential "family life" home for retarded people. Emphasized is a program which recognized her right to full citizenship and self-actualization. Also shown, and provocatively discussed, are the fears and misconceptions held by the neighbors. (27 min.)

Publisher requests material

Publisher preparing a series of picture books about children with physical or mental disabilities would like to look at manuscript between 1,000 and 2,000 words for children between 4-10 years of age. Payment either outright purchase or advance-royalty. Send manuscript with SASE to Mr. Jim Masters, Box 1332, Brooklyn, N.Y. 11201. If you have questions call him at 212-596-1598.

Retarded artists show at the Met

Four residents of Bernard Fineson Developmental Center, Glen Oaks unit recently received certificates of merit for work exhibited at the Metropolitan Museum of Art.

The artists, Amos Ferreri, Harold Hebler, Malcolm Pugh, and Timothy Shaughnessy, presented their work as part of an exhibition in the Museum's Children's Cafeteria in a show sponsored by the New York State Association for Retarded Children.

The severely and profoundly retarded artists, all former residents of Willowbrook, have made enormous gains in skill and confidence through art therapy. One artist paints with a brush attached to a head pointer, another was taught to paint although he is severely crippled by cerebral palsy.

The work reflects development from scribbles to interesting primitive art, and shows what can be done when proper services are made available to retarded citizens.

Eleanor Riegert, art therapist at Glen Oaks, arranged the display of these four artists to illustrate the course of their development.

The artists were taken to see their work on exhibit in the Children's Cafeteria. They were later awarded their certificates by Geraldine Sherwood representing ARC and Dolores Wright, representing the Metropolitan Museum of Art.

The Metropolitan Museum is encouraging mentally retarded adults to take the opportunity to be introduced to great art. Developmental Centers and voluntary agencies who wish to participate in this program should contact Charles Steiner, Assistant Museum Educator and Project Director for Museum Education for Retarded Adults, at the Museum: 212-879-5500, ext. 307.

Tentative Program

THURSDAY, OCTOBER 26, 1978

4:00 p.m. YOUTH
Board meeting
6:00 p.m. Dinner with Speakers,
Adult Meetings

FRIDAY, OCTOBER 27, 1978

9:00 - 2:00 Registration
LUNCH ON OWN
11:30 - 12:30 Candidates, Local
President/Advisor
Meeting
12:30 - 1:30 "Passages" Getting off
to a running start.
1:30 - 3:15 "Passages" Method
and Madness
3:15 - 4:45 "Passages" Great
Expectations and
Pitfalls
5:00 - 6:30 Dinner
(opening remarks)
6:30 - 7:30 "Passages" Sneak
Preview ...
Growing Up
7:30 - 9:00 "Passages" You're in
Good Company
9:00 - 10:00 "Passages"
"Predictable Crisis; Is
there life in YOUTH ..
Regional Meetings
10:00 - 10:30
Curfew

SATURDAY, OCTOBER 28, 1978

7:30 - 8:30 Breakfast
8:30 - 10:30 "Passages" If I'm Late
start the crisis without
me
10:30 - 11:15 "Passages" Living out
the Fantasy and
Reality
11:15 - 11:45 PIE IN THE EYE
12:15 - 1:30 Luncheon
1:45 - 4:30 General Business
Session
4:45 - 5:30 "Passages" New views
of energy-redefined
attitudes for YOUTH
FREE TIME
5:30 - 6:30 Party
6:30 - 7:30 Banquet and
entertainment
7:30
Curfew

SUNDAY, OCTOBER 29, 1978

8:00 - 9:00 Breakfast
9:00 - 11:00 New Board Meeting
Closing of Convention

YOUTH

plans

Convention

with adults

but... let me choose the colors

MY WORLD

**N.Y.S. YOUTH
ARC CONVENTION
HOLIDAY INN - ROCHESTER
OCTOBER 26-29**

REGISTRATION COSTS:


\$65.00 — Full registration with meals and lodging if registration is postmarked before 8/15/78.
\$70.00 — Full registration if postmarked after 8/15/78.
\$35.00 — Day registration, meals, no lodging if postmarked before 8/15/78.
\$40.00 — Day registration, meals, no lodging if postmarked after 8/15/78.
\$ 5.00 — Day registration, no meals, no lodging if postmarked before 8/15/78.
\$ 8.00 — Day registration, no meals, no lodging if postmarked after 8/15/78.

FACTS ON REGISTRATION:

Deadline for Early Registration is August 15, 1978, midnight. All registrations that are postmarked after August 15, 1978 will be charged with a late fee.

Return completed Registration Forms including check/money order made payable to:
NYS YOUTH-ARC Convention Committee
send to:
NYS YOUTH-ARC Convention
159 Belcoda Drive
Rochester, N.Y. 14617

NOTE: If you are under 18 years of age, you must have the release of liability signed and returned with your registration form.



"COLOR MY WORLD ... BUT ... LET ME CHOOSE THE COLORS"

N.Y.S. Y.O.U.T.H.-ARC CONVENTION

OCTOBER 26-29, 1978

ROCHESTER, N.Y.

It is my understanding that the New York State Association for Retarded Children, the New York State YOUTH Association for Retarded Children will make every effort to provide reasonable care, accommodations, protection and supervision for the Youth delegates while they are at the Holiday Inn of Rochester.

I hereby release the State Association, State YOUTH Association and the Holiday Inn, from any responsibility for the safety and welfare of

while en route, participating in, or returning from the NYS YOUTH-ARC Convention at the Holiday Inn of Rochester, October 26-29, 1978.

If, in the opinion of a doctor, my son/daughter is in need of any medical care as a result of any injury sustained, I give my permission for such treatment.

Signature of Parent/Guardian

Area Code/Phone Number

Emergency Contact other than parent or guardian

Area Code/Phone Number

PLEASE TYPE OR PRINT CLEARLY

REGISTRATION FORM

Name: Last First Middle Initial Age

Permanent Address: Male/Female

City State Zip

Person to contact in case of emergency:

Name Telephone: Area Code/#

Address City State Zip

Do YOU have any outstanding medical problems that the Conference Committee should be aware of? (allergies, etc.)

TRANSPORTATION INFORMATION

Name:

Arriving From:

MODE OF TRANSPORTATION (Please check one)

____ Airline ____ Date ____ Time ____ Flight #
____ Train ____ Date ____ Time ____ Train #
____ Bus ____ Date ____ Greyhound ____ Trailways

____ Own vehicle or charter ____ Arrival ____ Time
Date

____ Check if you need shuttle service. Shuttle service will be provided at \$2.00 per person round trip.



1979 Special Olympics to be held in Brockport

The Fifth International Special Olympics Games for the mentally retarded, world's second largest officially designated Olympic event, will take place at the State University of New York at Brockport in August 1979, it has been announced by Governor Hugh L. Carey; Eunice Kennedy Shriver, executive vice president of the Joseph P. Kennedy, Jr. Foundation, creator and sponsor of the Special Olympics; and Dr. Albert Brown, president of the College.

The 1979 International Special Olympics Games is expected to attract more than 3,500 participants and 1,000 coaches and chaperones from every state and over 20 countries throughout the world.

The Games, which will be held on the campus of the State University of New York at Brockport, will consist of competitions in track and field, swimming, diving, gymnastics, basketball, volleyball, bowling, floor and poly hockey, and wheelchair races.

Soccer will be introduced as an official sport of the 1979 Games, and there will be sports teaching clinics, demonstrations, and major celebrity events. The climax of the four day Games will be an Adventure Day at Niagara Falls for all Special Olympians and their coaches.

Held every four years, the International Special Olympics Games is the culmination of more than 17,000 local, area, chapter, and national training programs and competitive meets in which over 700,000 mentally retarded athletes take part throughout the world.

Describing the significance of the selection of SUNY at Brockport as the International Games site, Mrs. Shriver said "Only a major institution in a great state like New York has the resources and facilities, and the dedication to host the International Special Olympics Games."

The world's finest international program offering sports training and athletic competition for the mentally retarded, Special Olympics was founded in 1968 by Eunice Kennedy Shriver. Since that date, it has grown from a single track and field event held at Soldier Field in Chicago to a network of year-round sports training programs and meets in 90 percent of the counties in every state of the United States, every province of Canada, and 19 other nations from Hong Kong to Columbia.

From fewer than 1,000 participants in 1968, Special Olympics now involves more than 700,000 mentally retarded children and adults worldwide. The program is operated almost entirely by more than 250,000 volunteers making it the largest volunteer activity for the handicapped in the world.

More than 300 of the world's leading amateur and professional athletes serve as Special Olympics coaches under the leadership of Head Coaches Rafer Johnson, Bruce Jenner, Pele, Joh Havlicek, Billy Kidd, Donna DeVarona, Frank Gifford and Brian Watson.

All mentally retarded individuals from the age of eight, regardless of the extent of their disabilities, are eligible to participate in Special Olympics whose competitive events are organized by age group and level of performance. Research conducted since the program's inception offers strong evidence that physical training and athletic competition for the retarded not only enhance their physical, emotional, and intellectual development, but, equally important, strengthen their motivation, confidence, and self-esteem and prepare them for independent living in their communities.

The site of the 1979 International Special Olympics, the State University of New York at Brockport, served as the host site for the 1975 and 1976 New York Games.

One to One thanks Weingold

Paul R. Dolan of One to One, sent a special thank you to Jerry Weingold for his interview in an article in Community Living.

In his letter Dolan said, "I am sure that your views and knowledge about the needs of the retarded in New York will be both interesting and helpful to many in the field. All of us at One to One recognize the vital work you are doing. If there are any ways in which we may be of assistance, please let us know."

The article will appear in a future issue of Community Living.

Beyond deinstitutionalization

Some critics of deinstitutionalization are concerned about the availability and appropriateness of services provided the mentally retarded in the community, as well as the provisions which must be made to insure their physical safety and freedom from harm. Already, there is evidence accumulating that deinstitutionalization is not yielding the expected improvements for many retarded persons; it is therefore insufficient to simply espouse the concept of deinstitutionalization and community placement. The challenge is now to design the least restrictive, most appropriate service models for each individual's needs.

To date, the studies on the efficacy of deinstitutionalization have been more descriptive than truly experimental. Most studies are follow-up studies of deinstitutionalized persons placed in the community. Because such studies lack a control group, any conclusions drawn can only be impressionistic and imprecise at best. Very few studies compare the treatment modality in one setting (i.e., the institution) with the treatment modality in another setting (i.e., a group home). The initial studies reviewed foretell of both negative and positive experiences in the deinstitutionalization of the mentally retarded.

On January 7, 1977, the Comptroller General of the United States submitted a report to the U.S. Congress entitled, "Returning the Mentally Disabled to the Community: Government Needs to do More." Based on a follow-up study of 164 mentally retarded persons discharged into the community, the following major findings were reported: (1) mentally retarded persons were placed in nursing homes where the quality of care was worse than the institution; (2) the treatment administered consisted primarily of medication; (3) mentally retarded persons were readmitted to institutions because of the lack of community facilities and services. Throughout the report it was recommended that state and local agencies monitor and evaluate the quality of services provided the mentally retarded in the community.

A number of studies indicate that the deinstitutionalization of mentally retarded persons is resulting in beneficial effects. For example, Lyon and Bland conducted a 15 month follow-up study of 94 retarded

persons who were placed in nursing homes. Based on data from interviews and questionnaires, the investigators concluded that the residents in the nursing homes received a better quality of care than what they would have received in the state hospital.

It has been demonstrated that mentally retarded persons who have spent many years in large, total institutions can receive a better quality of care in smaller, community alternatives. The research shows, however, that the quality of community services varies considerably and that the results of deinstitutionalization are not always an improved lifestyle. Our value system, which espouses deinstitutionalization, must look to the situations which have had positive experiences in order to develop sound knowledge of what in fact constitutes successful alternatives.

It becomes increasingly important that the decision-makers use all the information available to them in formulating policy that reflects reason rather than chance.

Jefferson ARC will pay taxes

The Jefferson County Chapter will begin making payments in lieu of taxes for hostels it owns, according to Harold F. Hopkins, ARC executive director.

Although a taxed exempt body, the Chapter will pay the equivalent of taxes on \$55,400 worth of property or \$5,467 based on last year's tax votes. In the city of Watertown, there are five hostels and the ARC will also be paying in lieu of taxes for hostels in Chaumont, Evans Mills, and Rodman.

Hopkins said he had fought with the state to allow the in lieu of payments to be considered a reimbursable expense. But he also said, "If we're going to have a large community based program, we can't be a parasite on the community."

The ARC had been criticized from certain quarters for acquiring the homes for hostels in the community, and taking them off the tax rolls.

Court orders payment for summer program

In a decision of great significance to all our chapters, Family Court Judge Pomilio, County of Oneida, has made an order for payment for tuition and cost of transportation in connection with the summer program conducted by our Oneida County Chapter.

The county opposed the granting of the relief on various grounds, such as there is no showing that the parents could not pay the cost of tuition and transportation; cost of transportation was a proper charge on local school districts; the Oneida County Association was funded totally by the county and the payments requested would constitute double payment, and finally, that transportation should be provided under the regular Education Law.

The uncontradicted testimony was that the summer program was a continuing education program with emphasis on each child's special needs and the effort to help these 50 profoundly retarded children socially and academically.

Judge Anthony R. Pomilio, Family Court Judge for Oneida County, ruled "The children would regress, with serious consequences, without the continuation of the educational program during the summer."

Furthermore, the Judge ruled, citing other authorities, that children of preschool age could attend the program in a private school a public expense without any charge to the parents for tuition or transportation. Chapter 853, Laws of 1976, the Family Court retains jurisdiction for two classes of handicapped children: those attending summer programs and those under 5 who are not entitled to attend public school or receive services provided by the Education Law.

The Court also stated that "overriding the fiscal considerations it is a requirement by state and federal statutes (P.L. 94-142) to make available to all children free appropriate education in order to develop their greatest potential."

Reach out to save a child

Senator Conklin on prevention

In a recent speech at the New York State Savings Banks Annual Convention, Sen. William Conklin spoke on Preventive Health Measures to protect our children. Some excerpts from that excellent talk are shared here with our readers:

The most important concerns that mothers and, indeed, all parents have for their children are for their health and happiness. We can't, of course, guarantee happiness to every child that's born into this world although "the pursuit of happiness" is acknowledged as every person's right in the declaration of independence.

We can, however, do our best to ensure the health of our children. It is of the highest priority. After all, how many times have you heard this reply from an expectant mother when she is asked whether she prefers to have a boy or a girl, "All I want is a healthy baby."

But not every woman is so blessed as to give birth to a healthy baby. In fact, approximately 24 million Americans are in some way affected — either themselves or in their families — by the serious health problem of mental retardation. As the father of a retarded son, I am one of those 24 million people. As one who has witnessed the experiences of this lifetime handicap, I am deeply committed to not only improving the quality of life for the mentally retarded, but also to instituting preventative measures for the children of the future.

NEW YORK STATE IN FOREFRONT

We have made great strides in New York State toward both of these goals, and in the years ahead, we hope to achieve even more.

With the trend toward removing the mentally retarded from institutional settings and placing them in the communities where they can better respond to treatment, we have tried to ease housing restrictions for community residences. And we have made great gains in protecting the rights of retarded individuals.

PKU TEST HEARLDS INFANT SCREENING

But it is in the area of detection and prevention that one of our greatest breakthroughs was achieved. We learned that through a simple blood test administered to a newborn infant, it can be determined if an inherited metabolic disease known as phenylketonuria (PKU) afflicts the child. Undetected and untreated, PKU generally results in mental retardation. When detected by this test, however, immediate steps to treat the disease by a modification in the child's diet can be taken and a lifetime of mental retardation averted.

Since the PKU Law was enacted, we have extended the infant screening program to include testing for several other diseases, most of which result in mental retardation. More recently, my proposal to add hypothyroidism to the list was adopted during this past legislative session. With its high incidence rate, hypothyroidism can result in mental retardation if untreaded during the infant's first three months of life. Early detection can lead to successful treatment.

As I am sure you can well imagine, having a mentally retarded child can be traumatic to parents. The "It couldn't happen to me" logic does not hold. But the devastating burden on the family is not only emotional; it can be a tremendous financial strain, too. And that's the reality of the situation. In New York State, the cost to maintain a mentally retarded child in an institution may well reach \$250,000 over the lifetime of the child, with the state, which really means the taxpayer, picking up much of the expense. But for a

mere \$2 per child for the screening tests, the drain on emotions and financial resources can be avoided. Prevention and detection of some forms of mental retardation at early, treatable stages are of the utmost importance. That's why our testing program has proven so valuable.

Prenatal diagnostic testing is also coming to the forefront in terms of prevention of birth defects. Amniocentesis, the procedure in which a small amount of the amniotic fluid surrounding the fetus is drawn from the womb early in pregnancy and tested, can be performed.

At the present time, we are considering a mandate for the screening of all women of child-bearing age for their susceptibility to rubella, better known as German measles. Our ideal, of course, would be to immunize all women against rubella before they reach child-bearing age.

EARLY IMMUNIZATION IS CRITICAL

Another means of protecting your children's health is to have them inoculated against childhood diseases. That's obvious, you may think, but you would be surprised how many children lack this most basic protection. New York State law requires that a child be immunized against diphtheria, polio, measles, mumps, and rubella before he or she is allowed to enter school. Outbreaks of these diseases in some localities threaten not only the health of children in the community, but their incidence can also endanger the health of senior citizens and can have serious implications for pregnant women because of the often greater severity of the disease in adults.

Despite the fact that we have this knowledge, alarming numbers of children have not received this protection. Recent studies have shown that as many as 50 per cent of the children about to enter school in New York City have not been immunized against diphtheria and polio. News reports from Detroit indicate that 6000 children were turned away from schools because they could not prove they had been immunized. It is difficult to rationalize these figures when the vaccines are so widely available and free of charge, if necessary.

In response to this serious situation, I introduced a very important legislation this year to reduce the number of unprotected children. It is designed to withhold needed state aid to schools that cannot certify to the commissioner of education that each child admitted to that school has been properly immunized. Indeed, it is unfortunate that we have to resort to such a measure because enforcement of the law has been lax.

VACCINATION NEGLECT TERMED "DISGRACE"

In March of this year, a *New York Times* editorial observed that "vaccination seems to be going out of style" and called the trend a "national disgrace." The latter does, in fact, seem to be true, but all of us, as parents, cannot allow these needed immunizations for their children to be ignored or go out of style.

That's really my point in speaking with you here today. So much good preventive medicine is within our grasp. For the sake of our children and ourselves, we should make the most of it. Years of dedicated research have brought substantial gains in the health field, and the root of the issue is prevention.

If we can protect our youngsters from some of the more serious complications of mumps such as deafness by having them immunized, then it is our responsibility to have them immunized. If we can prevent mental retardation in our youngsters by

testing them as infants for PKU or hypothyroidism, then it is our responsibility to have them tested. In the long run, immeasurable human suffering and emotional and financial distress can be avoided.

It is one thing to successfully treat a disease with all its accompanying pain and suffering after it has been contracted. It is quite another thing to altogether avoid the disease in the first place. And that's where we need to focus our efforts. Governmental action to ease the tragedy of these diseases for both child and parent is one response. But the primary and proper role of government is to prevent the affliction before it strikes.

The children of this country are our greatest natural resource and our only hope for the future. We must do all that we can allow them a lifetime of health, happiness, and productivity whenever it is within our power to do so.



Left to right standing: Al Berbary, Marc Brandt, Paul Nigra. Left to right seated: Anthony Terranova, Joseph Weingold and Evald Gassstrom, Chairman.

N.Y.S. ARC Vocational Rehab Committee meets

N.Y.S.A.R.C. Vocational Rehabilitation Committee met on March 15th to discuss its priorities and voice its concerns regarding the grossly inappropriate funding allocated in the Governor's Budget for Community Services to the mentally retarded and the developmentally disabled.

The results of a recent survey conducted by the Vocational Rehabilitation Committee prompted a Press Release by Mr. Weingold:

A recent survey of the 58 Chapters of the Association providing most of the vocational rehabilitation services for the mentally retarded in New York State, indicates a waiting list of over 800. In addition, it is anticipated that about 2200 will have to be served in the year 1978-1979, one-half from the institutions, and one-half from the communities.

There is no physical space to place these people. To serve them we need, almost immediately, 400,000 square feet of additional space. With construction costs at about \$40 per square foot, this would mean an immediate appropriation of \$16 million by the State or some state leasing arrangement.

Plattsburgh infant program

Twenty infants in Clinton County are currently being served by the Early Infant Intervention Program (EIIP) implemented in April through the county chapter of the Association for Retarded Children, Inc.

"To date, this represents twice as many as were predicted for the first year," said Peter Frederick, co-director of the Northeastern Chapter of the Association for the Learning Disabled (ALD). He added, "It certainly points up to a need for this type of service."

EIIP is designed to provide assistance for developmentally delayed children through proper planning to acquire learnings that will minimize problems encountered in later years.

"Parents are the best teachers is the basic philosophy of the program and family interaction a necessity," Mrs. Jo Wayman, program coordinator says. Detailing the way the new program works, Mrs. Wayman explained:

— Referrals are accepted from physicians, social service agencies, public health, parents and friends. Problems stem from many sources. The main emphasis is to catch them early and forget the old saying, "They will outgrow it," she said.

— A home visit is made for the Denver Developmental Screening and to obtain medical histories.

— Each infant is evaluated by a consultant team consisting of a pediatrician, psychologist, nurse practitioner, physical therapist, occupational therapist and speech therapist.

— The staff designs an individualized program, or if another agency might better meet the child's needs, a referral is made.

— Home educators visit the child once a week and train the parents in the routine they are to follow.

Further information may be obtained by contacting Mrs. Wayman at 563-0930 at the Chapter's office at RFD 3, Salmon River Road in Plattsburgh 12901.

The Committee also endorsed four specific pieces of legislation:

S. 8106 — Levy et. al.
A 10530 — Amatucci et. al. — Authorize SEP payments immediately upon completion of EVAL and Personal Adjustment Services effective 90 days after enacted

S 7486 — Donovan
A 9731 — Murphy et. al. — Authorizes payments for SEP of not less than \$1,500 and not more than \$3,000 effective immediately

S 770 — Gold — Authorizes the Education Department to pay for transportation of clients to qualified sheltered workshops. Appropriates \$5,000,000 effective — July 1st.

S 8246 — Padavan
A 10301 — DeSalvio — Increases State Aid for community mental health and mental retardation services to 75 per cent.

Committees on Handicapped DO function

Handicapped children in the Altmar-Parish-Williamstown Central School District in Oswego County are not merely placed in a program and ignored.

According to federal law, with state implementation, every school district is required to form an active committee on the handicapped.

This committee is responsible for reviewing each child's capabilities, recommending proper placement for each child, assessing the various programs and reviewing placements.

It is also mandated that each handicapped child be given a psychological examination every three years.

By law, the committee should consist of the school psychologist, the school physician, one special education teacher and one parent of handicapped child.

For this school year, there are approximately 80 children placed in special education programs.

Four children attend the Oswego County Chapter of the New York State Association for Retarded Children preschool class.

The committee strives to provide the least restrictive environment for each child, which includes mainstreaming as often as it is appropriate for each one's particular situation.

State regulations mandate that the school districts be responsible for the

identification of handicapped children from birth to age 21. The districts are responsible for the education of these children from age 5 to age 21.

The APW school district would rather intervene quickly to do evaluations for concerned parents or provide information if any parents suspect a developmental lag in their child. Many problems can and should be recognized, and actions should be taken before the child is registered for school.

The Committee on the Handicapped meets at least once a month to discuss the placement of the handicapped children in the APW school district and to assess the various placements.

Parents are invited to submit information which may be helpful in understanding their child's capabilities.

All information is completely confidential between the parents and the committee.

Representatives from the committee make annual visits to each center in which students are placed to ensure that the placement is appropriate.

Besides educational programs, the committee makes referrals for places of employment such as the Association for Retarded Children Sheltered Workshop in Fulton for children in their late teens to age 21.

Where have all the parents gone?

By Ruthie Pattison

Local units of the Association for Retarded Citizens are facing an identity crisis. Did we do our jobs too well?

We ARC's (parents mostly) struggled all these years to get services for our kids. Every service my son had was a first-time thing in the community, sponsored by the ARC who pushed hard enough to finally get something. Education, recreation, religious nurture, civil rights, job training, social opportunities, residential care — even scholarships and education programs for future professionals in the field — were initiated through action of the ARC. We've come a long way baby! Can we quit now?

My husband and I kind of hoped so. At least, we felt we could slack off. Mental retardation had been our whole preoccupation for many years of struggle. Now our son is quite well served and we felt we could take time to develop our other interests.

Attending local ARC meetings became a drag because there were so few there, and we really didn't do much except hear the same things over and over — mostly appeals to serve on committees, give time, give money, get involved!

But suddenly we realized we'd better stay in there! At the last meeting the majority of those attending were not parents, not the "consumers" of all the good things that had been accomplished, but professional people who are involved in serving the mentally retarded. And they are telling us "what we are doing" for "your kids". Oh, I'm grateful to the professionals for their presence and their services to the mentally retarded, and to the ARC. We longed for them back in the old days. But we've got to be more than a "professional society."

SO WHERE HAVE ALL THE PARENTS GONE? I submit that this is the best time of all for parents to become active members of ARC — much of the hard work has been accomplished. They should belong even if their child has been mainstreamed into the system, carefully not labeled as mentally retarded, learning to cope and integrate with "normal" society.

Local unit meetings are great forums for parents to "dialogue" with professionals on the services that are being provided for their children. To ask questions and get answers. What's happening in education, in residential programs, in work-training. And what we are doing for new parents?

How can we get parents to forget the idea that if they are involved in an ARC they are labelling their children as mentally retarded? How can we show parents that "getting involved" is one of the best ways to serve their child's best interests? How can we make it exciting again? We need both parents and professionals — let's not let the professionals carry the whole show.

WHERE HAVE ALL THE PARENTS GONE?

Lead count down

A study by the Department of Housing and Urban Development found that lead levels in the blood of New York City children dropped significantly between 1970 and 1976... decreasing by 30 per cent over the 6 year period.

Certain aspects of the study raised new questions as to whether lead based paint is the major cause of abnormal lead levels among inner-city children as has been commonly assumed, or whether polluted air is also to blame.

Although it was emphasized that officials still feel that peeling lead paint is a hazard to small children they added:

"Presently, we do not know whether lead in the air or lead from the paint is the more important of the two. This study does not provide answers, but does raise additional serious questions about where and how children get their lead. These questions must be answered."

The link was made because of a parallel between a drop in both lead in the blood and lead in air, suggesting that a relationship between the two may exist. Regulations governing gasoline and automobile engines that have been enacted recently may account for the decline in air lead counts.

Head HUD project begins



Left to right, Ed Emmer, Jerry Weingold, State ARC staff, and Harvey Berg and Laurence Werfel, Architects, at the signing of the contract for the 12 hostel HUD project.

Judgment denied in action for fees

In an action brought by the State of New York Department of Mental Hygiene against Murray Schneps, parent of a retarded child, for fees the state claims Schneps owed for services to his child while at Willowbrook, the Civil Court of the City of New York denied the state's motion for a summary judgment.

In denying this motion, the court stated, "There are triable issues of fact involved in this action which can only be resolved by a trial. One of said issues is whether plaintiff rendered the proper care and supervision to defendant's child for which plaintiff is claiming a balance due."

It is, of course, the contention of the State Association that the parents do not owe these fees for a number of reasons. The state has embarked on a series of actions against parents which are being defended by the individual parents. The present decision is an encouraging indication that there is some question as to whether the state is entitled to this money, if for no other reason because the state did not render proper care and supervision of the resident involved.

Posthumous letter from a friend

Recently, a member of the Board from Tompkins County, Dr. Alvin Knepper, died.

This is sad enough in itself, but among his effects was found a letter dated February 15, 1978, when he knew he was very ill, and probably would not live, addressed to Jerry Weingold.

The letter follows. It expresses, we hope, some of the esprit de corps that we hope exists on our Board of Governors and among our members. "Dear Jerry, with sadness, I must hereby resign as a Governor of your Board as soon as I can be replaced by the local chapter from which I had already resigned for personal reasons. The continued deterioration of my health has limited my activity and I, therefore, must resign from the Governor's Board, so that a healthy person can fully participate in the work and objectives of the Association. My illness is terminal.

I pray that I have been of some little value to the Board and Association. I shall always be grateful to you all for your trust, faith and re-election of me at the last Board meeting.

I want to thank you, Jerry, especially for your inspiring dedication and assistance which you have always made available to me. Also, please extend my regards to John and your excellent staff.

God bless you and I would appreciate your acknowledgement of receipt of this letter for my media and files. Cordially yours, Alvin Knepper."

Wassaic suit settled

In June, 1976, fifteen parents of retarded residents of Wassaic Developmental Center and the New York State Association for Retarded Children, Inc., brought an action against Governor Hugh Carey, Commissioner of Mental Hygiene Kolb, Commissioner of Mental Retardation Coughlin, Commissioner of Education Nyquist and Richard Merges, Director of Wassaic Developmental Center, to bring quality care and treatment to the residents of Wassaic. Plaintiffs sought to use this lawsuit as a vehicle to bring Willowbrook standards for care and treatment to the Wassaic residents by alleging it is unconstitutional for the State of New York to provide the same kind of care and treatment at another developmental center. (Wassaic) Plaintiffs hoped to gain improved community facilities and services and a commitment from the Wassaic Administration that the residents of Wassaic would become more involved in community life, activities and events. Plaintiffs were represented by Jack Bernstein, Executive Director and General Counsel of PASDD and volunteer attorneys Walter C. Redfield and Augustus M. Jacobs.

Improvements occurred at Wassaic as a result of the pending lawsuit. In March, 1977, counsel for Plaintiffs and Defendants began to discuss the possibility of settling the case. In October, 1977, a settlement was reached and on November 4, 1977 a Stipulation discontinuing the action was filed by all the parties.

The terms of the settlement call for the creation of an operational plan for Wassaic Developmental Center to establish quality facilities and services for the residents in accordance with their needs. Throughout the initial phases of the lawsuit, Plaintiffs brought twelve experts to Wassaic to conduct lengthy detailed inspections of the existing conditions at Wassaic. Part of the settlement provides that Plaintiff's experts will have ongoing input into the creation of the operational plan. PASDD will monitor the implementation of the operational plan once it is completed, reviewed and accepted by Plaintiffs and their attorneys. It should be understood that an operational plan means a document which sets forth, in a detailed manner, the goals of the institution, the various functions of every part of that institution and how those goals and functions are to be brought to bear upon the problems of the residents of the institution. For the first time, Wassaic will have a means of marshalling its resources in order to concentrate on specific needs of the residents in an organized and efficient manner. The end result, better services to the residents, should generate staff enthusiasm. They will know that specific steps undertaken with a particular resident will, in fact, lead to an achievable goal.

Pros and cons of "Who is Client?"

The article in the January issue of OCV... Who is the Client, Parent or Child? ... written by Robert J. Hodgson, brought several strong responses. Three are reprinted here and argue for and against the question. The first is from Ira L. Fisher of the Syracuse Developmental Center, the second from Betty Pendler, Chairman of the Education Committee of the N.Y.S. Association for Retarded Children and the third is a condensed version of a statement signed by 34 of 39 available staff members of the NYC AHRC Training Center.

"ETERNAL PARENTHOOD CONSIGNS RETARDED PERSONS TO ETERNAL CHILDHOOD"

I read your letter, "Who is Client," reprinted in the February, 1978 edition of *Update*, the Syracuse Developmental Center newsletter. You state that "when there is a disagreement between the child and the parents, it is the parents (sic) wishes which will control, and not the child. . . ." You speak of two groups of persons, those who are under age, and those who are "incapable because of mental retardation."

I see room for disagreement with your contentions for both age groups, but the issue is not as clear for children. Let me concentrate on the age group with and for whom I work, adults who have been labelled mentally retarded.

I believe that most prodigious handicap facing adults living at Syracuse Developmental Center is the myriad manifestations of the prevailing societal attitude that they are "incapable because of mental retardation." My duty is to fight and disprove that attitude wherever it appears: among acquaintances, friends, colleagues, administrators, legislators, parents, or those persons who have been so labelled. Only when the global assumption of incapability or incompetency is overcome, can individuals, all of whom are citizens of the United States, begin to develop the skills necessary to live in our society.

The methods I and my colleagues choose to employ are rooted not in the technological expertise of various "professions," but in a value-based ideology, which has been called normalization. Briefly and simplistically defined, normalization seeks age and culture appropriate behaviors, forms of address, and appearances, and seeks to elicit these using means that are as culturally normative as possible. There are many ramifications of normalization which are not readily apparent. One, which I think germane to concerns expressed and implicit in your letter, is the dignity of risk.

If adults are to learn those skills typically expected of persons their age, they will necessarily encounter dangers. A person using hot water may be burned; a person learning to cross streets and use public transportation may be involved in an accident or get lost; a person working with machinery may be injured. The decision to face, and possibly invite certain risks must always be made prudently, but in every person's life, it must be made. This decision is bound with the exercise of human rights. The history of many mentally retarded persons is filled with decision points, which I categorize as follows:

- 1) a possible learning experience, with elements of risk appears;
- 2) the decision is left to someone other than the retarded person;
- 3) the decision is made not to encounter the risk; and
- 4) the learning experience has been wasted, and the loss is a denial of human rights.

I do not think it possible, let alone fair, to say that one group of persons, be they parents, clergy, physicians, or hearing officers, hold any special claim on wisdom. All of us have been inbred with prejudice toward handicapped persons all of our lives, and that prejudice continues to color our decisions. But one thing is certain. We must escape from that prejudice. I think that only when we have examined and confronted our persistent devaluation of mentally retarded persons can we begin to provide adequate, comprehensive, integrated services.

In 1973, at the insistence of a handicapped adult, the National Association for Retarded Children became the National Association for Retarded Citizens. Thus far, the New York State Association has resisted that change. It is highly symbolic that you argue that the "client" is always the parent. If we have eternal parenthood, we consign retarded persons to eternal childhood.

Ira Fisher
Syracuse Developmental
Center

"IN MAKING SOME DECISIONS, SHE USES POOR JUDGMENT"

As usual, you sure hit the nail on the head with your excellent article in the last of OCV "Who is Client? Parent or Child?"

I am sure you have made many parents happy with that article and I hope you gave some professionals food for thought.

It seems to me a good professional should understand and appreciate the parent's genuine concern, and not immediately label it as being "resistive" or over protective. Fortunately there are many such professionals, but there are those who have not yet accepted the premise that parent and professional can both have a legitimate point of view, and that indeed many clients are not capable of making a decision based on clear judgment. My contention is that if they could, the professionals wouldn't have a job in the field of mental retardation, nor would the client be mentally retarded!

That is not to say that there are not, indeed, many parents who are resistive to suggestions made by professionals, or many parents who are over-protective; but unfortunately, there are many professionals who feel they have a greater right to make decisions than the parents, or that their opinion about the competency of the client is always correct.

Many professionals working with the adult who is retarded seem to feel that they ought not to listen to the parent, since their primary responsibility is to engender independent thinking on the part of the adult retardate. I always get a slight inference from some professionals that they feel the parents are interfering with their sincere effort to make the adult more independent, and they are working to undo all the irreparable harm that the over protective parent has committed up until this time.

I submit, in this are, as in others, parents are aware of the strengths and weaknesses of their offspring, and I personally believe that one of the weaknesses inherent in many persons who are mentally retarded is lack of clear judgment. I had a personal experience where my daughter was being interviewed regarding the type of group home most suitable for her. I was politely told that this was a decision for her to make, and not me. I tried to explain that she constantly talks about having her own home, baby etc., which to me is fantasizing, she talks about moving to California to live with her TV hero, David Cassidy, to which the worker responded "I still think Lisa knows what she wants".

I respect this worker, although she chided me gently for trying to make up Lisa's mind as to the choice of 2-3 homes under discussion, and she insisted that Lisa respond to her question which was "in which home do you want to live?" to which Lisa quickly answered "Oh, I want to move out of my house, but I want to go to California and live with David Cassidy"!!!

I hope this remark convinced the worker that although Lisa has many strengths in many areas, that in making some decisions she uses poor judgment.

Betty Pendler
N.Y.S. Assn.
Education Committee

"RETARDED PERSONS HAVE RIGHTS"

Mr. Hodgson says that, "When there is a disagreement between the child and the parents, it is the parents' wishes which will control. . . ." He applies this to adults as well as to minors. He seems to believe that parents are always correct because they are parents. Parenthood confers upon us neither omniscience nor omnipotence. As parents, we remain humans, and as humans we err. We err out of our limitations in understanding, out of anger, anxiety, frustration, inner conflict, bias and despair, out of our inability to cope with overwhelming problems. We also can err with the love which sometimes infantilizes and constricts. Like the rest of humankind, some parents are also mentally handicapped. Sometimes parents do know best. Sometimes the retarded person knows best. Sometimes the workers whom Mr. Hodgson scorns know best. Sometimes, alas, no one knows best.

Mr. Hodgson justifies total parental control over the "of-age" retarded person as over the minor on the ground that all retarded people are "incapable because of mental retardation," the incapacity being one of "managing his own person and affairs." Out of a quarter century of intensive work with thousands of retarded adults, our Shop knows that they vary vastly in their ability to manage "person and affairs." Mr. Hodgson implies they are incapable of significant improvement but we know this is untrue. A parent may know a son or daughter well but a worker gets to know hundreds of retarded people well. The parent is in danger of seeking all retarded people as identical with his or her own child.

Mr. Hodgson says that the client is not the retarded person but the parent. "We are a parents' organization, and the client is the parent." We see both parents and retarded persons as clients if they want service. We try to help both retarded people and their parents respect their sometimes conflicting needs and wishes. We often have to help them decide whether to remain in conflict with each other or to yield or compromise. We have helped many retarded people achieve manifestations of adulthood such as jobs, intimacies, new homes, and the management of money, time and energy in the face of their parents' resistance.

Mr. Hodgson says, "Any social worker who forgets or ignores this (viz., the right of a parent totally to control a retarded person) should be immediately terminated." He urges parents "to take a baseball bat to the person making the decision" opposed to a parent. He ridicules workers who differ with parents as of "immature judgment" and "not dry behind the ears." He urges parents "to turn the child over to the person with a demand that he or she assume full, financial and other responsibility for feeding, clothing and raising the child." Would Mr. Hodgson really give up the "child" rather than accept a worker's

support of that "child's" point of view? Is this love of child or love of power? Yet, Mr. Hodgson associates with "Hitler and Mussolini or Mao Tse Tung" not himself but the workers who differ with him.

Mr. Hodgson seems unaware that in obliterating the rights of retarded people vis a vis their parents, he supports their growing up into passive, dependent, incompetent, craven adults, whom the public widely associates with bizarre children. That association evokes public contempt, class discrimination and denial of opportunities. (Our insistence on calling retarded adults "children" strengthens public hostility toward retarded people, for people have contempt for adults they see as children.) We tell society to give them adult jobs to perform, adult domiciles in which to live, and adult incomes to make living possible.

Fortunately, we are in an era of increasing appreciation of the life-giving value of respecting retarded people as people. Retarded people have rights as do the rest of us, to be yielded only for individual reasons and through a rigorous due process to which we are all entitled. In this era, Mr. Hodgson's statement sounds a dissonant clangor.

Staff,
NYCAHRC
Training Center

Program by One-to-One

Paul Dolan, director of One-to-One has announced plans for an extensive Spring Public Education Campaign, involving a cooperative effort of retardation agencies throughout New York State. The cooperative project will include:

1. The **Media Awards** ceremony to acknowledge and encourage responsible press attention to the needs and abilities of the retarded.
2. The **June television special** to raise funds for community residences, and to raise the level of public understanding.
3. An extensive **public speaking** campaign, and the creation of a **Speakers Bureau** to reach schools and community organizations.
4. "Operation Open House" — an effort to reach community, political, religious and media leaders on a direct and personal level through inviting small groups to community residences to share a meal and to meet the individuals behind the label "retarded".
5. One-to-One has asked Governor Carey, Governor Byrne and Mrs. Rosalynn Carter to issue proclamations or messages of support. Top music performer Stevie Wonder has agreed to "carry the message" to the music world press, and visit one of the homes. The School of Visual Arts has designed a special series of posters to increase the public's understanding of the retarded and community care.

Here's How You Can Participate:

1. Send copies of any exemplary media coverage about the retarded which you feel should be rewarded.
2. Increase your efforts to reach community organizations through speaking engagements and other efforts.
3. Participate in "Operation Open House" and try to reach individuals who may not already be aware or supportive of community care for the retarded.

For additional details regarding the project, posters, information on press and mass media effort, contact One-To-One, 1330 Avenue of the Americas, New York City 10019 (telephone 212-874-2410).

Budget Statement

Continued from Page 1

\$2,250,000 to the parents and relatives who take their children out of institutions, not one nickel for those who have kept their children at home through years and years of torment, sweat and hard work.

\$1,404,290 for sheltered workshops to provide some of the back-up services for the adults coming out of the institutions. For this amount we can build one and one-half workshops to serve, perhaps, 300 people. It is an insult to one's intelligence to have this little amount there calculated to take care of the back-up services, which now do not exist for these people.

And, finally, what do we have for those who are in the community and where the law states that the Department of Mental Hygiene will match dollar for dollar what the community puts up for these community services — \$19,762,000, an increase of \$3,661,981 over last year, barely enough to take care of cost of living increases let alone the great demand for services in the community which the state is not able to match. It is providing a pittance for the development of the back-up services necessary, not only for those coming out of the institutions, but those in the community. Without these, it will be a dumping operation.

WHO IS BEING SERVED?

Now who is being served by this, except for the last item? The total institutional population is about 2 per cent of all the mentally retarded in the state. The 620 and other services represent a fraction of this 2 per cent. Thus, this budget including the over \$300 million for the institution will be serving about 3-4 per cent of the total mental retardation population in the state with a measly \$19 million for the other 96 or 97 per cent of the mentally retarded in the community.

In effect, what the Governor is doing is robbing the mentally retarded and their parents in the community in order to achieve a "deinstitutionalization program".

If we add to this the absolutely unreal statement of the commissioner that there are no admissions to the institutions because the communities have developed all the services needed, we really stand back and wonder at this nonsense. There are hundreds, perhaps several thousand mentally retarded persons in this state who need at this point 24 hour a day supervised care and medical attention that can only be given in institutions and they are not in the institution because the state has dropped an iron curtain against admission.

We do urge there be some realignment of priorities especially with regard to local assistance for community local services and that the budget of \$19,762,000 proposed by the Governor be revised upward so that we can get a 75-25 per cent reimbursement for such services instead of 50-50. We suggest a 50 per cent increase over last year's budget (\$16 million plus) to \$24 million instead of \$19,762,000 or, an increase of \$5 million over what the Governor asks.

HELP FOR COMMUNITY AGENCIES

In addition to helping the community agencies carry out what we consider our moral responsibility, (although some people seem to think it is our legal responsibility) to provide community services for the mentally retarded and developmentally disabled, it will provide the hard beset counties with indirect state aid relieving them of the 25 per cent many of them now contribute to these community services. What better way of giving aid to the community and at the same time rendering a human service than this?

How can we achieve this? We think it can be achieved without increasing this budget at all.

For example, the Governor proposes to place 1300 people into additional beds in the community during the next fiscal year. This is in addition to the 1200 clients in the community (not all of them from institutions by any means) who have been placed in community residences since 1966. Let's cut this from 1300 to 600 and we immediately lop off 25 per cent of the \$17,290,000 budget or a saving of over \$4 million.

Why should parents be rewarded for taking their children home at an expenditure of \$2,250,000 by the state? Let us eliminate this from the budget and we save another \$2,250,000. We already have enough to cover the \$5 million that we have recommended in increase.

Now what can we do with this excess? Why, we can increase the budget for the construction or implementation of sheltered workshops as back-up services for those 600 whom we are going to place in the community, as well as those who are going to need it as they grow older in the community not having been in institutions.

Where is the state putting its priority? It is putting its priority heavily on 4 per cent of 100 per cent of the population. It just does not make sense. There is a tremendous backlash in the community against this kind of thing and in the end it is counterproductive to what we are trying to do.

VOCATIONAL REHABILITATION BUDGET

Since 1969, when the Education Law was amended to permit partial support of long-range employment of the mentally retarded and then amended to include the mentally ill and physically handicapped, except for one year, the agencies have never received more than \$1000 per year for this program. The cost to the agencies is \$4500 average, some more, some less. This deficit of \$3500, if the agency qualifies for a contract with the local mental hygiene apparatus, is reduced by half so that each agency has to shell out \$1750, at best, to support this program.

The law permits payment up to \$1500 but the money has never been appropriated. It is unreasonable to expect the agencies now represented by a coalition of all of them to continue such a program, which is of tremendous value, not only to the clients, but the state itself. Such a program has at its end the prevention of institutionalization, the maintenance of the client in the community, at enormous savings to the state.

POLICY IS NOT REGULATION

In addition to this starvation rate, at the end of the time when vocational rehabilitation finishes its sponsorship for training these handicapped endure a waiting period of up to two years before the agency can receive any money under the long-range employment program. During this time, the agency is spending all its own money, up to \$4500 a year. We are asking that the law be amended or that the policy be disregarded since it is not part of the regulations of the commissioner and that we receive funding of \$1500 a year for these 1300 as well, or another \$1,575,000.

The total, therefore, that we are asking is \$500 times 6200 for \$3,100,000 plus the \$1,575,000 or \$4,675,000. From this must be subtracted what the Department of Mental Hygiene is now contributing through local contracts, approximately \$2 million, leaving a total net increase of \$2,675,000.

This is not a net increase, anymore than what we asked in mental hygiene. Let us look at page 179 of the Governor's budget. There the Education Department asks for \$458,000 to reorganize the administrative structure of the central office by putting in high level positions, principals, stenographers, internal audit, creation of a vendor review, etc. This money,

This money, \$458,000 should go toward the support of services instead of another bureaucracy.

If we add to this the \$243,000 to reorganize three major local offices by "the infusion of about 10 positions... to provide managerial direction, etc." and the establishment of an Office of Policy Evaluation, whatever that means, we have almost \$1 million to put against this \$2,175,000 and the increase, going directly into services will have some meaning.

In summary, therefore, we are asking you to overcome the imbalance between the 100 per cent funding that the state is giving for deinstitutionalization, and the 50 per cent to those who were never institutionalized; to equalize the treatment of the parents who never sent their children to institutions with those who take their children out of institutions, to help the agencies that have suffered alone so long in vocational rehabilitation of the mentally retarded and developmentally disabled.

For all this we are asking a net increase in the budget of less than \$4,000,000, but even more important than that, is the realignment of priorities, and saying at last that the emperor is without clothes.

SSI for workshops clarified

The Social Security Administration recently issued a change to the **SSI Claims Manual** outlining new procedures for determining whether remuneration received by sheltered workshop clients should be treated as earned or unearned income. The purpose of the new policy is to eliminate ambiguities in previous policies which led some SSA District Offices to treat the wages of long term workshop employees as unearned income, thus eliminating or sharply reducing their monthly SSI benefits.

The new procedure states that a disabled individual engaged in a rehabilitative training phase of sheltered work may or may not be found to be engaged in an employee-employer relationship, depending on the circumstances. However, unlike the previous policy, the new one makes it clear that "when a handicapped individual continues in some type of a sheltered workshop environment after the completion of this rehabilitative training program, and receives remuneration for such work activity, then the recipient may be performing services in an employer-employee relationship... and may be receiving earned income."

If a workshop client has FICA and/or other payroll taxes deducted from his wages, normally he will be considered to be engaged in an employer-employee relationship and, thus, his wages will be treated as earned income. If taxes are not being withheld, then it is necessary to determine if an employer-employee relationship exists under the "common law test." "Where the primary purpose for the individual's being in the workshop is to participate in a vocational rehabilitation training program and the intent of the supervision and control of the individual who performs the services is to rehabilitate and protect him and to accustom him gradually to work conditions outside the workshop," an employer-employee relationship normally does not exist and any remuneration received by the client is treated as unearned income. To determine if an SSI eligible individual is involved in a formal rehabilitation program, SSA staff are instructed to contact the workshop. The views of workshop officials are "to be given considerable weight..." in determining whether the individual has completed the rehabilitation phase of his program.

Two colleges open doors to retarded

Despite the general boom in continuing education on hundreds of American campuses, universities have given little thought to the educational needs of retarded people once they have moved beyond special education classes in public high schools or institutions.

This is beginning to change. S.U.N.Y. at Brockport has established a program, known as "Basic Skills for Independent Living," for adult retarded students, as an integral part of its regular continuing education offerings. Another such effort has been started by Broward Community College in Fort Lauderdale, Florida.

Even when they leave school, retarded students are often deficient in many areas, such as social and job-related skills, few of them are able to find post-high school education programs that emphasize these areas. "Many retarded adults who hold jobs in their communities really don't benefit from their tax dollars used to support the local college," Dr. Eileen Corcoran, director of the program, said.

Dr. Corcoran, a professor of educational psychology, began the program with eight students in January 1974 with the goal of breaking through what she calls the "wall of elitism" that often separates a college from the diverse population of the community surrounding it. With the aid of one state grant and donations, she has led its growth to its present enrollment of 125 students.

Through a series of one-semester courses, moderately and severely retarded "clients" work with a non-disabled college-student volunteer and choose from a variety of leisure-time activities designed to develop adult social behaviors.

Each evening session is divided into three periods of instruction in which clients and volunteers select from activities such as bowling, swimming, ice-skating and gymnastics. Volunteers aid retarded students in tackling unfamiliar activities, becoming proficient in favorite sports and in fostering adult social relationships among retarded peers.

The development of social skills is a major goal. "The young people are repatriated from institutional settings to group homes and supervised apartments and many hold jobs in their communities, yet they had never been taught how to effectively use their leisure time," Dr. Corcoran said. "In school and in institutions the retarded have always been supervised." Few had the opportunity to select a place to go, pay for an activity and participate independently. This program fosters those independent social skills, using the excellent facilities that the college provides.

Dr. Corcoran, who does not view the absence of a special education department at Brockport as a detriment, states that "too often programs like these have originated because college special education students needed a field placement. They needed to see what a retarded person looked like. My premise is that this program can and should exist with or without college-student volunteers."

"Each retarded person has a right to function as fully as he can in his community," she said. "The continuing education program at the local college is the logical place for the retarded student to begin."

The New York State Association for Retarded Children strongly feels that all community colleges should offer programs for the retarded. Many retarded adults would benefit greatly from such programs.

LETTERS — LETTERS — LETTERS

EXCHANGE ON AMNIOCENTESIS

Mrs. Francis Faber of Deer Park, New York writes a criticism of the article in the June 1977 issue of *Our Children's Voice*, entitled "Prenatal Diagnosis: Project Funded." Jerry Weingold's response to the letter follows:

As a mother of a three year old boy with Down's Syndrome, I must express not congratulations but disappointment and disapproval of the information imparted by an article in your last issue.

Is amniocentesis the great boon that the medical profession is now offering the retarded and the parents of defective children? Is not this the same profession to be blamed for pushing the retarded into institutions in the past? Now are they to go beyond that and suggest parents destroy the defective fetus before it is born. Are they now saying: "Save yourselves, society and the child himself a great deal of trouble"?

Let's not fool ourselves. Amniocentesis can do nothing for the defective fetus. A mother who underwent amniocentesis at North Shore University Hospital in Manhasset told me, "If the fetus is found to be defective, it's taken for granted that you will have an abortion."

I am a mother (and believe me there are many of us) who thanks God for her child and asks merely for help and guidance in allowing him to develop his full potential — help which a great number of professionals stand ready and willing to give. A visit to the school run by the Association for Children with Downs Syndrome, located in East Meadow, New York gave me reason to hope beyond all measure. I believe at no other time in history have the handicapped — even those with Downs Syndrome — so many positive things going for them.

Dr. Jahiel and Mr. Weingold, with friends like you, the retarded have no need of enemies.

Dear Mrs. Faber:

In this free country, everyone has a right to express an opinion, if that opinion does not do psyche or bodily harm to anyone else. Unfortunately, your opinion that amniocentesis is and of itself should not be permitted, does do at least, in my opinion, harm to the psyche of women who unexpectedly give birth to defective children.

The mere fact you and my wife were subjected to this experience, does not make it necessarily the best in the world. I must say, there is nothing in this article which suggests in the least, that women who are being told through amniocentesis they are going to have defective children, should abort their children. This is for them and their husbands to decide, according to their religious or other beliefs.

I am sure you will agree we should not keep women in total ignorance of what might happen to them. That is all amniocentesis is.

If you think the good things that have happened in this state have not been due to the AHRC in your community and everywhere else in the state, you are very much mistaken. For you to label me, the executive director of the New York State Association for Retarded Children, Inc., as an enemy of the mentally retarded is not only unfair, but shows a total disregard of history.

I am sorry you feel the way you do about amniocentesis. I can only infer from your letter that you are unalterably opposed to abortion, and you fear that the temptation to abort is heightened when women learn through amniocentesis that their child will be defective.

In my opinion, the risk of such a decision is far outweighed by the necessity for every woman to know what is happening to her body and what she and her husband and family face in the future.

Sincerely,
Joseph T. Weingold
Executive Director

SUPPORT FROM PENNSYLVANIA

Theodore E. Johnson, Ed. D. Executive Director for Pennsylvania Association for Retarded Citizens, comments on Jerry Weingold's testimony on sterilization:

Just a note to tell you I have read your comments on the proposed regulations for sterilization and that I agree with you completely.

You have stated everything in the kind of way that makes me want to say, "I wish I had said that."

WARREN WASHINGTON ADVOCACY COMMITTEE SAYS THANK YOU

In a letter to John Bertrand, Assistant to the Executive Director of the State Association, Sally Threw, Chairperson of the Advocacy Committee of Warren Washington Counties, thanked the State Association for their information and support:

I took your good advice and invited Marilyn Wessels to a meeting of our Advocate Committee to discuss the Excess Cost Funding Provision and the Commissioner's Regulations pertaining to speech therapy.

Our meeting was very successful and I wanted to write and thank you for your suggestion. Our State Association is truly fortunate to have Marilyn as a representative. She is very well informed, easy to talk to, and talks in terms that both parents and professionals can understand.

I would like very much to have you attend a meeting of our committee when you are in our area. I'm very proud of the work our members are doing and the progress we have made. I feel as if we are answering the plea made at the meeting you attended, "Do something for the people living in our community!" We are prepared to aid anyone who is seeking "proper" educational, legal, medical, spiritual, and social programs for retarded persons.

Once again John, thank you for your suggestions and advice. You have been a real help to me. I've only been in ARC for a year and there is a great deal for me to learn.

IN PRAISE OF EDU-LETTER

Mary Kent of New Paltz, New York has written this letter about the importance of news about legislation for parents of the mentally retarded:

Just a note to tell you how great we feel the Edu-letter is and how important it is for teachers and parents to get the news about legislation for the mentally retarded children and adults from ARC's viewpoint.

The same old problem exists in many areas of some school administrators being ignorant of new laws and others deliberately misrepresenting them to suit their own purposes.

Locally, our coordinator of Special Education has ignored repeated requests from Spec. Ed. teachers for copies of new legislation, and so we find our own sources for getting copies of legislation and different interpretations of the legislation. ARC, as always, is a help to us.

EDUCATION COMMITTEE RESPONDS TO PROBLEMS

William Albertin, Jr., member of the Education Committee of the New York State Association for Retarded Children, wrote to Mrs. Shea Fierro in response to a letter sent to the Association. It shows again that the State's Education Committee is alive and awake in response to problems:

Dear Mrs. Fierro:

I have received a copy of a letter sent to you on October 24, 1977 from John W. Bertrand, Assistant to the Executive Director, New York State Association for Retarded Children, Inc. Mr. Bertrand also sent me copies of your letters to Sixty Minutes and the A.R.C.

I would, as did Mr. Bertrand, assume that your school district is no longer going to support your daughter in the Reinebeck Country School.

Your letter also leaves me to assume that you feel that a private school would be better for your daughter than a public school. This is a matter that I would be happy to discuss with you in person because it would be difficult to put into this letter the pros and cons.

I am enclosing with this letter a copy of, "Your Child's Right to an Education". This is a guide for parents of handicapped children in New York state which is published by the New York State Education Department.

You will find, from reading this booklet, that the Committee on the Handicapped has the responsibility to make recommendations regarding the education of your handicapped child. Be sure to understand that you have the right and

obligation to work closely with your committee. I hope that you also understand that if your committee is recommending a change in your daughter's current special education program, you must be notified in writing.

If and when you meet with the Committee on the Handicapped, be sure that the program they are recommending for your daughter is the best possible education program that will meet her individual needs.

I would like to point out to you that the Education Law very clearly states that no handicapped child shall be placed in a residential school unless there is no appropriate non-residential school program available to meet the needs of your child. The intent of the law is to make certain that handicapped children have as much opportunity as possible to have contact with nonhandicapped children.

If you disagree with a decision being made for your daughter, I would suggest that you read the section on your right to challenge educational decisions about your handicapped child which you will find on page 14 of the enclosed booklet.

I would be more than happy to meet with you and discuss this situation in more detail. My address is enclosed and my phone number is, home — 842-7594, work — 843-2230. If for some reason you are unable to get me on the phone, please leave your phone number and I will get back to you.

Sincerely,
William Albertin, Jr.
Member, Education Committee

"MY BROTHER IS RETARDED"

Retarded Children Need Care
And Love By Cara Smolen — Age 9

My brother is retarded. It is not funny. People make fun at my brother, they call him a ding bat. That's not very nice. My brother is 5-1-3rd years old. His name is Paul Scott. I am his sister. I am writing about him.

Well, at home we all love Paul. My family and I sometimes talk about times when we took him to doctors. Paul had to have things on his head and junk in his hair. Paul goes to a special school. At Paul's school they teach him things we can't teach Paul at home.

Sometimes we act as if Paul is not retarded, and sometimes we act that he is retarded and we yell at him. If I get nervous, I yell at Paul. Now I talk my problems out.

Paul has seizures. He has a great big one called Grand Mal. I hate when he has seizures. Like the seizures take over Paul's body.

My mom and dad talk about sending Paul to a sleep away school. I do not want Paul to go. But they can teach Paul what we can't. Paul needs special care. The care he needs is when he has seizures. He may hurt himself and we have to stay with him when he has seizures. And we must love Paul because we take very good care of him.

Retarded children need care and love, and I love my brother very much.

Cara Smolen
3 Oak Ridge Road
Pomona, New York 10970

Marilyn R. Wessels named to Panel on Handicapped

Commissioner of Education Gordon M. Ambach has appointed Marilyn R. Wessels, of 160 Clayton Road, Schenectady, to serve on his statewide Advisory Panel on the Education of Children with Handicapping Conditions.

Ms. Wessels, a member of the Education Committee of the New York State Association for Retarded Children, was appointed as one of five panel members who represent statewide organizations concerned with children with handicapping conditions.

Ms. Wessels, a parent of a child with a handicapping condition, is currently coordinator of Parents of Persons with Down's Syndrome; a member of the Steering Committee of the New York State Consumer Advocacy Network; and past president of the Schenectady City School

District's Parents Advisory Committee on Special Education.

She has conducted workshops around the State on the new rules and regulations pertaining to education of children with handicapping conditions. She has also been guest lecturer at Albany Medical College, Russel Sage College, and at area high schools. For the past two years, Ms. Wessels has been one of the major presenters at the State Health Department's Birth Defect Institute annual conference on genetics for the non-specialist.

The Advisory Panel consists of 25 members representing teachers, parents, state and local education officials, state associations and handicapped individuals. It meets regularly to advise the Commissioner of Education on programs and policies to meet the educational needs of children with handicapping conditions.



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