

Our Children's Voice

Retarded Children Can Be Helped

Vol. XXVIII No. 2

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

June 1976

Wassaic-Harlem V. moves halt

In a display of united effort, parents and friends of the mentally retarded from Westchester and Dutchess Counties, backed by the State Association office and the staff of SOAR, succeeded in halting the transfer of the first of 200 residents of Wassaic destined for a building on the grounds of Harlem Valley Psychiatric Center.

A REGRESSIVE, REACTIONARY STEP

The opposition of the Association and the Community League for Retarded Children, as well as those from the community to these transfers, was based on a number of factors. First, and foremost, was the opposition to the philosophy of mixing the mentally retarded with the mentally ill in one facility. In the opinion of the Association, this was a regressive and reactionary step harking back to the mid 19th century when "idiots" and "insane" were lumped together in one facility and not distinguished from each other.

FACILITY IS INAPPROPRIATE

Additionally the facility at Harlem Valley is completely inappropriate for the mentally retarded. It is a highrise building, originally with bars on the windows. Even after the bars were

removed, those who are going to be lodged there will be looking out of their windows at buildings surrounding them all around with bars on all of their windows. The so-called recreation ground is non-existent — with some apparatus for young children (transferees were to be adults) in front of the building.

An inspection of the building by a team from SOAR and the community showed it met few, if any, of the standards of intermediate care facilities. According to Mr. Weingold, executive director, New York State Association for Retarded Children, the state would lose \$14,000 in federal aid for every person transferred because of the failure of the facility to meet ICF standards.

M.H. DEPT. REGULATIONS IGNORED

Almost as important as all of these reasons, was the fact the Department completely ignored its own regulations for releases and transfers, according to a letter last year from Mr. Hayes, then Deputy Commissioner for Mental Retardation.

It was the feeling of the Association that both Dr. Kolb and Mr. Coughlin had broken their word to the Association that none of these transfers would be made;

that, indeed, they were contrary to the policy of the Department of Mental Hygiene.

In a telephone conversation with Mr. Weingold, Mr. Coughlin stated that he was "in the middle" of this business; that he did not know the transfers were being made. It became clearly evident that the regional director, Mr. James Forde, was taking the full authority for these transfers, certainly not without the sanction of the central office.

After these protests, the transfers were postponed for 30 days. The guidelines (75-10) were ordered to be put into effect.

STATE ASSN. CONSIDERS LEGAL ACTION

The State Association is not content with this, and wishes to stop this kind of transfer completely. It is investigating the possibility of legal action against the Department of Mental Hygiene to put an end to this move.

In a letter to Dr. Kolb, Mr. Weingold asked for a person-to-person meeting with members of the Association to discuss

this question but to date has not received a reply.

This is part of a total scheme to create so-called "multi-functional institutions" which, in essence, means dumping the mentally retarded in to the empty buildings in psychiatric centers. A typical example of this would be the attempt to phase out J.N. Adams by moving the residents of J.N. Adams to Gowanda Psychiatric Center, a facility that was built in the late 19th century and which in itself should be phased out and the building torn down.

It is interesting to note that the facility at the Harlem Valley Psychiatric Center, which is in Dutchess County, is to be called a Satellite or branch of the Westchester Developmental Center.

The land acquired by the state in White Plains for the erection of a small facility for White Plains residents in other institutions has never been utilized for that purpose, but millions of dollars are being spent on psychiatric centers for the transfer of residents, many of them coming from Westchester.

New separate office bill

On March 15, Deputy Majority Leader of the Senate, William T. Conklin (R-Brooklyn) and Assemblyman Irwin J. Landes (D-Great Neck) announced the introduction of legislation to establish a separate Office of Developmental Disabilities and Mental Retardation (S. 8831; A. 11183).

Legislation was first introduced in 1972 and sponsored in the Senate by William T. Conklin and in the Assembly by Vincent Riccio. It was vetoed that year by Governor Rockefeller.

CAREY VETO IN 1975

Last year, the legislation introduced by Senator Conklin and Assemblyman Steingut, Speaker of the Assembly, passed overwhelmingly but was again vetoed by Governor Carey despite public statements in which he promised to back the bill, and almost against unanimous legislative support of the measure. In 1975, the Assembly passed the bill by a landslide 128-17. The measure passed the Senate by 45-6.

TASK FORCE RECOMMENDATION IGNORED

In that year, a Task Force on Mental Health, with a Subcommittee on Mental Retardation, was created by Governor Carey, excluding any member of the Association from participation. Nevertheless, under the chairmanship of Dr. Joseph Wortis, the Subcommittee recommended the creation of a separate office. This was ignored by Dr. Kevin Cahill, Advisor to the Governor, and his report did not mention this at all.

The Task Force created by the New York State Association for Retarded

Children recommended to the Governor the formation of such an Office stressing community involvement for the delivery of services to the state's mentally retarded and their families.

Senator Conklin called the veto "an irresponsible and deceitful act" which he said showed "an arrogant defiance of the overwhelming will of the Legislature and the specific rejection of his (Governor Carey's) personal pledge to sign such a bill".

CONKLIN-LANDES STATEMENT IN 1976

In connection with the introduction of the bill, Senator Conklin and Assemblyman Landes issued a joint release which stated, in part, as follows:

"We have today introduced the legislation which would separate mental retardation and developmental disabilities programs from the Department of Mental Hygiene by establishing a new office within the Executive Branch, the Office for Developmental Disabilities and Mental Retardation.

Last year, the Legislature overwhelmingly expressed itself in favor of such a separation. Governor Carey vetoed the bill, citing his own efforts to reform the broken down bureaucracy. He suggested that compliance with the Willowbrook Decree would alleviate many of the problems from which parents of the developmentally disabled have sought relief.

Fifteen months have passed since Dr. Lawrence C. Kolb became Commissioner of the Department. Yet, today, the internal administration exists largely unchanged, save a few new faces. Inefficiency, poor

Continued on Page 3

Westchester to host convention

The Annual Convention of the New York State A.R.C. will be held at the beautiful Rye Town Hilton Inn in Port Chester, N.Y. October 7-10, 1976. Following our traditional Convention format, the 1976 version appears headed in the direction of stuffing more activity into the usual time frame than ever before.

The first portion of the Convention will be given over to the usual Thursday evening - Friday morning meeting of the Board of Governors, Friday afternoon tours and the opening Business sessions Friday night and Saturday morning. The Saturday afternoon workshops, however, are more numerous than ever before, with no less than five separate areas demanding attention.

For those who can still be active after all this, there will be a dinner - dance

Saturday evening, under the inspired leadership of Convention Chairman Bob Meltzer, himself.

Already a household word in Westchester County for his outstanding performances with Westchester Annual Ball, Bob will no doubt plan an evening full of thrills, enough to surpass even last year's "Glass Chips in Fruit Cup" Caper in Buffalo.

Of course, all of this will be more exciting because it's at the Rye Town Hilton. Two swimming pools — indoors and out, tennis courts and paddle tennis will help fill any free hours you may have. Then saunas and whirlpools to ease your aching muscles.

After all this, we're sure you can't resist, so make your reservations now on the registration blanks on Page 16.

Reville Building dedicated



The Medical Surgical Building at Letchworth Village Developmental Center was dedicated as a memorial to the late James F. Reville, past president of Welfare League and of the New York State Association for Retarded Children. Story on Page 7.

Ignored again?

A recent publication of the President's Committee on Mental Retardation, "People Live in Houses", describing programs for group homes for mentally retarded adults, while including many programs throughout the United States, failed to mention a single one operated by the ARC.

Since we feel that the ARC probably operates more group homes than any single agency in the United States at this time, our executive director wrote to the President's Committee:

"I could not let this day go by without congratulating you on your ability to avoid mentioning in your publication, 'People Live in Houses', the programs of this Association in the development of group homes for mentally retarded adults — male and female all over the state of New York.

"I do not see why this should surprise us as you are no doubt following the President's stance that New York does not exist, and if it does, it is a nuisance."

In a soft answer to this, Fred Krause, Executive Director of the President's Committee on Mental Retardation said that he was sorry the publication was interpreted to have purposely excluded our efforts in New York State.

What lent some wry or black humor to his letter is that Miles Santamour, from Utica, New York is the author of the booklet. One would think he would be fully familiar with what goes on in New York State. The next sentence, however, casts

some doubt on this. "He received his professional training and initial professional experience with the New York State Mental Hygiene system."

Four projects in New York State are included as examples. But not one of them is run by an ARC.

"I am truly sorry", writes Fred, "you found this publication offensive and hope it has not damaged the fine relationship we have enjoyed to date." If Fred means our personal fine relationship, certainly it has not damaged that. If he means the fine relationship with the President's Committee on Mental Retardation, all we can ask is, "what relationship?"

Gov. appoints

ARC members

Two members of the New York State Association for Retarded Children have received important appointments by Governor Carey.

Joseph T. Weingold, Executive Director, was appointed on January 21, 1976 to the prestigious Mental Hygiene Council, the highest advisory council in the Department of Mental Hygiene. Although its functions are not very clearly delineated in the Mental Hygiene Law, the Council is important in advising the commissioner of Mental Hygiene, commenting on his regulations, etc.

On April 15th, Governor Carey also announced the appointment of Eleanor C. Pattison of West Sand Lake to the Board of Visitors of Oswald D. Heck Developmental Center in Schenectady. Mrs. Pattison is Northeast Regional Vice President of the New York State Association for Retarded Children and former President of Rensselaer County Chapter and a member of the Board of Governors of the State Association. She was also a member of the Rensselaer County Mental Health Society and consultant on volunteer participation to the New York State Department of Mental Hygiene.

Lottery bill

does not deliver

When the proposal to reinstate the lottery in New York State was made, Governor Carey made the widespread statement that the funds from the lottery would be used for education of the handicapped.

He estimated there would be \$60 million for this purpose.

In its best year, however, the lottery earned only \$54 million.

The bill was finally passed (Chapter 92, Laws of 1976). It does not fully carry out what the Governor said was its intent. For the first year, all of the money will go to replace local school district funds, including their overall programs. In the second year only, and thereafter, there will be additional aid to the handicapped. School districts may receive, on the basis of average daily attendance twice and three times as much as for the normal children (in a complicated formula). However, not all of the money will go to the handicapped. Furthermore, none of the funds are earmarked.

At at time when classes for the handicapped are being cut back, when teachers are being dismissed, when the school districts find themselves in dire straits for funds, when the whole structure of funding of school districts through local real estate taxes is being questioned in the courts, we should not be misled by slogans, such as "aid to handicapped".

In our opinion, such aid should be on the basis of registration, earmarked and over and above all other state aid.



George G. Hirsch and Dorothy Gasman, President Welfare League, at the installation of Mrs. Gasman as President.

ATTENTION ADVERTISERS

Now, you can get your message across to over 30,000 parents and friends of the mentally retarded and professionals in the field of mental retardation throughout New York State.

Effective with the Fall, 1976 issue, display advertising will be accepted for OUR CHILDREN'S VOICE, the official publication of the New York State Association for Retarded Children.

Published a minimum of three times each year, OUR CHILDREN'S VOICE could be the perfect medium for your advertising needs.

FOR RATES AND MECHANICAL REQUIREMENTS

Write:

Our Children's Voice
New York State Assn.
for Retarded Children
175 Fifth Avenue
New York, New York 10010

*All copy will be subject to approval by the
New York State Association for Retarded Children.*

Report child abuse

800-342-3720. No, That number won't get you a room in a fancy hotel, rent a car or sell you a recording or a swimming pool. This is the number of the New York State Child Abuse Register. Anyone wishing to report abuse of a retarded person under 19 years of age in, or out, of an institution may do so by calling this toll free number.

This is being published because an increasing number of families report they have not been notified of situations where relatives have received serious injury or have been abused psychologically in Developmental Centers and Community Placement Programs.

The State has rules and regulations which provide for such notification. For whatever reason, too often they are not being followed.

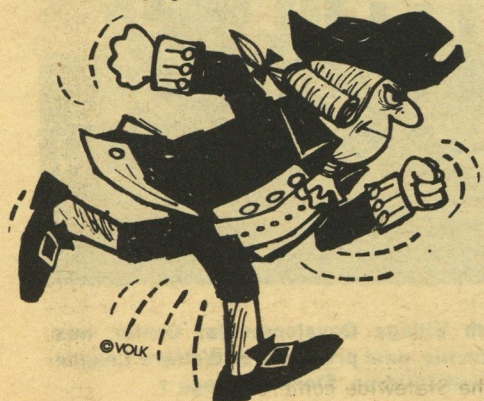
Anyone should feel free to report to the Department of Mental Hygiene, Division of Mental Retardation any cases of such abuse or late notification to family by those responsible for such notification.

Since there is no toll-free number for this in the Department of Mental Hygiene, we suggest you write them at 44 Holland Ave.

Parents on Visitor Boards

Did you know that each board of visitors of an institution of the Department of Mental Hygiene now must have three persons who are parents or blood relatives of the patients or residents?

Run to Rye . . . Sign up now



Our Children's Voice
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NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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Education bill back

Senator Leo Giuffreda (R-Suffolk) has reintroduced his extensive bill to change the delivery of educational services for the handicapped in New York State (S. 9470).

This voluminous bill does away with the practice of funding through the Family Court and, in effect, establishes free public education for all those in the state who need it. The bill requires each school district to determine whether a handicapped child, age 5 to 21, may be educated in the school district, BOCES, in another school district, in a private day school within or without the state, or a private residential school within or without the state under contract with the education district.

Essentially, the funding would be by the payment of what the district would ordinarily spend for the education of such a child if educated in the school district with the state picking up the difference.

Important in this legislation is the establishment by law of Committees for the Handicapped in each school district. Unfortunately, however, these committees will have on them only one parent and are heavily loaded with professionals chosen by the school district.

A major criticism of the bill by the Association for Retarded Children, Inc. is that any dispute which goes to arbitration will come before an arbitrator (impartial) chosen by the superintendent of schools or the chief administrator of the school.

Although this bill is a considerable improvement over last year's, there are omissions in it that the Association supported in last year's bill. One of these is the provision for education of the handicapped from age 3 which is omitted from the present bill. On the other hand, the funding is much simpler.

In a release accompanying this bill, Senator Giuffreda pointed out that the implementation date is 1977 to give everyone a chance to comment and provide for amendment to this bill in the 1977 Legislature.

Separate office

Continued from Page 1

staff utilization, resident neglect, poor service, and a lack of programs still exist in too many of the state's developmental centers. The simplest bureaucratic task takes months to accomplish and severely impedes fulfillment of the Willowbrook Decree. Establishment of two hostels in one community would take more than a year, because getting a simple rental appraisal from the Department has taken 83 and 82 days, respectively.

More disheartening is the fact that the Department continues the practice of benign neglect of 97 per cent of the 600,000 developmentally disabled and mentally retarded who reside with their families in the community; the department provides only \$28 million for their needs of the \$1.05 billion budget. . . . The Department of Mental Hygiene continues to be unable to break out of the confines of the psychiatric institution model which has consistently prevented fulfillment of community-based care to all the developmentally disabled. The Department willingly provides (\$60,000 a child) for rehabilitating young criminals in the proposed budget while keeping innocent retarded, autistic and other handicapped children waiting for service. . . .

The Willowbrook Decree consented to by the Governor and the Department eleven months ago, has not been implemented. Few hostel contracts for community programs have been contracted for as required by the Decree. It is unlikely that even the limited goal of 200 community placements at one institution required by



Geoffrey R. Simmonds, Chairman and Chief Executive Officer of Simmonds Precision, presents the deed to the building and property at Midland Drive and Walnut Street, Norwich, to John W. McHale, Executive Director of the A.R.C. Community Workshop. Looking on, left, is Howard P. Rowell, Vice President of Simmonds Precision and President of the company's Engine Systems Division. The Midland Drive facility, donated by Simmonds Precision to the Chenango County Chapter of the New York State Association for Retarded Children, will serve as the workshop's permanent headquarters.

A company with a heart

About two decades ago, a major steel producing company liked to be known as "The Company With A Heart", because of all its philanthropic endeavors. While that reputation is no longer so readily connected to the Company, our Chenango County Chapter is ready to tell anyone about another firm that has quite evidently adopted that slogan, and has proven that it has the heart.

On December 10, 1975, Mr. Geoffrey R. Simmonds, Chairman and Chief Executive Officer of Simmonds Precision, made a special trip into Norwich, to personally present the Chenango County Chapter with the deed for a building, which has become the new home of the Chapter. The building, which formerly housed a part of the Simmonds Company's Engine Systems Division, was donated to the Chapter at a luncheon attended by well over 100 Chenango County residents, and hosted by the Simmonds Company.

What this means to the mentally retarded and handicapped of the County is immediately evident. The space was provided at no purchase cost to the Chapter. It also doubled their space for clients, enabling the Chapter to serve 200 or more persons.

The New York State A.R.C. was

Electric therapy halted

In a letter dated October 30, 1975, Dr. Lawrence C. Kolb, commissioner of Mental Hygiene wrote to Mr. Weingold, executive director, New York State Association for Retarded Children, replying to his letter of October 15, that the Wilton Developmental Center will discontinue the use of electric stimulation in a behavior modification program.

The Director of the Wilton Developmental Center has requested the project be continued on an ongoing 24-hour basis, but, wrote Dr. Kolb, "It is my opinion that this particular type of conditioning is not appropriate as an ongoing therapy tool. Therefore, I am directing Mr. Coughlin, deputy commissioner for Mental Retardation, to advise Dr. Rechter, Director of Wilton Developmental Center, to cease all aversive (electrical stimulation) conditioning until further notice."

Dr. Kolb closed his letter with "Thank you for your concern and bringing to my attention the specific program at Wilton."

the Decree will be made within the foreseeable future. \$2 million appropriated by the Legislature for this purpose remains untapped. This is further evidence of the inability of the Department that tries to administer to the mentally ill and the developmentally disabled, to meet the needs of the mentally disabled."

represented at the ceremonies by John W. Bertrand, Assistant Executive Director. Upon his return to the office, John was not only still impressed with Mr. Simmonds' generosity but with the conversation they held at the luncheon. He reported that Mr. Simmonds indicated it was his hope, that other firms, seeing what was being done, would follow this lead, and make similar facilities available to agencies in their area.

Truly, Mr. Simmonds is a person with a heart and Simmonds Precision, a Company with a heart.

Pa. statute unconstitutional

A three judge federal court has declared unconstitutional a Pennsylvania statute providing for the commitment of children to mental health and mental retardation facilities and ordered the state to discharge or readmit over 5000 juveniles in state operated facilities.

The decision in the case of Bartley, et al. v. Kremens, et al. was originally rendered by U.S. District Court for Eastern Pennsylvania on July 24, 1975. On November 17, the court filed an order specifying the steps the state must take to comply with this decision.

After rejecting the Commonwealth argument that parents effectively waive the rights of their children by voluntarily committing them to a state facility, District Judge Daniel H. Huyett, III laid down the minimal due process safeguards to be observed before any person, eighteen years of age or younger, can be admitted to a Pennsylvania mental health or mental retardation facility: (a) a probable cause hearing to be held within 72 hours of the date of initial detention; (b) a post-commitment hearing to be held within two weeks of the date of the initial detention; (c) the client must be furnished written notice, including the date, time and place of the post-commitment hearing, and a statement of the grounds for the proposed commitment; (d) the client must be afforded the right to legal counsel at all significant stages of the commitment process and, if indigent, the right to the appointment of free counsel; (e) the client must have the right to be present at all hearings; (f) a decision to commit must be based on "clear and convincing proof" that the individual is in need of in-

This year, the Governor proposed the creation of an Office of Alcohol and Drug Abuse Services, removing these from the Department of Mental Hygiene.

Interestingly, the Governor seemed no longer concerned with costs or fragmented services, two reasons he gave for vetoing the M.R. Bill.

Workshops are important

Workshops, for the training of mentally retarded, blind and other disabled persons, serve an important role in the rehabilitation process, according to a study announced in December by Dr. Andrew S. Adams, Commissioner of HEW's Rehabilitation Services Administration (RSA).

The study, *The Role of the Sheltered Workshops in the Rehabilitation of the Severely Handicapped*, a special report to Congress was mandated by the Rehabilitation Act of 1973 and shows that an estimated one-half of those sampled, who went through the workshop experience, displayed a positive improvement towards overcoming their problems, particularly in self-care.

The study showed that, of the 2,766 certified workshops, 53 per cent of the clients were mentally retarded, 19 per cent classified as mentally ill, 10 per cent as blind and 5 per cent have orthopedic disabilities.

In a random sample of 400 workshops, the study projects 410,000 clients are served annually while 182,000 leave the workshops each year.

An estimated 10 per cent of workshop clients from the total certified workshops in the country are placed each year in competitive employment, and 100,000 of the 140,000 being served daily by workshops are engaged in long-term remunerative employment.

Summaries of the study can be obtained by writing to: Commissioner, Rehabilitation Services Administration, HEW, Washington, D.C. 20201.

stitutionalization; and (g) the client must be given the right to confront and cross-examine witnesses and present evidence on his own behalf.

Since the November 17 order was handed down, the U.S. Supreme Court has issued a December 15 stay order upon the petition of attorneys for the Commonwealth. The state argued it would be impossible to arrange due process hearings within 120 days for the over 5000 juveniles in Pennsylvania facilities who are affected by the Bartley decision.

More ARC appointments

Governor Hugh L. Carey recently announced the appointments of George G. Hirsch, President, New York State Association for Retarded Children, and Hon. Robert Wagner, Supreme Court Justice, and past President of the New York State Association for Retarded Children to the 20-member steering committee for the New York State Conference on the Handicapped. The group will meet in September "to devise ways to help government provide for those among us who are most in need."

The Council will hold hearings on June 2nd in Buffalo, June 9th, New York City, June 16th in Syracuse, and June 23rd in Hauppauge, L.I. under the Chairmanship of Dr. Kevin M. Cahill, Special Assistant to the Governor for Health Affairs, and Secretary of State Mario Cuomo.

The purpose of the sessions will be to help determine the agenda for the State Conference on the Handicapped to be held on September 14-16, 1976 in Albany.

As part of its agenda, the Statewide conference will develop a State position to be presented at a White House Conference on the Handicapped in Spring of 1977. It will also set up a permanent lobbying effort to promote the needs of the handicapped before federal, state and local governments. Governor Carey will chair the Statewide conference.

HOSTELS: *How they are (not) started*

By Hy Clurfeld

It has been ten years since the State of New York embarked on a bold and innovative venture (i.e., for New York State) to establish hostels for the mentally retarded. As a result of the "unstinting" support of Governors Rockefeller, Wilson and Carey, the undertaking has been heralded as the wave of the future. In the New Standard Dictionary of Political Language the word, "future," has been defined as, "after the next election."

To be fair, in order to comprehend the complexities faced by the State in moving forward with a program of such magnitude, we should acknowledge the three basic rules pertaining to acts performed by public employees:

(1) No application may be approved by any public employee unless it has been rejected at least three times for any of the following reasons:

(a) the public employee will have additional time to learn what he is being paid to do; or

(b) the applicant may get tired and give up; or

(c) the public employee may resign, retire or be transferred to another job in the interim; in either of which events the problem will go away.

(2) No application may be approved unless the applicant has satisfied the conditions of no less than three statutes imposed by no less than three public agencies.

(3) Logic and common sense must never interfere with the due administration of government or the enforcement of any law.

In recognition of the fact that New York State has abandoned its primary responsibility to the mentally retarded, this Association committed itself to the fulfillment of the State's promise. What happened afterwards reminds me of the story of the fellow who dove into a whirlpool to save a drowning stranger, only to be admonished by the stranger that swimming was prohibited.

As Chaucer once said, "Money is the root of all hostels." Our first order of business, therefore, was to ascertain what funding resources were available.

About two years ago, the New York State Housing Finance Agency, after protracted negotiations, agreed to grant a loan for the Mid-Hudson Hostel Project. The Housing Finance Agency, acting jointly with the Department of Mental Hygiene, directed us to organize a new corporation under the Not-For-Profit Corporation Law and the Mental Hygiene Law with a life limited to three years. This required approval of the State Board of Social Welfare, the Department of Education, the Department of Mental Hygiene, the Attorney General, a Supreme Court Justice and the Department of State.

As soon as we completed the tortuous process of incorporating NYSARC Community Mental Retardation Services Co., Inc., the H.F.A. advised that there was no money for us. After all, not every romance makes a marriage.

At the suggestion of the H.F.A. and the Department of Mental Hygiene, we then turned to private lending institutions for financing. However, since no bank would grant a twenty-year mortgage to a corporation with a three-year life, it became necessary to amend the certificate of incorporation and to repeat the process of obtaining approval of the State Board of Social Welfare, the Department of Education, the Department of Mental Hygiene, the Attorney General, a Supreme Court Justice and the Department of State. Several months later we finally had a corporation with a perpetual life, but still insolvent.

Because we were so cooperative in keeping the bureaucrats employed (which is good for the economy) they rewarded us with \$1,000,000 from the Department of Mental Hygiene and \$480,000 in the form of a federal grant. However, no part of these funds may be advanced to us until we have incurred all the expenses incidental to the acquisition of the properties (purchase price, title company charges, architects, surveys, local counsel, test borings, etc.). The bureaucrats were profoundly sympathetic to the fact that the Chapters involved did not have a spare \$250,000.00; but after all, the law is the law—or as Dickens said, "a tushy."

Meanwhile we learned that federal funds, including start-up costs, were available through H.U.D., and an application was submitted. Since this did not involve New York State funds, we decided to organize a new corporation, NYSARC Hostels, Inc., without approval of the State Board of Social Welfare, the Department of Mental Hygiene or the Department of Education (the Attorney General, the Supreme Court and the Department of State are protected by law in all events). The purpose was to avoid the paralysis we would suffer from the ministrations of the conglomerate of New York bureaucrats.

We must confess that our attempt to cut red tape was the unkindest cut of all to the loving bureaucrats who have "assisted" us in our long struggle on behalf of the retarded. After all that they have done for (sic) us, should we not hang our heads in shame for even thinking of depriving them of their conjugal rights? Having "conjugated" us for more than a quarter of a century, how could we now consider asking them to stop? It is indeed a sad commentary on our sense of loyalty.

The folly of our judgment was evident from the beginning. The Attorney General rejected the certificate of NYSARC Hostels, Inc., on the grounds that we did not have the prior consent of the State Board of Social Welfare. When we called to inquire as to the statutory authority granting jurisdiction to the State Board, the Attorney General advised, after a long, reflective pause, "Write me a letter." (See Rule 1(a) above).

In response to our letter the Attorney General forwarded a copy of a letter from the State Board claiming jurisdiction pursuant to Section 757 of the Executive Law. (See Rule 2 above). We then called the Attorney General to point out that Section 757 dealt with unemployed youth, unwed mothers, the aged, invalid and convalescent, destitute, delinquent, abandoned and neglected children, and that there was no mention of the mentally retarded. He replied that it was not for the Attorney General to interpret the law and that it was sufficient that his client, the State Board, had made the determination. (See Rule 3 above).

We then called the State Board to inquire as to the basis for including the mentally retarded within the scope of Section 757, and we were advised (after the second joint reading of the statute) that the mentally retarded were included within the definition of the word, "invalid." When we expressed our amazement, their counsel stated that, "invalid includes the mentally as well as the physically ill and that the mentally retarded are mentally ill." We replied (in patent disregard of Rule 3), "Really! Would you put that in writing?" The answer was, "Oh no, I will not."

A petition was then filed in Supreme Court for approval of the certificate of incorporation, and it was reassuring to observe the zeal with which the Attorney General opposed us. The citizens of New York may take comfort in the knowledge

that the Attorney General is vigorous in protecting the public against the onslaughts of those who would question the judgment or motives of any bureaucrat. Since there is "honor among politicians," any position to the contrary would be unthinkable.

During the argument re: NYSARC Hostels, Inc. in the Supreme Court, we asked the Attorney General to advise the learned Justice as to which word drew the mentally retarded within the ambit of Section 757 of the Executive Law. He refused to commit himself to the word, "invalid," or any other word, and responded by stating that it was for his client to decide what the law was. Nevertheless, we should credit him for the diligence exhibited during a recess in the hearing when he advised the Court that he had called the Department of State and that their learned counsel advised that if the learned Justice signed our certificate the Department of State would reject it.

After a month the learned Justice denied our application, but he failed to state any reason, apparently relying on Rule 3 above. Our recourse is by appeal to the Appellate Division.

During the course of the above games, the Nassau Chapter was called upon to assist in delighting the bureaucrats by attempting to organize Nassau Hostels, Inc., which name was chosen because of prior approvals of Jefferson Hostels, Inc. and Suffolk Hostels, Inc. Since the name, purposes and powers were identical, we contemplated immediate approval by the Attorney General, a Supreme Court Justice and the Department of State. Not to be outdone, the Nassau Chapter, in utter disdain for the vested rights of our exalted bureaucracy, proceeded forthwith to violate Rules 1(a), 2 and 3 above.

Since Jefferson Hostels, Inc. and Suffolk Hostels, Inc. were filed without approval of the State Board of Social Welfare, Nassau had the unmitigated, consummate gall to request the same treatment. We were met at the pass by a pistol-packing female from the Attorney General's office, whose pleas were too much to refuse. (Said she: "Depart from procedure and add a few words and I'll tell the State Board to go to the birds"). Seduced and beguiled, Nassau agreed to redraft its certificate to include just a few words not required of Jefferson or Suffolk. Shame on its President and a plague on its counsel!

The new certificate was prepared, approved by the Attorney General and then forwarded to the Nassau Supreme Court for signature of a Justice. It was promptly rejected because another learned Justice ruled that a hostel is a "psychiatric clinic," thereby requiring approval of the State Board of Social Welfare (although already waived by the Attorney General) under Section 404 of the Not-for-Profit Corporation Law.

The certificate was resubmitted to another Justice whose learned law secretary favored rejection because it had already been rejected by another learned Justice. How dare we question an act of a public official? Fortunately, the certificate was signed and all that remained was to file it with the Department of State.

We then forwarded the certificate with the Attorney General's waiver and the signature of a Supreme Court Justice to the Secretary of State who promptly rejected it for the following reasons: (1) the name would mislead the public; (2) a hostel might include a "hospital"; and (3) leasing of hostel property to corporations servicing the mentally retarded is a "business" purpose, not authorized for a not-for-profit corporation.

We then called the Department of State and requested a reconciliation of the rejection of Nassau Hostels, Inc. after the acceptance of Suffolk Hostels, Inc., Jefferson Hostels, Inc., BSRC Residential Projects Corp. and Associated Residential Centers, Inc., the latter two during the same week that Nassau Hostels, Inc. was submitted. All five corporations are identical in all respects; but, of course, logic and common sense must never interfere with the due administration of government (Rule 3).

When the Secretary of State was asked why "Nassau Hostels, Inc." would mislead the public he replied that people might think we were going to "operate" hostels. We then posed a patently unfair and irrelevant question: "Why Nassau and not Suffolk and Jefferson?" — to which the Secretary retorted angrily, "I'm too busy now. I'll look into it." (Rule 1(a)). We are still waiting for an answer.

The Secretary was also pressed for an explanation of his fear of the word, "hostel," as opposed to the word, "residential," and we are still waiting for an answer. We are also waiting for an explanation of why it is a "business" purpose for Nassau to lease hostels when it was not so considered regarding all the other corporations.

It appears that the Secretary of State has recanted his statement that a hostel includes a hospital, but he has failed to acknowledge it in writing (maybe the devil made him do it). In any event, we are on our way to the Supreme Court in an Article 78 proceeding against Mario Cuomo.

In summary, it seems that the bureaucrats of this state have a burning desire to prevent us from doing the job that the State has failed to do. What we need is a Gulliver to put out their fire in his own special way.

By-laws approved

The Chapters of the Association have recently ratified two amendments to the State Association By-laws proposed to the Convention, in Buffalo, last September. One of these deals with the good standing of Chapters and the other with the clarification of the status of State Board members.

The latter amendment, concerning the Board, changed Article III, Section 2 of the By-laws to state that at least two-thirds of the Board of Governors shall consist of parents or "blood relatives" of retarded children. The addition of the words "blood relatives" finally makes official a situation which had been agreed upon at the 1973 Convention in Albany.

The other amendment involves the good standing of Chapters at the State Convention. This is the amendment to Article VII Section 4. Presently that Article requires that the Chapter dues for the current year and assessment for the previous year should be paid 90 days prior to the Convention. It now adds the following phrase "and if the Chapter has transmitted to the central office, 75 days prior to the end of the fiscal year of the Association, its latest financial report, on the forms prescribed by the Association".

It is hoped this will encourage those Chapters who are frequently delinquent in submitting financial report forms to do so. Failure to comply will forfeit their right to vote at the Convention.

Follow me to the
Rye Town Hilton



Camp Catskill time again

With thanks to Mr. Walter Schofield, in the Department of Mental Hygiene, who puts forth a special effort on our behalf each year, the Association is able to once again offer the facility of Camp Catskill to almost 500 retarded persons during this coming summer. Operated under a contract with the Department of Mental Hygiene, Camp Catskill takes 160 campers in each of 3 sessions and provides them with 20 days of summer fun.

In 1976, the first session for campers age 13 through 20 will operate from June 26 through July 15. Our youngest group, campers age 5 through 12, will run July 17 through Aug. 5 and our adult session will run Aug. 7 - Aug. 26.

Due to the increased cost of operation of the camp, the fee for this year was raised \$225 for the 20 day period; the first increase ever in Camp Catskill fees.

As always, 60 youngsters from the State Institutions are selected by the Department of Mental Hygiene to participate in each session, and 100 campers are accepted thru the State Office and our New York City Chapter.

This year, the camp is under the Direction of Michael Larson. Michael comes to us with the background of both experiences with the mentally retarded and being able to "rough it", as a former U.S. Marine.

As always, the premium on camper slots is very great, with our adult session having been filled, and building a waiting list well before April 1.

Willowbrook Unit

Barbara B. Blum named

Barbara B. Blum, a leading advocate for improved children's services, heads the State Department of Mental Hygiene's newly established Metropolitan Placement Unit in New York City. It is designed to speed the movement of mentally retarded clients from Willowbrook into appropriate residential and service areas in the New York City area.

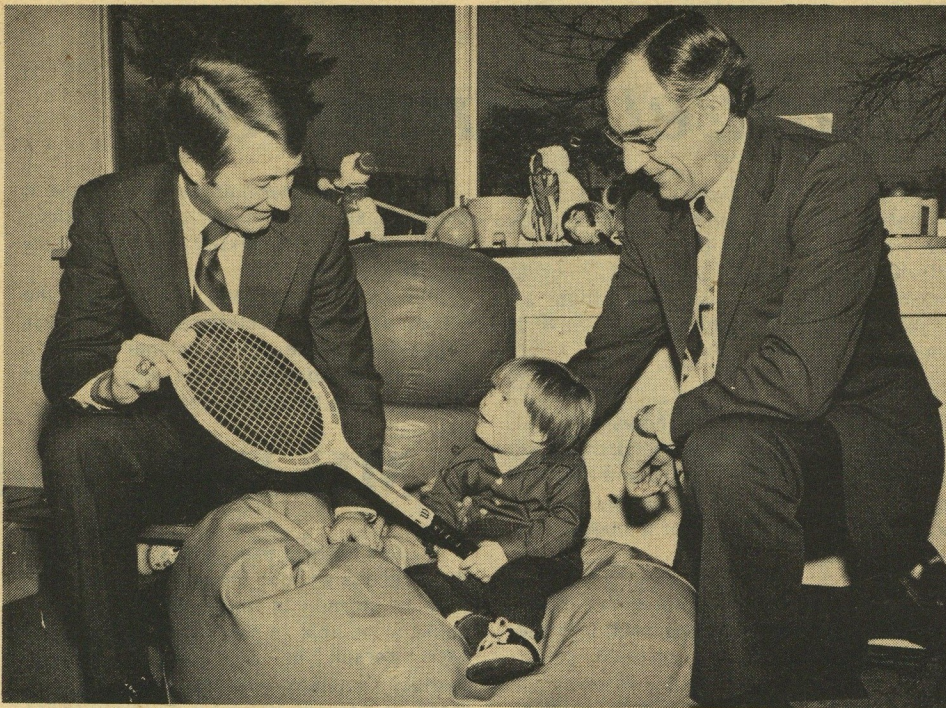
Announcing the appointment, Dr. Lawrence C. Kolb said, "The Department is fortunate to have a person like Mrs. Blum with background and experience to accept such a challenging assignment."

The establishment of the unit is the first time responsibility for the development of a Metropolitan - wide network of community and residential service programs for the retarded has been placed under a single aegis. In the past, state developmental centers in each of the boroughs were responsible for the identification and development of their own community placement programs.

At a hearing before Judge Judd in the Willowbrook Case, it was also revealed that Deputy Commissioner Thomas Coughlin now has full authority over this unit and does not have to answer to the regional director.

At this hearing Mr. Weingold suggested that Mr. Coughlin have authority over all regional directors with regard to mental retardation as the Willowbrook Class is scattered over other parts of the state. This did not meet with a positive response.

One of the problems placing persons from Willowbrook into the community, at this point, is that a great proportion of the residents at Willowbrook are severely and profoundly retarded. Many of them have physical disabilities as well. These are very difficult to place.



Here, 3-year old Michael McClenahan, a pre-school student at the Association's facility at 600 South Wilbur Avenue, gets his first grasp on a tennis racket held by John F. X. Mannion, president of Unity Life. Looking on is Robert J. Horn, Association President and Vice President of Lincoln First Bank — Central.

Tennis Tourney benefits Onondaga County Chapter

"Love Enough to go Around" was the theme when local tennis players took to the courts in a tournament benefitting the Onondaga County Association for Retarded Children.

Sponsored as a community service by Unity Mutual Life Insurance Company of Syracuse, New York, the mixed doubles event was held April 9, 10 and 11 at the new

Cross Court indoor tennis facility in Dewitt. The first annual tournament was divided into two sections: a 16 entry professional category and a 32 entry amateur category. The \$15 team entry fee was tax deductible and all proceeds were donated to the Association for Retarded Children.

Threat of mass exodus

The so-called policy of deinstitutionalization, which, in effect, is depopulation of institutions, poses significant threats to parents of the residents of the state institutions.

All of them asked the question "what is the meaning to us of such a mass exodus?"

We could only share with you what Dorothy Gasman, president of Welfare League, Letchworth Village Chapter, thinks the parents should ask for a minimum.

These are:

1. A guarantee of lifetime care and safety for your child.
2. Adequate supervision which you or Welfare League can review.
3. Suitable housing which is convenient for you to visit.
4. Treatment programs and habilitation services.
5. Recognition of the human rights of the

Labor Dept. sues Calif.

The U.S. Department of Labor has filed suit against the State of California for refusing to pay minimum wages to working residents in 11 state mental health and mental retardation facilities. The purpose of the suit, according to solicitor of labor, William J. Kilberg, is to enforce the Department's patient - worker regulations issued in February of 1975 in response to the 1973 decision of the U.S. Court for the district of Columbia in the case of Souder V. Brennan.

According to Mr. John Miller, Chief of State Hospitals for the Mentally Retarded and the Mentally Ill in the Health Department, the State of California plans to vigorously contest the Labor Department's suit. The State's defense will hinge on the therapeutic benefit of labor to the 1500 patient-workers in the state operated facilities and the fact that the state pays for the residents' food, board and services.

retarded to live in safety, dignity and comfort.

In addition to these, it is important that the Department of Mental Hygiene follow its own directive and that of Commissioner Kolb that committees be appointed from the Association to participate with the parents in making these plans, seeing to it that there is informed consent, objecting where necessary and, indeed, that all of the regulations of the Department be followed.

This in no way agrees that any of the transfers, even if all the regulations are followed, are in the best interests of the residents or in the best interests of mental retardation.

On the contrary, the Association has taken the stand that placing the mentally retarded in institutions for the mentally ill is a regressive step, bringing us 100 years back in history when "Idiots" and "insane" were lumped together in such institutions.

Housewives as trainers

Four Milwaukee housewives recently volunteered to take retarded young ladies into their homes and give them training in domestic skills. The three-week training program covered 12 household tasks: washing dishes, vacuuming, dusting, making beds, the like.

When a girl learned one step completely, the housewife would introduce a new one and would review the old. Toward the end of the program, all 12 tasks were reviewed.

Said the housewives after the training had ended: "No reason why these young ladies can't get full-time jobs as domestics in private homes. They have the makings of success."

From the President's Committee on Employment of the Handicapped newsletter.



Governor's budget trimmed

The Legislature has cut \$11.8 million from the Governor's Department of Mental Hygiene budget. The budget, nevertheless, represents an increase over the 1974-1975 allocation.

The major cut was \$7.4 million allocated for 1316 new positions the Governor had requested for the developmental centers to begin bringing the old centers up to Willowbrook standards. The rationale for this cut in the budget was that the Department had presented no plans to the respective budget and finance committee of the Legislature for this money: how it was going to be used and where the positions were going to be utilized.

At this writing, the Governor does not seem willing to ask the Legislature to replace this in the Supplemental Budget.

As a consequence of this cut, it may well be that \$128 million of federal funds are threatened.

Another \$1.6 million was cut by closing down laundries and telling the Department to contract for outside laundry and medical care.

A sidelight on this money saving scheme is that all chauffeurs and servants paid by the state to serve the directors of the institutions should be eliminated. Another sidelight is the suggestion that all physicians now work 40 hours instead of 35 hours.

It is interesting to note, however, that the \$6½ million for the acquisition of hostels, etc. has been retained and that the Legislature is suggesting a \$6 million increase over the Governor's budget for local service.

The Association is making every effort to get the 1316 new positions back into the Supplemental Budget.

Other cuts were contained in shutting down or diminishing in-house rentals. This means, if the director or staff have houses on the grounds, they will be charged the normal rental for such facilities or be asked to get quarters elsewhere.

Strong recommendations were made to combine services of various institutions such as Northeast, Nassau and Kings Park Psychiatric, etc.

The budget virtually eliminates the Office of Public Relations. It has been suggested to the commissioner that the Division of Administration and Internal Management be consolidated.



MH Dept. and Willowbrook

"I can't believe that in this state, where the average annual income of a working man or woman is about \$12,500, we are going to be able to pay \$40,000 a year for each person in an institution," Dr. Samuel Ornstein told the State Department of Mental Hygiene Conference on Clinical and Program Management in Albany early in December of 1975.

Ignoring the fact that the State Department of Mental Hygiene is paying \$60,000 a year for young criminals being served by the Department of Mental Hygiene, Ornstein was hyper-critical of the programs under the Willowbrook Decree.

Ornstein, who is Assistant Deputy Commissioner of DMH's Division of Mental Retardation, said he had "serious doubts" about the overall cost and effectiveness of the court decree, handed down in April 1975 by the Federal Court to improve the highly publicized conditions at the Willowbrook Developmental Center on Staten Island.

Misdirecting his criticism by pointing to the decree itself, he puts his finger exactly on the spot by stating that a proliferation of advisory groups overseeing the implementation of the decree has "paralyzed" the center's operation to the point that every time we want a resident to leave Willowbrook and reduce the population, 8 different groups have to approve it.

"We entrusted the system with far too many surveyors and not nearly enough fixers," Dr. Ornstein boldly states that the decree is a "fraud".

"We, the professional people, have been saying all along that what we need for quality care was enough psychologists, enough staff people, better facilities, and so on," Ornstein said.

"I think we are finding out now that these individual pieces do not necessarily make a good whole, that what we thought was a model program does not work. It's a fraud."

He does not go into the question of who is supposed to make these pieces fit together, other than the Department of Mental Hygiene.

"I don't think we can go on like this," he said. "I don't think all these expensive requirements will come out with a decent respect for either people or money. We have to start reconsidering our professional model."

Commenting on this, Mr. Weingold said, "Isn't this exactly what we have been saying, that the Department of Mental Hygiene must get away from the medical-psychiatric model of services into an educational service model?"

This the Department is absolutely unable to do under its present set-up.

In the same conference, Mr. Peter Knauss, assistant director of Functional Programming for DMH said that there would be a need for places for 9000 retarded persons in hostels by the year 1984.

Commenting on all this, a spokesman for the State Association said, "of course there is fraud, but by whom is the fraud being perpetrated and on whom? Certainly it is not the Willowbrook Decree, certainly it is not the parents perpetrating this fraud. The inference to be drawn is left to those who read this."

AMITA award for Giannini

Margaret J. Giannini, M.D., F.A.A.P., Director of the Mental Retardation Institute of New York Medical College at Valhalla, has been designated to receive the coveted AMITA Achievement Award in recognition of her outstanding leadership in the field of mental retardation. The award will be presented to Dr. Giannini at a formal Awards banquet to be held Sunday, November 16, 1976, in the Grand Ballroom of the Plaza Hotel in New York.

1976 marks the nineteenth year in which AMITA Awards for Achievement have been given to American women for achievement in the arts, religion, business and various professional fields. Previous winners have included ballerina Marina Svetlova, Princess Diane von Furstenberg, Jenny Grossinger, actress Betsy Palmer, Mrs. Catherine Basie and Dr. Marianne Wallis.

Dr. Giannini, a long time pioneer in mental retardation, founded the Mental Retardation Institute in 1950 as the nation's first full time clinic devoted exclusively to treating mental retardation. Under her leadership, the Institute has grown to a two campus facility employing a professional staff of more than 300 and serving more than 15,000 disabled patients and their families each year.

Boards of Visitors

How effective are they?

A patient is repeatedly abused by a staff member at a facility operated by the New York State Department of Mental Hygiene. Rumors about it spread through the community. What can the Board of Visitors do? What do they do?

Although they are supposed to be a "watchdog", the group is limited to investigating "alleged" abuse — it has no jurisdiction to look into "suspected" abuse.

Mr. Ross, a Buffalo attorney, a member of the Board of Visitors of West Seneca Developmental Center and President of the Association of Boards of Visitors of the Mental Hygiene Facilities of New York State, said the public misunderstands what the job of Boards of Visitors is. "If we are to do the job which is expected of us and which we are criticized for not doing, then we would need additional powers."

In the 1800's, the Boards of Managers ran each institution with duties ranging from hiring to negotiating state funds. In 1927, the Department of Mental Hygiene replaced the old State Board of Charities and the Boards of Managers became Boards of Visitors. There was also a role change with each Board becoming a community advisory group with limited power which would report to the facility director, state mental hygiene commissioner and governor.

Series wins award

The Mental Hygiene Series, "Wasted Dollars - Wasted Lives" which appeared last year in the Times Union and was reprinted in full by the New York State Association for Retarded Children has won the first place newspaper public service award from the New York State Publishers Association.

"We were all very proud of the award," writes Jerry Budgar of the Times Union, "particularly since we were in the category that includes all the largest newspapers in the state."

"In addition, we were told the judges had a very difficult time selecting the winner because the caliber of the entries was so high."

"It's not only nice to have your efforts realized in this way," concludes Jerry, "but we get the feeling the department will never be what and like it was in the past, and that's certainly the best news."

"The function of the Boards of Visitors today, is as a 'watchdog' on the administration of the institutions they serve, with the aim being the welfare of the patients," Mr. Ross said.

Under a new law passed last year, Boards of Visitors now must have three parents as members. The total membership is seven. One of the problems has been in filling vacancies with an institution like J.N. Adams Developmental Center, in Perrysburg, for example, which has no Board of Visitors. This is a clear violation of the law.

In addition to the right to investigate suspected patient abuse, mandated visits, etc., Mr. Ross states the group wants the right to inspect all records, books and reports of the institution.

Broadening of the Board's function, he added, would lead to more effective administration of program and treatment and answer the needs of the patients.

Work-study and jobs

I.Q. LEVELS NOT SIGNIFICANT FACTOR TO FINDING JOBS

Work-study programs for the mentally retarded can double their odds of finding employment, according to a recent study by Albert VanDyke, Special Education Director of the Board of Cooperative Educational Services of Sullivan County, N.Y.

He followed up on 34 former students of special education classes. Half had engaged in work-study programs (in school part of the day, on the job part of the day). Half had not.

Of those with work-study backgrounds, 65 per cent were employed. Of those without it, only 35 per cent were employed.

Other findings:

— I.Q. levels were not significant factors in finding jobs. Those with lower I.Q.'s had as much success as those with higher I.Q.'s. What counted was work-study training.

— Those with work-study backgrounds were quick to use community services in job hunting (vocational rehabilitation, employment services, etc.). Those without it failed to use the services.

Services for severely handicapped

A memorandum issued earlier this year by the Bureau of Education for the Handicapped of the Department of HEW Office of Education, requests proposals for programs for severely handicapped children. Six RFP's dealing with severely handicapped children having particular areas of exceptionality are as follows:

RFP 76-17 Auditorially impaired multi-handicapped;

RFP 76-18 Emotionally disturbed multi-handicapped;

RFP 76-19 Orthopedically impaired multi-handicapped;

RFP 76-20 Visually impaired multi-handicapped;

RFP 76-21 Profoundly retarded children — ages birth to early childhood;

RFP 76-22 Profoundly retarded youth — ages nine through 21 years of age.

Although this may be a little late, interested persons should submit a written request enclosing a self-addressed mailing label to Attn: Mr. Landon A. Holmes, Grant and Procurement Management Division, School System and Handicapped Education Branch, 400 Maryland Avenue, S.W. (ROB No. 3, Rm. 5914), Washington, D.C. 20202.

Reports critical of MH Dept.

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In this short article we will review two or three reports of the Department of Mental Hygiene, all issued within weeks of each other.

The first is the report of the Legislative Commission on Expenditure Review of "Persons Released from State's Developmental Centers".

The very first statement in this report should be noted by everyone and is repeated over and over again. It is:

"MENTAL RETARDATION AND MENTAL ILLNESS ARE SEPARATE AND DISTINCT DISORDERS. MENTAL ILLNESS IS FREQUENTLY TEMPORARY AND REVERSIBLE, AND MAY OCCUR AT ANY TIME DURING AN INDIVIDUAL'S LIFE AND CAN BE TREATED AND AIDED OR CURED."

"... MENTAL RETARDATION... IS A CHRONIC AND LIFELONG CONDITION, ALTHOUGH IT MAY BE ALLEVIATED THROUGH SPECIAL EDUCATION, TRAINING, REHABILITATION AND PROPER CARE."

The report further points out, although the population in the state institutions has decreased about 24 per cent between 1970 and 1975, in that time, five new centers for the retarded (large residential centers) have been opened.

The report further points out, that although 6,419 individuals were admitted to DMH centers between April 1, 1965 and March 31, 1970, in the five years from 1970 to 1975, only 4,366 were admitted, a decline of approximately 32 per cent. But, the primary reason for this decrease was "DMH's closing of admissions in several institutions and restricting admissions to other centers to all but the most severely retarded in need of immediate institutionalization."

This is a study of 175 mentally retarded persons released to the community, family care, hostels, into their own homes and followed for a minimum of 23 months subsequent to their release.

Of the 175 persons as a sample, 39 per cent (68) were returned to developmental centers for any reason during the study period; 107 remained in the community for 23 months or more without being returned.

84 of the 175 residents (49 per cent) were placed in family care homes; 50 with their own families after release; independent living accounted for 17 placements and referrals to hostels, adult homes, and other residential facilities totaled only 15 placements (9 per cent). There was no reason given for this.

It is interesting to note, that only about 47 per cent of the people in the sample were referred for some type of program in the community. Of those referred for programs and services in the community, there was a higher overall success rate of remaining in the community 700 days or more than those not referred for services. No reason is given for non-referral to services. But the most common reason for return was identified as "adjustment problems".

The staff who made the study found few plans for those released.

As for services for the released residents under Chapter 620 and 621, it is interesting to note that only \$606,113 of the \$2 million appropriated was spent during fiscal 1974-1975. In the 3-month period from April through June 1975, only 164 persons eligible for assistance were released from developmental centers. The principle reason for this situation is that pre-released planning is bogging down as a result of the details required under Chapter 620 and 621 prior to community placement.

The study is certainly evidence of a failure to plan for community placement, a failure to prepare those who are going into the community to be able to survive in the community, a failure to take advantage of the resources afforded by the community to these former residents. Finally, even though this report is a sympathetic review of the whole situation,

including Willowbrook Decree, all the residents are referred to as "patients".

Copies of the report may be obtained from the Legislative Commission on Expenditure Review, State Capitol, Albany, N.Y.

The second report is a report by the Office of the Controller on the Operation of Private Schools for the Retarded certified by New York State Department of Mental Hygiene. This report was made in March 1976.

There are 28 private schools in New York State caring for 1,768 retarded residents, infants to adults over 65, says the report. Seven facilities housing 580 residents were opened in the last five years to alleviate overcrowding in the state facilities. Monthly rates for children ranged from \$300 to \$825 a month and for adults on SSI from \$300 to \$639 a month.

The Mental Hygiene Law requires the Department of Mental Hygiene to inspect and certify private schools and to regulate their services. Some of the major observations and recommendations were as follows:

— The Department of Mental Hygiene visits and certifies the private schools for retarded but provides minimal supervision and allows each school to develop its programs.

— The department does not establish any operating standards or prescribe specific activities to be provided.

— Department exercised no control over which clients were to be served and who was to be accepted.

— The Department was also not current in its routine inspections and school certification. 18 of the 28 facilities were operating with expired certificates (although legally enforced); 1 for as long as six years.

— The Department's regional office staff which is responsible for day-to-day monitoring makes visits to the schools on an irregular basis.

— The Department's excuse for this non-inspection, etc. is that the present staff of 2 has difficulty covering the 550 facilities for which the Department is responsible in addition to the schools. The recommendations were:

1. The Department should reappraise each adult school program in an effort to establish standards for the service to be provided.

2. Schools opened in an area should be coordinated in a network of care for the retarded. If there is a need for additional hostel or community residence beds to be served as charges, the Department should inform the community of these needs and stimulate community action to supply the additional facilities and reserves.

3. The regional office staff should visit all schools on a regular basis and make formal reports.

4. All children in DMH "purchase of care" programs should be enrolled in SSI upon admission to the School.

5. Finally, the Department of Mental Hygiene should develop guidelines for community programs, coordinate with the Department of Social Services in establishing appropriate SSI rates and notify all schools of the applicable SSI rates.

The third, and final, report presented is that of the Assembly Joint Committee to Study the Department of Mental Hygiene. Although its major recommendation that local care for the state's mentally retarded and mentally ill is of paramount importance, the report, in our opinion, fails to distinguish between mental retardation and mental illness. As a yardstick for measuring the effectiveness of this report, we refer to the first chapter which deals with the history of mental hygiene in this state where there is not one mention of mental retardation, the programs that were developed here, the pioneering of the State or anything else dealing with mental retardation. All of it is on mental illness. The report should be judged on that, and,



Mrs. James F. Reville addressing audience at the dedication.

Reville Building dedicated

The Medical - Surgical building at Letchworth Village Developmental Center was renamed in honor of the late James F. Reville, past president of Welfare League and of the New York State Association for Retarded Children.

More than 350 attended the ceremony at Letchworth Village to view the building that had been renovated to create sun rooms from open porches for use by the

physically handicapped throughout the year.

Mrs. James F. Reville, speaking at the dedication, said, "the solarium dedicated to my husband's memory will let the sun shine in for residents in the two wards of the James F. Reville building."

Mrs. Dorothy Gasman, president of the Welfare League, presented a bronze plaque bearing Mr. Reville's name which will be displayed in the building.

New regulations protect parent rights

New regulations have been issued by the Commissioner of Education, operable May 1, 1976, to protect the civil rights of the handicapped and their parents with regard to proper placement in the public school and education.

Regulations require every school district to create a Committee on the Handicapped who shall decide the proper placement of the handicapped child, whether it be in the public school system or in a private school system by contract with the local school district.

The parent is given the right to appear with counsel, make his own test, and appeal the decision to an "impartial" arbitrator, then to the commissioner and finally to the courts, if dissatisfied.

The regulations, however, according to the Association for Retarded Children, are inadequate in that the Committee on the Handicapped contains only one parent as a representative against a number of professionals all chosen by the superintendent of schools or the chief officer. In addition, the "impartial" arbitrator is also chosen by the chief school administrator.

This, in a sense, makes the school authorities judge, jury and executioner in all these matters.

One of the most controversial parts of the regulations deals with burden of proof.

As originally written, the burden of proof for the improper placement of a handicapped child was placed on the parents. Under strong protests from the parents around the State, as well as the ARC and others, this provision was removed entirely from the regulations. According to George Heymann, Associate Counsel, SOAR, this merely postpones a decision on the problem and is not a solution. The burden of proof according to SOAR, should be on the school district and those dealing with the problem in the community.

Still to be decided, is the real composition of the Committees on the Handicapped which must conform to the Federal law 94-142 of Education of All Handicapped. It is questionable whether one parent on such a committee would be acceptable.

In any case, it is a great advance that such Committees are now required by regulation.

Parents all over the State are urged to try to get on such Committees and to partake in the decision-making process in the education of their own and other handicapped children.

In this connection, the Education Committee of the State Association under Betty Pendler has been extremely active in meetings around the State and in hearings held on this subject.

Residence proposals criticized

At a series of public hearings on new proposed regulations for the operation of community residences for the mentally retarded and others, heavy criticism was directed at almost every aspect of the regulations.

In commenting on these regulations, Mr. Weingold testified that the proposed regulations were written for the mentally disabled. They include the mentally ill and others in the Department of Mental Hygiene with the mentally retarded in terms of the services they may need for living in the community.

on that alone, it is irrelevant to mental retardation.

"This leads to many confusions, not the least of which is the statement that the residence may provide a semi-independent residence in the community as an intermediate step between full hospitalization (emphasis ours) and independent living. The mere fact the word hospitalization is used," said Mr. Weingold, "as applied to the mentally retarded is an indication of the confusion that must arise from regulations that are being written both for the mentally retarded, the mentally ill and alcoholic."

There has been no attempt to involve communities serving the mentally retarded in such facilities in pre-writing conference on regulations.

CHAPTER NEWS

One of our really busy small County Chapters begins Chapter News this time, as we tell you of the annual report of our **ESSEX COUNTY CHAPTER**. Since November 1974, when the Chapter established its workshop in Mineville, where they are presently serving over 20 workers, they have grown very quickly, beginning the first hostel in March, 1975, and anticipating the second one in full swing during 1976. Very good for a small, young group . . . Another success story from **CHAUTAUQUA COUNTY CHAPTER** which reports 142 clients in their Jamestown workshop and 122 in Dunkirk. Interesting to note, that, like the many other chapters, **CHAUTAUQUA COUNTY** is now running a bingo night. This might be an idea for others. They started an interesting sideline called the "Special Project Fund". Taking a note from all of our friendly lending institutions, who give us a little payment book with monthly coupons to tear out, the Chapter is suggesting that persons who want to make a contribution to the special project fund can do so by paying 10 per cent of the amount they would like to contribute down, and the remainder in easy weekly installments. They offer to supply the necessary coupon book to remind the contributor of his obligation. That's what we call taking advantage of modern business practices, and good thinking. . . **MONTGOMERY COUNTY CHAPTER**, delighted that their building fund dance raised over \$4,000 for the Chapter. . . **ONONDAGA COUNTY CHAPTER** very pleased to be the recipient of funds from the opening night benefit performance of Man of La Mancha sponsored by their Auxiliary, Friends of the Retarded. The Chapter co-sponsored a public forum at Syracuse University on March 21, "A Discussion of Community Residential and Supportive Services". . . **SUFFOLK COUNTY CHAPTER** is pleased to announce the beginning of the construction of their 75,000 square foot training center in Bohemia. The comprehensive center will initially house 550 mentally retarded adults in vocational services, a sheltered workshop, and activities of daily living and will include such ancillary services as audiology, optometrics, clinical services and recreation. . . Thanks to Olean Aerie 616 Fraternal Order of Eagles who made a contribution of \$1000 to the **CATTARAUGUS COUNTY CHAPTER** of the Association. This was the second such contribution made by the Eagles and matches two contributions which have been made by their Auxiliary to help the Chapter replace the material lost in the disastrous 1972 floods. . . Congressman Hamilton Fish Jr. was present for the dedication of the new center of **PUTNAM COUNTY CHAPTER** on February 8. Located in Ludingtonville, the new workshop is the first opportunity to really spread out and get into the workshop business seriously. . . **ST. LAWRENCE COUNTY CHAPTER**, which mails our OCV, has done something very interesting with their monthly newsletter. Turned it into booklet form to show some of the skills of their printing department. . . **GENESEE COUNTY CHAPTER** very pleased with the full page spread appearing in the Batavia Daily News on March 20 showing many of the activities of the Chapter's workshop in their new quarters at 64 Walnut Street in Batavia. These quarters were made available thru an OVR Grant made to the Chapter in the summer of 1975. . . Never pass an opportunity to talk about **JEFFERSON COUNTY'S** Pizza sale, even though it took place some time ago. 250 persons worked on the Semi-annual event. The Chapter sold about 9,000 Pizzas and earned \$5,500 for their effort. . . **NEW YORK CITY CHAPTER** was pleased to announce two



Joyce Belza and Tom Swartz, foreground, continue a "blistering" pace in their fund raising effort for Albany County Chapter. Their 24 hour stint in a Dance-a-Thon at SUNY-Albany was the top money maker for the Chapter.

new programs opening in March 1976. At the Chapter's general office at 200 Park Ave., So., a new Developmental Evaluation Clinic, under the direction of Dr. Jack Gorelick, opened on March 1. This clinic, which has been designated by the New York City Department of Mental Health & Retardation as the official provider of diagnostic and treatment services for South Manhattan, will offer a full range of medical and psychological evaluations, together with extensive, ongoing treatment services for the retarded. Dr. Gorelick, who assumed the position of Director of that service on March 1, will be replaced as the Department Head of the Occupation Day Center by Mr. Zev Weiss. It is also anticipated that the Chapter's new East 5th Street residence, located next door to the O.D.C., for 14 adults, will open about the same time. . . Mildred Reed, President of **LEWIS COUNTY CHAPTER**, went above and beyond the call of the duty when she turned her cellar over to the senior class at Lowville High School to create a spook house for 4 days. People lined up to see the show and between the donations that were "frightened" out of those who attended, and the sale of cider and donuts, over \$500 was contributed to **LEWIS COUNTY CHAPTER**. Thanks to Lowville High School. . . Delight to note in the **MONROE COUNTY CHAPTER** newsletter that there are now Homemaker Services available in their community for parents who need that all important service. Also, everyone ought to write and ask for a copy of their March newsletter which opens with very interesting story entitled "How to Drive Your Child Sane". . . Good advice. . . I really think we should give an award to **ULSTER COUNTY CHAPTER** for the very bold manner in which they are coming forth on the front page of their newsletter. Their January 1976 issue was a real zinger with regard to the Department of Mental Hygiene and I was impressed with the outspoken statement in the February issue, when the Chapter had received approval from OVR for their workshop and another local workshop, Gateways, opposed. Having been approved, they let the world know

right where they stood on this issue, which I thought was just fine. . . It's hard to believe they've been around that long, but did you know that the **WELFARE LEAGUE CHAPTER** is already making plans for its 37th annual luncheon this fall? . . . **NIAGARA COUNTY CHAPTER** writes to say, that after considerable frustration on getting under way with their new building, a special session was held in March to put plans together for using federal and state grants totalling more than \$600,000 to purchase and renovate an existing building in the County to accommodate approximately 200 mentally disabled adults in a sheltered workshop. This has long been a dream of **NIAGARA COUNTY CHAPTER** and we certainly hope it will soon be a reality. . . **FULTON COUNTY CHAPTER** is, as always, very busy, and most important, the relocation of Chapter to its new building, on a 25,000 square foot center on an 18 acre site in the City of Johnstown. They also have added a weekly 5 minute radio broadcast on station went in Gloversville. Again, one of the new and exciting programs is a baby sitting

program in which they will provide a list of reliable sitters for days, evenings and occasional weekends. The twist to this program is that the **FULTON COUNTY CHAPTER** has agreed to pay 75 cent per hour toward the pay that the sitters and the child's family agree upon. . . Raymond A. Lewandowski, Exec. Director of **MADISON COUNTY CHAPTER** (moved from Acting Exec.) has done some very interesting things with the Chapter's newsletter. Where this was formerly a mimeographed plain sheet, without any sort of heading, and sometimes hard to read, in his first shot, Mr. Lewandowski has created a new and interesting letterhead, an interesting doodle for a back cover, a nice name in "Reflections" and an honest statement in which he said "It has come to my attention that our newsletter has not been the most interesting paper circulating in the County". He is also correct in saying "usually it is packed with information but, it seems to me we get an awful lot of information and seldom know what to do with it". . .

ONEIDA COUNTY CHAPTER delighted to have moved their operation to a new location at 14 Arnold Avenue in Utica. . . I wonder what the program was like in

SCHENECTADY COUNTY CHAPTER in February when Dr. Ted Di Buono, Pediatrician and Deputy Director of Clinical Services at Syracuse Developmental Center gave a presentation on "What you've always wanted to know about comprehensive community services but were afraid to ask". Note also, that in March, Schenectady had a presentation on Upjohn Homemakers program which has been very helpful in many localities. . .

COMMUNITY LEAGUE recently made things easier for the Vocational Rehabilitation Department at Wassaic Developmental Center with the contribution of a \$14,000, 24 foot International Truck. The truck, with a 2000 lb capacity, is used by the Voc. Rehab. Dept. to transport their contract overload of work to local ARC workshops and privately sponsored Rehab. programs which serve Wassaic residents in the community and, because of the truck, many more of Wassaic residents are able to do meaningful work. . . Congratulations, or is it condolences, to Winston Hamilton, President of our **FRANKLIN COUNTY CHAPTER**, who became the Chairman of Franklin County Mental Health Board in January. Naturally, to avoid Department of Mental Hygiene concern about conflict of interest, Winston has resigned as President of **FRANKLIN COUNTY CHAPTER**. . . **CLINTON COUNTY CHAPTER** very pleased that in the Month



Judy O'Rourke, fund raising Chairperson, and helper Priscilla Lockwood push raffles at West Seneca Chapter's Champagne Party. Fifty Foster Grandparents who became Chapter members were invited to the party. We hope they all made it safely home.

What our chapters are doing and saying for our children.

of February alone, 7 clients were placed in the community in competitive employment with salaries ranging from \$2.30 per hour to a projected income of \$7,000 per year. It appears the Chapter has done a good job of getting people back into the community. One client who came to the Chapter thru the Commission for the Visually Handicapped will be the full time vending stand operator in the county office complex in **CLINTON COUNTY**... From **COLUMBIA COUNTY** comes the following news:

On January 12th, the Columbia County Chapter officially opened the doors to its new home in Mellenville. The Chapter relocated its Community Workshop and Chapter's main offices, into the middle of the County, seven miles outside of Hudson. The one-story, 42,000 square foot structure now houses the Chapter's vocational rehabilitation services, a cooperative work-study program coordinated with BOCES, and a pre-vocational program involving shared staff from Eleanor Roosevelt Developmental Center. There are now 230 people attending the training



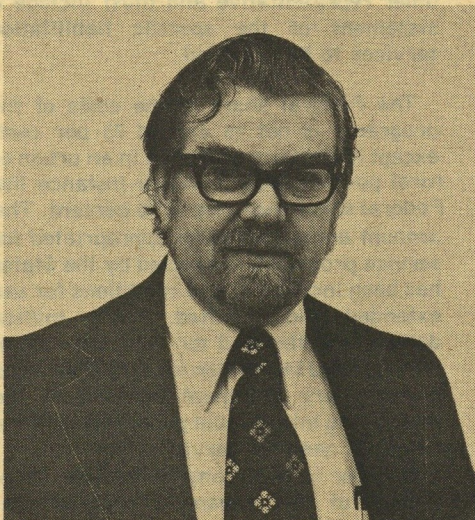
In Wayne County's D.T.C., learning to make needs and feelings understood is a primary goal. Ready to relieve his hunger pangs, this deaf child signs "food" to his teacher and receives his lunch.

and treatment center on a daily basis, in addition to a total staff, from various county and state agencies, of 45 people. In July, we will celebrate the 5th anniversary of the opening of the workshop. The Chapter's first hostel should be opening this spring in Hudson. We are now hiring staff, and making preparations for our 10 hostel residents. . . **STUBEN COUNTY CHAPTER** having a real struggle trying to find adequate funds for the operation of two workshop programs. One had to close early in March and the Chapter is fighting hard to try to find alternatives to that type of problem. . . **BROME TIOGA ARC** has been doing very well with their Stoneware Pottery. In addition to supplying many retail outlets in their area, they have opened up sales right in their workshop. They, too, were pleased with the full page review of their activities they received in their local newsletter during the month of March. . . Our thanks to

WILLOWBROOK CHAPTER for hosting the Southeast Regional Meeting of the Association. Chapter very much involved these days in the follow up of the **WILLOWBROOK** Consent Decree. . .

CORTLAND COUNTY enjoyed their annual dinner on May 4 with John Bertrand of the State office as speaker. The reason for John's return to the Chapter was that this is the 10th anniversary of the founding of **CORTLAND COUNTY CHAPTER**, in which he was the State Association's representative. . .

SARATOGA COUNTY CHAPTER welcomes new Executive Director, Mr. Donald Propeck. Mr. Propeck comes to the Chapter from **ERIE COUNTY** where he worked for People Inc. Mr. Propeck was selected from more than 50 applicants for the Saratoga County position. . .



Donald Propeck, new Executive Director, Saratoga County Chapter.

HERKIMER COUNTY CHAPTER is currently recycling about ten tons of glass every week but need 15 to make their operation possible — So reads an article in one of their area newspapers. Our comment is that we wish all of you out there in **HERKIMER COUNTY** would drink a little more beer and be sure to turn the bottles in to the Chapter. . . **WEST SENECA DEVELOPMENTAL CENTER CHAPTER** sent us their recent newsletter listing 3 pages of activities by the Chapter. We agree with President Toni Parisi who said "We are not a cookies and coffee bunch. We are doers!" At the January meeting of

WEST SENECA CHAPTER, administrative representatives were invited to discuss the landry and clothing problems and they came up with a better system of accountability. Had a champagne party on March 10, perhaps why everyone in the picture has their eyes shut. They are raising money for recreation articles such as bowling machine for the population at West Seneca. . . **NASSAU COUNTY CHAPTER** looking forward to their 19th annual Rose Ball at the New York Hilton on Saturday June 19th. Here is the Chapter that knows how to discuss money. The front page story of a recent issue of their newspaper tells that their November Bazaar proved to be a rather good fund raiser with the net result being over \$38,000. . . We really wish that we could reprint in full the tremendous story on North Hall, one of **CAYUGA COUNTY'S** hostels, which appeared in the March 7 issue of The Citizen People of Auburn. It showed how good a hostel could be, and came with a really warm letter from a staff member, asking us to consider it. Space is too tight for a full reprint, but we'll close this issue by suggesting you write Cayuga County for a copy.



Many bills proposed to amend MH Law

Literally dozens of bills have been introduced to amend the Mental Hygiene Law. This is clear evidence, according to Joseph T. Weingold, Executive Director, New York State Association for Retarded Children, of the failure of the Mental Hygiene Law to serve the mentally retarded, either in the institutions or in the community.

Typical of such legislation is a bill introduced by Assemblyman DeToro which seeks to do away with the Legislature's power to create developmental centers or psychiatric centers. The purpose of this bill, of course, is to permit the Commissioner to create what he calls "multi-functional institutions"; this, in other words, is to mix the mentally retarded with the mentally ill and bring our conditions of service back 100 years when the mentally retarded ("idiots") and the "insane" were lumped together in one institution.

Calling this an arrogant invasion of the rights and privileges of the legislative branch of service, Mr. Weingold urged

that this bill not be reported and that the Legislature maintain its independence of the Executive Branch of government.

Another bill introduced by Senator Donovan and Assemblyman McCabe, was obviously a ploy against the Conklin-Landes bill for a separate Office. This creates another Division of Developmental Disabilities and Mental Retardation in the Department of Mental Hygiene and gives it powers, which according to a spokesman for the Association, could easily be granted to them by administrative action of the Commissioner.

Vital legislation such as increase of state support of community mental health and mental retardation projects to 75 per cent instead of 50 per cent, calling for hearings on the Budget of mental health boards thirty days before they are submitted to the commissioner, amending the insurance law to prohibit discrimination against the mentally retarded by life insurance companies as well as in health and accident policies, all languish in committees as of this writing and have shown no movement.

Willowbrook stipends polarize state

In another attempt for what is euphemistically called "deinstitutionalization", the Department of Mental Hygiene, in addition to its program of offering stipends on a family care basis to parents of adults who take their children home, has offered to pay a monthly allowance of \$291 to parents of retarded residents at Willowbrook Developmental Center to take them home and care for them there.

The program will apply to both children and adults covered by the Willowbrook Decree. The stipend will be paid for by a combination of state funds and federal SSI income.

Deputy Commissioner Coughlin stated that this approach has been tried experimentally with institutionalized adults, those over 21 years of age, throughout the state since last July, and that "not a great number" of them had gone home.

In response to requests for comments on this program, the State Office has received numerous communications, all of them highly critical of this approach. The criticism is directed to the approach that

only parents of children who were in institutions would receive this stipend if they took their children home.

"What of the child who has been kept at home all through his life," stated one of the letters. "Don't we as parents of these children have the same needs for support as the others? Why is there a special attention paid to them based on saving the state money. Isn't the state saving money because the children we are keeping at home are not being institutionalized?"

Although the program is an interesting approach to this problem, said a spokesman for the Association, it is obviously polarizing the parents of the children in the community versus those with children in the institutions. This is similar to the program under chapter 620 of the Laws of 1974 whereby the state pays 100 per cent for community services for those in institutions who are released and who have been in the institutions for five years or more. The retarded remaining in the community are funded at only 50 per cent for services whereas these are funded at 100 per cent.

Ammendments progress

Contracts under the Javits Wagner-O'Day amendments, which provided for priority in government contracts to agencies engaged in the rehabilitation of handicaps other than the blind have begun to seep through to the retarded.

A most recent news issue of Rehabilitation Industries for the Handicapped, the regional counterpart of

National Industries for Severely Handicapped, highlights these movements.

Occupations, Inc., a rehabilitation agency in Orange County, has received a \$650,000 contract to provide the federal government with nearly 30,000 lamps.

The Oneida County ARC Workshop is in the price proposal stage (may have already received it at this writing) for the production of tent pins, (\$300,000.)

Jefferson County ARC is in the price proposal stage for janitorial custodial services for \$7100 and plastic collar I.D. tags for \$28,000. Jefferson County is also placed on the procurement list for janitorial custodial service for the U.S. Army at Camp Drum for under \$10,000 and Oneida County is involved in the procurement list for surveyor stakes for under \$10,000.

The contracts for the ARC's aren't very much compared with the \$600-700 and \$800,000 for contracts that we see moving around, but certainly they are a step in the right direction. We will continue to watch this with a great deal of attention.

Beating the drum . . .
for you to come to Rye
in October

Development Disabilities Assistance and Bill of Rights Act of 1975

The Developmental Disabilities Assistance and Bill of Rights Act of 1975 (P.L. 94-103) was signed by the President on October 4, 1975. This legislation, like the Education for Handicapped Children Act, relies on the Federal grant-in-aid device with a formula grant providing money to the States. Both of these bills reflect a current and very serious dilemma in the Congressional process. On the one hand, Congress is deeply concerned with the problems of the disabled and the handicapped. Thus the bills are both broad in scope and generous in provisions. On the other hand, the legislation does not reflect the fiscal limitations which the Congress has acknowledged in creating the new budget process. The central issue which will emerge for both bills is how much will be appropriated. What is likely to occur is a partial funding of these new authorizations.

Federal interest in programs for the developmentally disabled may be traced back to 1963 legislation which emphasized research in developmental disability and the training of people in university affiliated facilities for research and services. In 1967, the program was extended and expanded to include persons with other neurological conditions in addition to the mentally retarded. 1970 legislation again focused on university training facilities and emphasized the multi-disciplinary approach while further expanding the program to include epileptics and cerebral palsied persons.

In 1974, Congress received a requested report on a General Accounting Office (GAO) study of the operations of the developmental disabilities programs in the states. This report pointed to gross differences between and within States as to services offered, delays in service, and funding levels. Working from this report, Congress has now enacted legislation to provide a better framework for the program, more careful planning and more effective evaluation.

The developmental disability legislation has always relied on the universities for research, demonstration, and the training of personnel, especially interdisciplinary personnel. The Developmental Disability Act of 1975 provides for increased funding for these activities and for the establishment of satellite clinics to be operated from the university affiliated facilities in areas which do not have a university engaged in the work. This would bring the program of services for the developmentally disabled into parts of the country now denied service. The bill also projects that funds will be made available to assist the universities in construction of facilities.

P.L. 94-103 authorizes the Secretary of the Department of Health, Education, and Welfare (HEW) to make grants to public or nonprofit organizations for the purpose of mounting demonstration projects. These grants could include activities such as parent counseling and training, screening and intervention, infant and preschool programs, seizure control systems, and legal advocacy services. Funds authorized to be appropriated under this section of the new law come to \$18 million in 1976, \$22 million in 1977, and \$25 million in 1978. In making decisions on applications for these funds, the Secretary is to consult with the National Council on Services and Facilities for the Developmentally Disabled.

The 1975 legislation redefines both the disability and the services. "Developmental disability" will now refer to a disability which:

— is attributable to mental retardation, cerebral palsy, or autism;

— is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in similar impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similar to those required for such persons;

— is attributable to dyslexia resulting from a disability described above;

— originates before the person attains age 18 and has continued or can be expected to continue indefinitely;

— and constitutes a substantial handicap to such person's ability to function normally in society.

Title II of the Act is directed to the establishment and protection of the rights of persons with developmental disabilities. There is general statement of rights of individuals in terms of the responsibilities of the Federal government and the States. For those of the developmentally disabled who must live in institutions, there are criteria for standards for such institutions. For all person aided by the Federal funds there are provisions for habilitation plans and for the protection and advocacy of individual rights.

The standards for institutions include criteria for adequacy of the food diet, provision of medical and dental services, prohibition of physical restraints unless absolutely necessary, limitations on the use of chemical restraints, assurance that close relatives may visit at reasonable hours, and compliance with normal fire and safety requirements of law. Care must be adequate to the needs of the individual. Habilitation plans are now a requirement for the receipt of Federal funds. These

plans are to be individually developed by the agency or institution jointly with the individual, if feasible, or his family or other representative and must include a statement of the specific habilitation services to be provided.

The Federal share of the costs of the programs is not to exceed 75 per cent, except if a project is located in an urban or rural poverty area in which instance the Federal share may rise to 90 percent. The amount authorized to be appropriated for service programs conducted by the States has been increased, and conditions for use extended and clarified. Forty million dollars is authorized for 1976, \$50 million for 1977; and \$60 million for 1978. There is a discretionary allotment formula in the law, taking into account population and the extent of need for services.

In order to avoid any immediate fiscal impact of the expanded program incorporated in P.L. 94-103, the new statute provides for a simple extension of all authorizations under previously enacted legislation for one year. Thus the increased funding will not appear until fiscal years 1976 and 1977. At that time, the program for the developmentally disabled must enter into the new Congressional budget process and seek allocations to implement the authorizations of this bill for 1977 and the years thereafter.

It is interesting to note that a special section is devoted to advocacy with a \$3 million (later reduced) authorization to the states to develop a systems of socio-legal advocacy for the mentally disabled.

The New York State Association for Retarded Children hopes that SOAR, broadened to include representation from other organizations, will be that vehicle.

Study finds test safe

AMNIOCENTESIS SAFE, NIH FINDS

Amniocentesis, the process of taking some amniotic fluid from pregnant women about the 12th week of pregnancy and run the fluid through tests to do a chromosomal analysis, has no significant adverse effect on pregnant women or their babies, according to a four-year NIH financed study of more than 2000 women.

About half the women underwent the procedure, which identified 19 fetuses with chromosomal defect, 15 with serious abnormalities of metabolism or body chemistry, and 11 with a 50 per cent risk of other disorders.

Thirty-five women chose abortion and eight of their aborted fetuses proved to have Down's syndrome or mongolism.

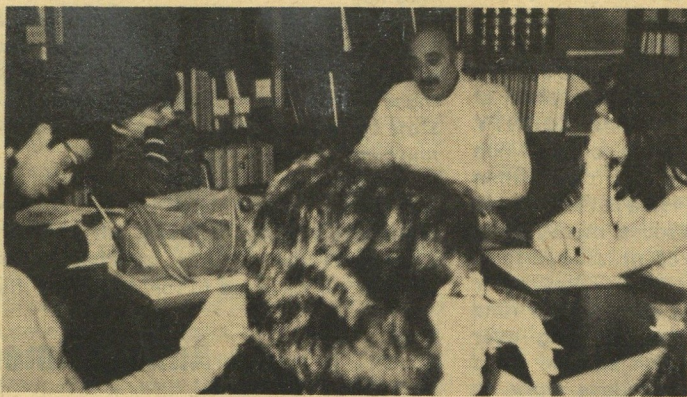
Among the half of the women who did not have amniocentesis, seven gave birth to Down's children.

While the study lends weight to the statement that the incidence of mental retardation can be reduced 50 per cent by applying what is now known, the NIH scientists, in reporting the findings, point out that many more specialists must be trained before the test can be given to most pregnant women thirty-five and over. In this group the risk of having a child with mongolism is significantly greater.

Reporting on a separate study, The National Foundation - March of Dimes said that more than 97 per cent, of 2000 pregnant women who sought amniocentesis in 1974 were reassured that the suspected defect was not present.

The tests also can determine sex of the unborn child.

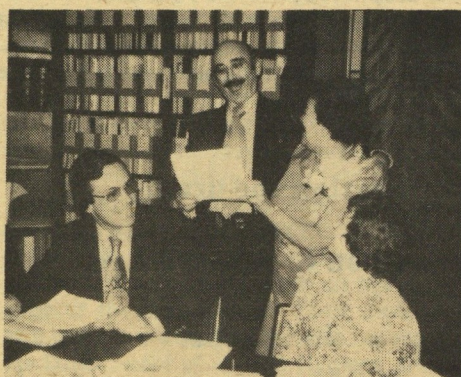
Committees in action



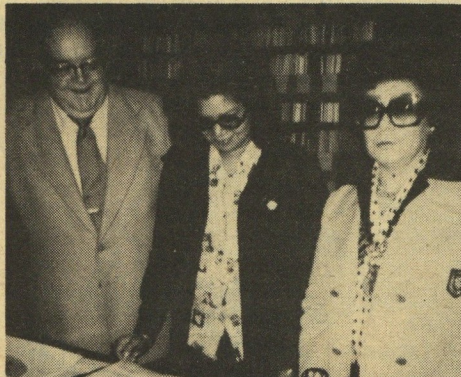
At the State Youth Board meeting in the State Office library, January 1976 left to right, Jon Weingold, Kathy Baker, Pres., Jerry Weingold, Michelle Norgren, N.E. Rep., Hilarie Seifert, Secy.



At the Institutions Committee meeting, March 6, 1976, left to right, Mary Andrews, Toni Parisi, George Hirsch, Dorothy Bingel, Ellen Maroun. Others present were Bill Eberhardt, and Frances Reville, and Karin Burgess.



Jerry Weingold laughing at the Education Committee budget presented by Betty Pendler. Jim Johnson and Shirley Reynolds smile.



Showing the Christmas Card Designs, Edward License, Chrm., Scholarship and Awards Committee, Dolores Wright and Chad Dowling.



At the Education Committee meeting, left to right, Georgia Sullivan, George Heymann, of SOAR, Tom Scholl and Marilyn Wessells.

Court cases: *What they mean*

Dr. Herbert Goldstein, Director, Curriculum Research and Development Center in Mental Retardation, Ferkau Graduate School of Humanities and Social Services, Yeshiva University (reprinted from the Centerline).

"The very nature of the many court cases on behalf of handicapped children, where they are held and who is involved, gives them a quality of remoteness from the perspective of the practitioner. Most cases are heard in courtrooms in state capitols or thereabouts during working hours. And the cast of the characters is usually confined to the legal representatives of both sides, an array of "expert" witnesses, more often than not university people from other states, and representatives of the "accused" and, perhaps, the state director of special education and some of his or her staff. Spectators constitute a small, mixed number; an interested parent or two, a reporter from the local newspaper and some educators from nearby districts.

There is a tendency, therefore, to view these cases as win-lose phenomena without any immediate impact on the day-to-day activities in the classroom; a "they" got theirs and "they" better change their ways, ipso facto: dismissal of the event. The fact is there is no "they" apart from all of us. Or, as Pogo's friend Porky put it, "We have met the enemy — and he is us." In a class action suit, the defendants are more often than not the state education authority and all local school districts, and the plaintiffs are parents of severely and profoundly handicapped children who want their youngsters accepted into the public schools. And even though there are sides, all of the testimony is within the context of "education" as a social institution and "special education" as one element of the institution. In essence and without intending to oversimplify a complex situation, the plaintiffs claim that their children have the same entitlements to education as all other children and that existing facilities other than the schools are too sparse, too remote and too overpopulated to get the job done. The state, on the other hand, pleads poverty of finances and facilities, questions the relevance of education for these children and—or their eligibility for a place in the public schools and related arguments. The plaintiffs respond with redefinitions of education, the inadequacy of extant educational opportunities for their children, reinterpretations of the role of the school recommendations for changes in financing and the deployment of facilities and the like.

My point here is that the testimony of both sides gets built into the judge's decisions. These in turn become elements in the requirement for compliance of the education authority. Thus, the results of court actions consist of more than changes in the school code or legislative reforms. They include statements having bearing on everything a teacher does and therefore everything curriculum developers do.

Here are a few observations filtered firsthand from a lot of testimony from both sides. Let's take redefinitions of education first. It has almost become a courtroom tradition that, sooner or later, an expert witness is asked for his definition of education. While there are often variations on the theme, the theme comes through strongly, namely, that education is any purposeful intervention leading to the enhancement of the learner's behavior, aptitudes and skills. I think you would agree that this is more inclusive than conventional definitions that governed our earlier experiences. More important, it takes learnings that have been valued for their own sake and requires that they be integrated developmentally into a total educational program. To put it another

way, toilet training, travel skills, lacing shoes, etc., etc. are part of the child's educational experience and not accomplishments that have to be gotten out of the way in order to ease the teaching burden. And so, there are no longer legitimate distinctions between management objectives and educational objectives providing that you accept the new definition.

It appears clear to me that, whether we subscribe to this broader definition of education or not, is beside the point. It is becoming more and more a part of the educational scene. Indications are, then, that we are going to have to shift our objectives for handicapped kids from making them less of a burden to others to the enhancement of their inherent abilities which, incidentally, increases the probability of their self-sufficiency.

Another fact of life that is emerging from the court cases is the role of parents in decision-making about the in-school experiences of their children. Every case I've been involved in or have read about has a due process provision which effectively gives parents the right to challenge decisions on placement, curriculum, and the like. The onus is on the school people to demonstrate the validity of their actions. The theory behind this, as articulated by one judge, is that parents have a right not only to be informed, but, beyond this, to contribute to the decision-making process what they feel is right for their child.

The decisions of the courts include a requirement that a due process procedure be established including a neutral hearing officer and, should the parents desire it, the advice of their counsel. It seems to me that most due process hearings thus far have been concerned with placement decisions and categorizing children, e.g., in classes for the brain-injured vs. mentally retarded, or labeling a child educable vs. trainable. They are exercising due process rights about the content of instruction or the quality of ancillary services. If they do, it is our responsibility to make a case for what we are doing and why. If we can do so to the satisfaction of the hearing officer, we are on solid ground.

Getting back to definitions and the like. Did you ever think that you could be done in by educational terminology? Believe it. In one case that will live long in my memory, a strong point in the state department's strategy was to challenge the relevance of educating trainable mentally retarded children. "If the objective of the schools is to educate," said the Assistant Attorney General, "how can you propose that children who according to educational terminology are not educable be included?" Well, it took some fancy footwork to get out of that semantic trap. The judge was no help since he took our terminology literally. At first I was tempted to deny that there was any real distinction between the terms "trainable" and "educable", but even in my panic I could see that this would make us all look like a bunch of superficial morons. Instead, I babbled on at some length about innovations and progress that have led to changes in performance and expectations which, in turn, raise questions about the current validity of old labels and categories. Fortunately, the judge could decipher my incoherence and ultimately accepted the premise that an inclusive definition of education makes distinctions such as trainability and educability irrelevant; that all children are learners to one degree or another and therefore educable. Incidentally, the Assistant Attorney General had a great time in pushing this issue for which I am happy, seeing as how he was an eventual loser. But our mission in life does not include

bringing a bit of lightness into the lives of Assistant Attorney Generals. So kindly watch it, out there. Let's get our terminology so precise that it speaks for itself or, if that is not possible, so ambiguous that any explanation is acceptable.

When we put the outcomes of court cases together, an inclusive definition of education plus access to a relevant education plus due process, it is clear that the sum of these must be equal to the total classroom as a productive rather than accommodating setting. The extent to which this balance is going to be attained will depend in great part on the relevance of the curriculum and teaching method and the kind of support teachers need in the form of information about children, productive technologies and coordination across the program.

The one fact we all have to face is that we cannot back away from a court order as we can from plans we evolve on our own. I don't get the feeling that the courts or the parents refuse us the flexibility we need to experiment with program, facilities and the like. At the same time, they do have the right to raise the questions that test our accountability. From the looks of things, then, we're getting into a whole new ball game, involving the participation of those who were once relegated to the sidelines. It will be interesting.

Hear ye!

Don't miss
Westchester
in October



PCB may cause brain damage

Recent articles about dangerous levels of PCB in samples of striped bass and other fish taken from the Hudson River prompted an inquiry by our executive director to Robert P. Whalen, M.C., Commissioner of Health and Dr. Lawrence Kolb, Commissioner of Mental Hygiene. He questioned whether the ingestion of such fish over a number of years is able to cause brain damage and mental retardation.

Dr. Whalen responded that investigations (as to the long range effects of PCB on children) were inconclusive.

He cited two Japanese studies. The first was the effect of breast milk contaminated by PCB. Although the level of PCBs in breast milk tended to be higher in fishery districts and in urban and residential districts than in the agricultural districts, the results of the survey showed no correlation between the frequency of infants with abnormal findings and the mean level of PCBs in breast milk.

In the second study, designed to examine the effects of growth on school children exposed to PCBs, one Japanese worker reported a significantly smaller rate of increase in height and weight gain when compared to a control group. No other differences were reported.

Another Japanese investigator reported the presence of a high incidence of teeth with abnormal edges among children 7-8 years of age in areas where PCB contamination was widespread.

In his letter of March 9th, Commissioner Whalen states that these represent the only existing reports of systematic efforts to examine the problem of effect on school children.

"However," he writes, "they must be viewed with extreme caution, since the children exposed to PCB are the very same children likely to have been exposed to a wide variety of environmental contamination, including methyl mercury."

Zoning bill introduced

Following the lead of California, a bill has been introduced by Senator Conklin and Assemblyman Richard N. Gottfried, S. 8796, to prevent any political subdivision of the State from enforcing or passing any zoning ordinances which would prevent the operation or the establishment of group homes (with a maximum size) for the mentally disabled.

A similar bill was passed both in California and Montana and has been upheld by the Supreme Court of California and the appropriate court in Montana.

In both these cases, a statement was made by the court, that the intent of the Legislature was to provide for community residences for the mentally disabled, local communities cannot prevent this by ordinances that would restrict the development of these services.

All those who have tried to establish hostels for the mentally retarded are well aware of community opposition and local ordinances. This legislation would make the intent of the Legislature paramount and prevent local communities from frustrating this intent by restrictive zoning laws.

An extensive memorandum of law has been submitted by the staff of S.O.A.R. in support of this bill.

Since it restricts the power of local communities, this bill must be passed in to successive calendar years. In other words, if the bill passes this year it would have to be re-passed again next year for submission to the Governor.

Dr. Kolb referred Mr. Weingold's letter to Dr. Leon Roizin, senior pathologist at the New York State Psychiatric Institute. He states that inquiries have been initiated concerning available information on Hudson River fish. Dr. Dickenson Liu, a biochemist with the Canada Center for Inland Waters in Burlington, Ont. has devised a technique that can render PCBs harmless in a matter of days, according to Dr. Roizin.

Senator Conklin referred the letter to the New York State Department of Environmental Conservation. This source stated that ingestion of such fish could potentially cause these results if one assimilated enough of it over a long period of time.

"Although the official," writes Senator Conklin "was not certain of the amounts needed to cause such results, he did note that the minimum amount required to detect signs of disorders is .3 milligrams per kilogram of body weight, at which point the more common disorders are apparent, such as chloracne, changes in the pigmentation in fingernails, and swelling of the eyes and eyelids. Besides these afflictions, the presence of PCBs at higher levels has been linked to more extreme forms of disorders including brain damage, mental retardation, stillbirths, nervous disorders, skin cancer and even deaths."

The widely publicized cases of Yusho disease in Japan were the result of ingestion of rice oil contaminated with PCBs and DCBF (A contaminant of PCBs which is more toxic) and were apparent when amounts of these chemicals in combination were found in the body at 30 milligrams per kilogram of body weight.

"Certainly," concluded Senator Conklin, "these findings suggest an area of great concern to me and you."

YOUTH Group News

THANKS TO 23 WONDERFUL KINGSTON KIDS

By Marge Archibald, Kingston

It is a privilege for me to know all the members of the Area Youth for Retarded Children (A.Y.R.C.) as so very glowingly written up by Jon Powers.

I have a vested interest in the Kingston Area Children's Library and was quite upset about their recent disaster. I, along with many others, wanted to help on Begger's Night but would not have been able to do anything much alone. What then to do? I asked Scott Brandenburg, the A.Y.R.C. President for some help; let him have the use of our telephone for about one hour; and on Begger's Night I had 23 wonderful young people at my home ready to go out into the 2nd Ward to collect. Some even gave me their donations before starting out.

They then went out and collected several hundred dollars. Later, during the radiothon, a few who could not help us called in pledges of their own.

I would truly feel they need personal and individual mention. I would appreciate it if you would print their names. (They are not necessarily in any order of preference, just the way my list reads).

Scott Brandenburg, Leslie Murray, Wayne Albert, Lisa Long, Helen Blas, Pat Feldmuth, Michael Kadzielawski, Greg Jones, Kevin Mayes, Joan Reiman, Joanne Wolff, Beth Hixson, Francine Cook, Karen Miller, Glenn Clark, Licia Miller, Bob Clark, Steve Denis, Cindy Michols, Beth Cook, Beth Henry, and from our home and neighborhood, Dewt Archibald, Trish Albert and Donald Short.

I wish I could give them all medals. I feel one cannot do enough for them. I know that they cannot do enough for others.

SMITHTOWN AUXILIARY NEWS By Terri Hynes, YOUTH Treasurer

"People Touching People" — The next time you see teenagers wearing a tee-shirt emblazoned with that message, don't be alarmed. They are not advocates of group sex, or self-proclaimed groupers. They are members of the Smithtown Junior Auxiliary, proud of the chance to show off their new slogan and should not be confused with any of the above. Designed and voted on by auxiliary members, we feel this motto is synonymous with our relationships with our special friends. Not too long ago, members re-examined their purpose and changed their attitude from doing for, to doing with, the retarded. "People Touching People" expresses the necessity of both giving and taking in any relationship.

Individual activities, that's our new focus. Smaller, personalized relationships, where members really get to know their special friends. From this, our rapidly expanding one-to-one program has developed, where auxiliary members spend extra time with just one retarded friend, outside of our many auxiliary groups functions. During the past months, some of these activities have included phone calls, visits with a shut-in, bowling, shopping, skating, crocheting, cooking, and trips to the movies, planetarium, dog-sled races and to the beach.

One-to-one has been a most fulfilling and enjoyable experience. One boring afternoon we decided to take a trip to the beach to watch the sunset. It would have been nice had we been able to find the beach. Unfortunately, our sense of timing and direction was a little off that day, and we got to the beach after dark. Our activities were reduced to throwing rocks in the water and trying to locate the Big Dipper, where, again, our sense of direction proved to be off. For our next outing we decided on the dog-sled races at Blydenburgh Park. It was the coldest day of the year, and the wind chill factor put the temperature somewhere around 40 degrees below. Two hundred howling huskies, one complaining child, and three

drippy noses were more than we could take, and we headed off for McDonalds. Although they sound like disasters, our little excursions were really a lot of fun and we look forward to more in the future. Anyway, you know your one-to-one program is really a success when your special friend's little sister cries because she's not handicapped, and complains: "I never get to go anyplace."

SUFFOLK COUNTY Y.O.U.T.H. ACTIVITIES

By Jacki Mott

Hello World — We're back!

We're back and trying to reorganize our thoughts, our goals, our aims and our council. Some auxiliaries needed a little reorganization, some needed members, many need "special friends" to work with. Adam Strickland and I are helping with the reorganization. I will be speaking at the High Schools to recruit members and we need YOU, the parents of our special children to tell us of your needs: does your child need a "buddy"?; is your special teen interested in sports, dancing?; or would he or she just like to go to the Mall or to a movie?; does your child need help with his religious education?; does he like to go on special trips?; receive a special birthday or holiday card?; or do you need a babysitter?

There must be other ways we can help you. Won't you please let us know how we can better serve you? Please call 273-2626 (Area Code 516) for information on Junior Auxiliaries. Give your name and address to the operator and we will send you information about your local group, along with a form to fill out stating your preference of services.

We have so many teens anxiously awaiting a special friend. Is your special child waiting for a friend?

As we reorganize some groups, we are also reorganizing our council. Each month a different auxiliary will act as chairperson and secretary. They will be responsible for reporting to the board of directors and writing for the Lamplighter.

We hope that this will rekindle the spark of enthusiasm that has always been a part of council and will become a true sharing experience.

We are excited about... Brentwood Junior Auxiliary's March 5th program of "God-spell" for all workshop clients... Hope Junior Auxiliary's planned outing for twenty-five workshop friends to see "Fiddler on the Roof"... Smithtown Junior's canceling a sports night for March 5th so they would not conflict with Brentwoods program. Thanks.

We are looking forward to a great finish to a slow starting year. We know the teens are capable of truly great programs, so please don't forget to get your son or daughter on our mailing list.

WEEKEND FOR YOUTH

By David Barker and Kathy Baker

Who says Youth doesn't do anything? Youth State Board was busy at a Memorial Day Work-Weekend and State Camp-out at Camp Catskill.

At our State Board Meeting last January, Mr. Weingold spoke about the summer camp run by NYS-ARC and the expensive undertaking involved in preparing Camp Catskill each summer for our retarded youths and adults. In characteristic fashion, Youth Board Members unanimously volunteered to help defray expenses by providing some of the manpower needed to refurbish the cabins and grounds. This was not only our chance to experience an exciting service project that will benefit our retarded who attend Camp Catskill this summer, but it provided an ideal setting for statewide representation at Youth's Annual Spring Board Meeting which was held simultaneously.

Look for a follow-up report in your next issue of OCV.



Some familiar faces at the Westchester Ball at the Rye Town Inn. Left to right, Senator William T. Conklin, Jonathan Weingold, Billy Conklin and Jerry Weingold.

Art Show in Ulster

The retarded children and adults of Ulster County presented their Arts & Crafts in a special indoor - outdoor showing on Sunday, June 6, at the Association for Retarded Children's Workshop, in Kingston.

All mentally retarded persons ranging in age from pre-school children to senior citizens were eligible to enter the contest.

This show was the first of its kind in Ulster County, and represented a cooperative effort between the schools, agencies and facilities that serve the retarded — Association for Retarded Children.

Association for Retarded Children (Day Training Center, Kingston Workshop, Ellenville Workshop) Bloom House and Scardefield House (community residences), BOCES, Gateway Industries, Greenwood School, Hudson Hills Community Residence, Kingston City Schools, Pine Grove School, Ulster County Public School System, Wassaic Developmental Center, Wingdale Unit and Wassaic Home Care Facilities.

The agencies in this cooperative effort encouraged over 2,000 retarded children and adults to prepare materials for the show. Each facility held a pre-selection contest and the winners were on display at the show on June 6.

The exhibit included among other things, handmade rugs, pottery, furniture, sewing, mosaics, paintings, sketches and graphics.

The Honorary Judges were:

Stanley Coffman — President of the State University at New Platz (representing education).

Brian McQuade — Vice President of SIAC New York State Exchange (representing business).

A prominent panel representing the artistic community included:

Maurice Brown Ph.D. — Chairman of the Studio Art Department — State University at New Platz.

Lorraine Lilva — Arts Editor — The Kingston Freeman.

Janice Beskin Kiss — Sculptor representing Cragmoor School of Arts.

Steve Broson, Painter, and Phillip Gurriere, Sculptor, from the Woodstock Artists Community.

Retarded may vote

Thirty-three retarded men living at the New Lisbon State School in Woodland, N.J. do have the right to vote, according to a New Jersey state appeals court.

The unanimous decision by the Appellate Division of Superior Court said recently that the state law prohibits "idiots" and "insane" persons from the right to vote. But the court ruled that "a mentally retarded person" need not be an "idiot" and a mentally ill person need not be "insane". The court ordered that the 33 men be allowed to register to vote.

A recent survey of all 50 states and the District of Columbia found that 20 states have laws that grant the retarded the right to vote unless they have been adjudicated incompetent. Five other states informally granted the right to vote (Maine and Oregon have informal rulings from their attorney general that the retarded can vote). What is important is that there be some training program in what was known in the school days of your editor as "civics" to devise effective ways of education on political processes so the right to vote is more meaningful to retarded adults.

It is interesting to note ballots were given to educable mentally retarded whose mean I.Q. was 60.42 with a range of 42 to 79, the result showed that a mock election successfully predicted the outcome of the real election even though it was held a week earlier.

Preference for severely retarded

Citing an imperative need to increase the repatriation of severe and profound clients in overcrowded developmental centers, Dr. Lawrence Kolb, Commissioner of Mental Hygiene, directed the sending facilities to select residents in the severe and profound range for transfer to the department's newer developmental centers.

Dr. Kolb said that utilization of newer facilities should be toward providing services to those clients with the most difficult challenges in relation to needs, programming and service.

The new policy marks a change in the previous practice under which personnel from many of the newer developmental centers screened residents at the overcrowded centers for transfer.

\$500 scholarship offered

The New York State Association of Teachers of the Mentally Handicapped, Inc. is offering a \$500 scholarship to be awarded to a high school senior who plans to enter the field of teaching the mentally handicapped. Applicants must demonstrate adequate background in working with mentally handicapped persons.

Applications and further details may be obtained by writing Stanley P. Scher, Chairman, Professional Growth and Advancement Committee, 2168 77th Street, Brooklyn, 11214; or to Gary McDermott, Supervisor of Special Education, Jefferson - Lewis Counties BOCES, Starbuck School, 430 East Hoard Street, Watertown.

Response to Education Committee

Page 13

WITH AIDES FROM BETTY PENDLER, CHAIRPERSON

Mr. V. Paul Smith, President of Saratoga chapter, writes to committee member Tom Scholl, in response to the questionnaire sent him by the Education Committee: . . . "Out of a dozen school districts in our county, we have excellent relationships with two, and practically no relationships worth mentioning with the others. That's partly the individual board's (of Education) fault and partly the ARCParents in those districts who don't yet realize that they have much to gain by working with those boards. Some of our people are blind and not very receptive to the realities as some of us see them: (emphasis, chairperson's) . . . much to the advocacy work done in our county is not done by the chapter itself, but by the chapter members in their home communities and school districts."

Note: This is what the Education Committee is all about — to get each parent to work on a local-local level. We agree Mr. Smith — and hope your chapter will form a real education advocate committee — and then keep in touch with your regional education chairperson who is Marilyn Wessels, and she can be contacted at: Bldg. No. 1, D. Heck Developmental Center, Balltown Road, Schenectady, N.Y. 12304. Tel — 518 370-7496 (work).

LETTER FROM KATE KLEIN President of St. Lawrence County Chapter

Dear Mr. Scholl,

We commend you for consulting all the board membership for input into your Education Workshop, and it sounds like a quality performance and very much needed in chapters where such school services have not yet been organized. . . we run our own workshops up here. . . New changes in the law for handicapped persons are constantly being interpreted for us. We have found the BOCES personnel very helpful in conducting information sessions. Our Committee on the Handicapped is in full swing and we keep pushing for everything the law will allow. Good luck with your Education Committee workshop."

Note: Thanks Kate for those kind words — we wish other chapters would be as live-wire as you people are. We'll come to you for answers to some of our problems we get from other chapters."

Obviously this is an example of what a good strong Education Committee can do for a chapter — "going full swing".

LETTER FROM MRS. LOUISE COOKE Lewis County Chapter

Dear Mrs. Pendler,

Thought you might be interested in the enclosed news release from BOCES about our trainable classes. We feel that here in Lewis County our special education classes are top notch. As noted elsewhere in the bulletin, there is another note about special ed classes. Mr. Kellerhale is just marvelous — he is also vice-chairman of the Community Mental Health Board. I too get upset about not having parents on the committees for the handicapped. Maybe someday I can do something about it."

Note: Lucky Lewis County with top notch classes — but we have to be there monitoring.

I hope all our readers will see the need for every chapter to have an active working education committee in there pitching—

URGENT. . . WILL EVERY CHAPTER PLEASE SEND INTO THE STATE OFFICE THE NAME OF AN EDUCATION LIAISON PERSON WITH WHOM OUR REGIONAL CHAIRPERSON CAN MAKE CONTACT TO DISSEMINATE INFORMATION.

AND KEEP THOSE LETTERS COMING. . . WE WANT TO HEAR FROM ALL OF YOU. . . PROBLEMS, SUCCESS. . . FRUSTRATIONS. . . IDEAS. . . SUGGESTIONS. . .

QUOTE FROM HERKIMER COUNTY CHAPTER NEWSLETTER Education — By Janis Gillespie

"As the new chairperson for our ARC Education Committee, I would like to take an active role in assuring your handicapped children the same education and rights of any other student within the school system. I believe that it is the job of the ARC to support parents in any area of their frustrations, including those which are the result of our local educational system. If you, as parents, have had any difficulties in enrolling your child in school, being allowed to monitor his education, discussing your long-term goals for him with his teacher, getting bus transportation, integrating him into non academic classes or appealing his placement in a special class etc., these are the problems we would like to hear about. We would also like to have you share your experiences with other parents. While attending the State ARC Education Conference in Syracuse, it was brought to my attention that our chapter knows little about forces which rule our children's lives. For example, each school district should have a committee on the handicapped appointed by the Board of

Education. This committee has in its power the status of each "special" student. Each school district must have a committee on the handicapped to review and evaluate, at least once a year, the status of each child within the school district who is designated, "handicapped" to see if the child will require placement in regular class, special class or exclusion from school. The New York State regents recommends parent involvement in local committees, and yet our chapter had little knowledge of such committees within our school district. Who then has been placing your children and evaluating their progress? We must make our boards of education aware of their obligations to us and to our special students. The fight is not over".

Note: Yes indeed — you are quite right — thanks for alerting your parents to the need of more education advocacy. Good luck in your new chairperson's role, and we sure hope you are able to help your parents out. If you have any questions, contact the regional chairperson of your district who is: Tom Scholl, 701 Forest Drive, N. Syracuse, N.Y. 13212 (tel: 315-458-0969).

'How to be an educational advocate to effect changes'

Chapter Education Committee Onondaga workshop

The New York State Education Committee held its first workshop recently at the Syracuse Developmental Center, in the areas of communication, program evaluation and educational advocacy, with Onondaga Chapter hosting a large and lively crowd.

There were many Chapter educational representatives attending, and representatives from the New York State Department of Education and New York State Department of Mental Hygiene, listening to a stimulating panel of speakers. The participants during the morning gave very valuable information for all parents. A key sentence was uttered by Josephine Scro, of "Parent Coalition" in Syracuse who reminded us that "we parents recognize the value of the professionals — which we respect — but they must remember that we are the experts".

Mr. Steven Taylor, Research Association from the Center on Human Policy of Syracuse University, spoke on the "Right to Education" and talked about the parents on the move through the courts, with more and more class-action law suits against departments of education.

Mr. George Heymann, of SOAR, gave an excellent presentation listing steps for parent advocacy committees to take, with a key suggestion that we keep accurate and detailed records of everything we do — who we see, what they said, what telephone calls we made. He emphasized the need for us to have clear facts and objectives set prior to meeting with representatives of our school districts. Mrs. Jean Chatfield gave us very valuable hints on how to educate the community and the school system, getting on an "Advisory Board to Committee of the Handicapped" as the first step in the door.

Dr. Nicolas Collis, Executive Director, Onondaga County Chapter, gave a very informative talk on the elements of evaluating a program identifying solution to problems and implementing them.

John Ruf, Principal of the Fravor Road Middle School in Mexico, New York and a member of ARC spoke about the Parent as an Evaluator and urged us to check into the programs of the public school to see if they ever stop to "assess the needs".

By this time the serious tone of the meeting was broken by a humorous but relevant talk by the noted educator, Dr. John Readling, Chairman of Education, Administration, State University College of Oswego on how to "Understand the School Administrator". He agreed that parents know more about the business of running schools than administrators, but urged us to understand them and "join education from within" — attend public meetings, take notes in a conspicuous manner, that always gets the officials nervous.

We all learned a great deal about public relations from Susan Morse, Community Relations Director of Onondaga County Chapter as she gave us the tips of how to get publicity, free literature, etc. (Copies of her presentation will be available by writing to your regional member of the Education Committee.)

Prior to the running of the workshop, a questionnaire was sent out to all chapters asking that the person assigned to educational needs reply. The committee culled the areas of concern from the replies received. There appeared to be common concerns in many areas, such as pre-school services, adequate diagnosis placement and follow up, request for general information on laws, how to change attitudes within the schools, how to get to serve on the Committees on the Handicapped, how to implement educational rights, how to get more than lip service for parent involvement, etc.

Your Education Committee is planning to deal with each of these problems directly with the respective chapters through their new regional set up. Each regional representative will communicate with the local chapters to make contact with the educational liaison, and hopefully there will be frequent communications back and forth, sharing successes and failures, assisting in trying to get parents on committees. Information coming out of the State Office will be more readily passed onto individual chapters, and finally, in those cases where all local efforts do not succeed in solving a problem, the regional chairperson, in conjunction with SOAR, would attempt to assist.

SOAR: Education Advocacy

In the first of a series of books on advocacy for the mentally retarded and other developmentally disabled, George M. Heymann, J.D. of SOAR staff has written "Advocates Guide to New York State Education Laws for the Mentally Retarded and other Developmental Disabilities". This is an exhaustive presentation of the Education Laws, case law, regulations and other matters dealing with the rights of the mentally retarded and other developmentally disabled to free public education under the laws of the State of New York.

It is the first of a series of volumes which will codify all the laws of the State of New York dealing with the mentally retarded and developmentally disabled, and their rights, including, but not limited to, mental hygiene, social services, etc. In a foreword, the Honorable Robert H. Wagner, Justice of the Supreme Court, and administrative Judge of the Family Court's Fourth Department states, "Fortunately, in their 200 years of existence as a nation, the people of the United States had a peculiar and persistent concern for the rights of all citizens. From Thomas Payne to Thomas Jefferson, to Susan B. Anthony and Martin Luther King, there has been continuing ferment to both broaden and make specific those 'certain unalienable rights' which include life, liberty and the pursuit of happiness."

"The preparation of this Guide by SOAR, illuminating some of the newly gained rights for the mentally retarded, is most timely. Although it is said that all children have a right to a free public education, the full implications of Section 1, Article 11 of the New York State Constitution have not been explored. Only recently has this section been interpreted to authorize the extension of benefits to the handicapped of which the mentally retarded are a part.

"This Guide should provide assistance to those seeking to know the rights of the mentally retarded and how they may be enforced."

After the 49 pages of text there are tables of cases, statutes, references, and index; a section on due process and appeals in the Education Law; an examination of the Willowbrook Case in education, and education of the mentally disabled in institutions and family homes.

The book was edited by Joseph T. Weingold, LL.B. and Jack Bernstein, M.S.W., J.D.

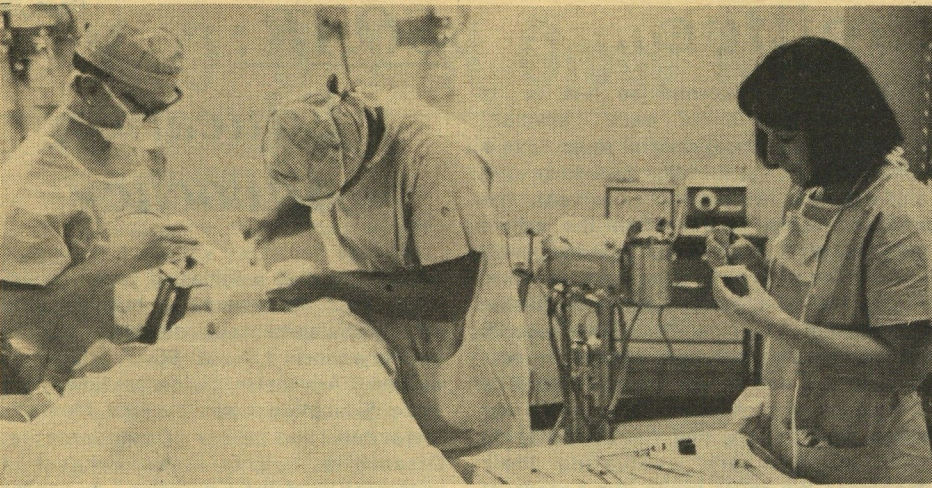
Individual copies of the book are available by request from the State Office at a charge of \$1.50 to cover postage and handling.

MH Dept. charges

Regulations proposed, as of November 19, 1975, set a new schedule of fees for service by the Department facilities:

Section 60.1 Schedule of fees for services by department facilities. Pursuant to the provisions of section 43.01 of the Mental Hygiene Law, the fees to be charged for services, care, maintenance, and treatment of patients and residents in programs operated by facilities in the Department of Mental Hygiene as of October 1, 1975 shall be in accordance with the definite schedule.

The regulations go on to describe in detail the in-patient facilities for the mentally ill, such as intensive services, unitized, continued services, etc. but there is no definition of services in the facilities for the mentally retarded.



Pictured left to right at Dental Surgery Clinic, Mental Retardation Institute, Dr. Francis S. Latteri, Anesthesiologist; Dr. Roy H. Jones, Dentist; Mrs. Colleen Brandon, Dental Assistant.

Dental Clinic opened by M.R.I.

The opening of a new Dental Surgery Clinic in the Dental Pavillion of the New York Medical College's Mental Retardation Institute at Valhalla has been announced by Margaret J. Giannini, M.D., Director of the Institute. The facility will provide surgical dental procedures for developmentally disabled persons of any age.

The Dental Pavillion of the Mental Retardation Institute is under the direction of Sydney C. Rappaport, D.D.S., of the Oral Surgery Department of New York Medical College. The clinic boasts the latest in surgical equipment and facilities. Patients receiving oral surgery will be

given pre-operative and post-operative care in the In-Patient Hospital unit of the Institute.

"We are delighted that we can now provide this important and badly-needed oral surgery service for handicapped people in Westchester County," Dr. Giannini said. She also pointed out that some dental surgery patients will be brought to the Valhalla facility from the Institute's second campus in Manhattan on East 106th Street.

Conklin on Willowbrook

In a letter dated March 11, 1976 to the Honorable Orin G. Judd, the Judge in the Willowbrook case, Senator Conklin expressed his concern that the Department would be unable to meet the requirements for the establishment of the 200 community placements.

Calling for an immediate review of the matter by the Judge to ascertain what steps might be taken to assure compliance by the Department of Mental Hygiene, Senator Conklin pointed out that Deputy Commissioner Coughlin was isolated from direct contact with operations at the developmental centers and community programs because of responsibilities that have been placed in the hands of the regional directors. "Such an organization scheme effectively isolates the top man in the Department responsible for mental retardation programs from supervising implementation of the Decree," wrote Senator Conklin.

At the hearing before Judge Judd that same month, Commissioner Coughlin pointed out that he has been given authority with regard to the Willowbrook case to do whatever was necessary and without prior approval of the regional director.

Speaking for the Association plaintiff in the case, Mr. Weingold pointed out that the Willowbrook class is scattered in many parts of the state, including Long Island and upstate. "It follows," said Mr. Weingold, "that Mr. Coughlin should be given this authority over all regional directors in the state with regard to the Willowbrook class, at the very least."

The Judge did not act on this at the meeting, but this obviously is going to remain a problem in implementation.



Keep your eye
on Rye!

Parents ignored in DMH decisions

The Department of Mental Hygiene, as evidenced by the actions of Regional Director James Forde, failed to appoint a facility advisory group under their own regulations. This ignores the parents in decision making process concerning movement of residents out of the institution.

On November 24, 1975, Mr. Weingold wrote to Commissioner Kolb protesting the directive of the developmental centers not including establishment of committees as provided under the guidelines of 75-10 regarding releases or transfers of residents.

On December 2, 1975, Dr. Kolb wrote Mr. Weingold thanking him for his letter and stating he issued Memorandum No. 96 to regional directors and facility directors reinforcing the Department's position that the facility advisory groups will be appointed and involved in accord with Memorandum No. 75-10.

The Memorandum No. 96 dated November 10, 1975 to all regional directors and all facility directors read, in part, "All facility directors will nominate and regional directors will appoint advisory committees pursuant to Memorandum No. 75-10. Please advise Mr. Coughlin, Deputy Commissioner for Mental Retardation, of the names of each facility's groups upon appointment."

"The success of the Department's programs depends, in large part, on inputs from consumer groups. We should make every effort to involve the parents and friends of the handicapped in our facilities in the decision-making process."

In spite of this, regional director James Forde, in connection with the transfer of residents from Wassaic Developmental Center to the Mid-Hudson Psychiatric Center, states the only thing he has not done with regard to implementing 75-10 is the appointment of such advisory groups who must come from the Association for Retarded Children.

This is like saying that the only thing that we are not doing in connection with transportation is providing a bus.

The question now must be asked: What is Dr. Kolb doing to discipline regional directors who are failing to carry out this order?

New SSI Regulations

RETARDED RECIPIENT IN PRIVATE SCHOOL

New regulations effective last August will make a considerable change in the eligibility of a mentally retarded person in private residential schools.

Until now, the payment of fees by parents on behalf of the mentally retarded in residential facilities was considered "unearned" income to the mentally retarded person. On this basis, if the parent pays \$5-6-7 8,000 or more per year, it was obvious that the mentally retarded person was ineligible for SSI merely on the basis of a means test.

This, of course, is entirely different under social security where unearned income is not figured in income to the recipient.

The many protests to our New York State Delegation of legislators brought little, if any, response and only a promise by one of them that legislation would be introduced (which it never was) to change this and remove the fees paid by parents from the unearned income provision.

Apparently, the pressure paid off because the new regulations state that the presumed value of support and maintenance in such a facility is no more than one-third of the federal benefit, \$72.56 or less if that is what is being contributed. Since the first \$20 of income is disregarded, then only \$52.56 is subtracted from the SSI payment.

The significance of this is not just the money, but the fact that the person now becomes eligible for SSI and a possible state supplement for a resident in a private school for the mentally retarded.

It is interesting to note, however, that this change in regulation was kept such a deep dark secret until it was unearthed by our SOAR people that we continued our protestations to the Congressional Delegation beyond the date of implementation of the regulations.



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the
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Oct. 7-10

Ford signs Education Bill

On November 29th, President Ford signed into law Public Law 94-142, the Education for All Handicapped Children Bill, revising and extending the Education of the Handicapped Act. The measure provides Federal assistance to state and local education agencies for the education of mentally retarded and emotionally disturbed children. On roll call vote, the House, on November 18th, passed 404 to 7 and the Senate, November 19th passed 87-7.

PROCEDURES AND TIMETABLE

The law requires the states, no later than August 21, 1976, establish policies and procedures to insure all handicapped children the right to free appropriate education in order to be eligible for federal funds. Policies and procedures include:

- Goals and time tables providing full education opportunities for all handicapped children,

- Methods for determining which children are "still unserved" and they are to receive priority,

- Free appropriate public education for all handicapped children between the ages of 3 and 18, inclusive, no later than September 1, 1978 and ages 3 to 21, inclusive, no later than September 1, 1980.

States will give priority to those children now receiving no educational services and those receiving an inadequate public education.

INCENTIVE GRANTS AVAILABLE

An incentive grant is available to states providing preschool educational services to handicapped children between the ages of 3 and 5. Each state will receive a bonus of \$300 per handicapped child served for each fiscal year.

The maximum estimated authorization beginning in 1978 and for all subsequent years is \$200 million per year.

The states must also be responsible for developing policies and procedures providing special education and related services for handicapped children placed in private facilities as a means of carrying out the requirements of the Act at no cost to parents and-or guardian.

Individualized written education programs are required beginning fiscal 1978.

FEDERAL FUNDING INCREASED

Although, initially, the funds were divided 50-50 on a matching basis between state and local education agencies, effective fiscal 1978 local agencies will receive a greater share of federal funding on a 25-75 matching basis with state educational agencies.

Beginning with fiscal 1978, the allotment formula will be implemented as follows: "number of handicapped children being served in each state school district between ages 3 to 21 inclusive which can amount to no more than 12 per cent of the state handicapped school children between the ages of 5 and 17, multiplied by the percentage of the national average expenditure per public pupil school child.

EDUCATION DEPT. POWERS DEFINED

Children now covered under programs funded through Title I of the Elementary Secondary Education Act, and that includes most children in Department of Mental Hygiene programs, cannot be counted under the new program. It is noteworthy, however, that the Act provides that the Education Department shall have some powers over the education of the mentally retarded in institutions of the Department of Mental Hygiene and everywhere else.

To comply with P.L. 94-142, New York State must provide adequate guaranteed funds to be equitably distributed for the extra costs of educating handicapped children, without recourse to the Family Court under Section 4403 of the Education Law. This has been a headache throughout the state with Family Courts reaching different decisions in different jurisdictions.

In addition, the Legislature must begin thinking of mandating education for the handicapped from age 3, as well as revising its formulas, such as in Section 4407 where parents receive only \$2500 and must go to the Family Court for excess costs.

A parent views help on keeping child at home

The following letter is from the parents of a severely retarded child who is keeping her child at home and protests the failure to give her any help. Her argument, that the state is putting a premium on institutionalized children in terms of financial support, is worthy of careful consideration.

We just received our January 1976 copy of "Our Children's Voice" published by the New York State Association for Retarded Children. I can't understand some of the reasoning behind what I read. I hope someone can clarify these points for me.

On page 5, I read that the Department of Mental Hygiene has adopted a plan to make family care payments to parents of individuals over 21 years of age who have returned to their home after being in an institution for more than two years. The rate of payment is \$208 a month in the upstate area and \$263 a month in New York City. In the same article the statement is made that 'the parent has a legal responsibility for a child under age 21, but upon achieving maturity the child is no longer the natural charge of the parent, according to law'. In the article on page 13 concerning the protest of Rome Developmental Center's cutback in the number of hours it sends relief persons to private homes to care for severely retarded children, the statement is made that the relief service 'had saved institutionalization with a cost of \$12 to \$15,000 a year to the state.'

Am I wrong, or is the state and federal government and the New York State Association for Retarded Children placing a premium on institutionalization of a child?

A year ago, my husband and I went to apply for SSI for our Karla. Karla was twelve at the time and the victim of Rubella. She is a severely retarded, multiple handicapped child. Karla never had received a day of schooling and the only help she's received in those twelve years was one eye examination, two hearing evaluations, a consultation at Sunnyview Clinic at Bassett Hospital every six months for four or five years and in the past three years, had been visited by a physical therapist every two months or so.

Our income for 1974 was \$8600 for our family of seven. Karla was not eligible for SSI benefits because our income was over the limit. I was not terribly upset by that fact because I realized the need for limits, but when the gentleman said if Karla were placed in an institution, foster home or some other facility, SSI would pay over \$150 a month toward her care, I wondered why any retarded child was in their own home.

I know why we chose to keep Karla home with us. We sleep better nights knowing Karla is in the next room warm, clean, well-fed and loved. Karla is ours and we feel we owe her a home and decent care as long as we are able to do so. But, I feel parents who keep these children home deserve some breaks in our laws, limitation, whatever. Why wouldn't it be far more reasonable to help these parents and children through SSI benefits or family care payments rather than making it more financially acceptable to place the child in an institution. We pay taxes, but Karla, like so many others, can't benefit from public schooling, so is exempt.

I will be very honest. We could use the \$208 a month family care payments or SSI assistance as I'm sure most parents who are caring for their severely retarded child at home could.

If Karla was in a state institution, tax dollars would pay for her care and we still could claim her as an exemption on our income tax, plus any tuition paid, cost for room and board, cost of sheltered workshop, and even our transportation costs for visiting her could be deducted as medical expenses. As it is, with our income, we never deduct a cent because of Karla's special needs. We could probably place her in a state institution for a fee to us of less than \$25.00 a month. Food alone costs over this amount for this child plus we have to buy special clothing, special toilet needs, baby sitting fees to go shopping or out, and this child even affects the type and cost of the medical insurance we can buy. Karla's last twelve years could have cost the state \$144,000 at the rate of \$12,000 per year in an institution.

Under the new Mental Hygiene plan, we could place Karla at age 19 in an institution, leave her there two years at a cost of \$24,000 to \$30,000 to the state and then bring her home and receive \$208. per month for her care. Do you realize that that \$30,000 for two years in a state institution would pay for about 12 years of care in our home under the new program of paying family care payments to parents? Please explain the rationalization of the more than two years placement in a state institution clause of this plan. If the individual home meets the standards of family care homes, why can't the parent be paid these payments without the cost of institutionalization to the state and without the traumatic experience of separation for the child from his family.

It doesn't seem that such programs give those of us with severely retarded children much incentive to go on caring for our children in our home. I am well aware that the Karla's of our state will never be able to benefit from the community programs now being advocated except perhaps the respite sitter service, but I am sure that we, as a family, hope we are doing the best we can for Karla and do not want to be forced to place her to ease the financial and sitter burdens. Certainly to place Karla would be the easiest answer. It would spread the wages at bit further for the other children, give more time to the others in the family, make it possible to meet appointments and shop at reasonable hours, and would let us go out for a day as a family without the hassle of finding a sitter or the inconvenience of trying to mobilize Karla, but then we read the articles about Willowbrook and decide Karla's place is at home.

I can understand that keeping a retarded child at home is virtually impossible for some families. During this past year as we've seen Karla regress to a point of about where we were six years ago, we've considered placing her in Broome Developmental Center. We have cared for Karla for almost 13 years and we can and want to go on caring for her in our home, but it sometimes seems impossible to go on when we cannot get a sitter who is willing to change her or able to lift her, and when we cannot obtain financial aid or the services needed. We cannot obtain the respite service sponsored by the Otsego County Chapter of the New York Association for Retarded Children and the Broome Developmental Center because I am a Foster Mother.

All I'm asking is WHY? WHY does it seem our society is advocating placement of our child? WHY, when I ask for help, is the first suggestion to visit Broome Developmental Center — WHY is the state willing to pay for institutional care at a rate of \$12 to \$15,000 a year? WHY is the county willing to pay \$2500 a year to a Foster Mother for the care of a child instead of helping the parents financially to care for their child at home? WHY is the

Mental Hygiene Department willing to pay a family caretaker \$208 a month for the board of the retarded, but the parents must care for their own child remaining at home unassisted. WHY can't we be helped to meet what we feel is our moral obligation to keep our severely retarded child at home?

It is up to all of us to help those who must place their child. I feel this is right and praise the new laws which made help possible. But please stop placing a premium on the parents who place their children in care facilities while that same child in his own home would have been able to receive nothing. Very truly yours, Mrs. Kenneth Hammond."

ARC protests proprietary hostels

In a strong letter to Commissioner Kolb, Joseph T. Weingold, Executive Director of the New York State Association, protested the policy of the Department of Mental Hygiene to give certificates of operation to "profit - making proprietors or corporations to operate group homes and other community facilities for the developmentally disabled."

"I think", wrote Mr. Weingold, "the Department is heading on a disastrous course and I suggest an immediate review and reversal of this policy."

This letter was prompted by the policy of the Department of Mental Hygiene to give certificates of operation to profit - making individuals and organizations in the field of group home care for the mentally retarded. In addition, an article in the December 20th New York Times stated that the State Health Department was



planning to transfer four nursing homes from a proprietary operator to non-profit institutions.

The Moreland Commission has strongly indicated that the operation of nursing homes by proprietary interests are not necessarily in the best interests of the clients and should be re-examined very carefully.

It is interesting to note, the Mental Hygiene Law itself does not speak of state aid to proprietary operated hostels but only to voluntary agencies.

Nevertheless, the Commissioner and the Department are intent upon this course, on the theory, perhaps, that those who are there for a profit motive will create the facilities faster than the voluntary agencies which must be helped with funds for acquisition.

Expense appeal lost

The Court of Appeals recently unanimously approved the right of the Family Court in New York City to order the parents of handicapped children to contribute to the maintenance of their youngsters in connection with their education in private schools ordered by the Family Court.

Parents of three mentally disturbed youngsters lodged their appeal after the Family Court had granted their application for payment of full tuition and transportation expenses but denied their application for payment for board and lodging.

Their appeal was based primarily on the ground they were denied equal protection of the law because no such contributions are required of deaf or blind children.

In his opinion, Appeals Judge Hugh Jones wrote: "A rational basis does exist for the distinction made in relieving the parents of blind and deaf children from any financial responsibility in connection with their children's education while at the same time requiring parents whose children are otherwise handicapped to contribute to the maintenance component of education expenses."

Maroon appointed

Congratulations to James D. Maroon, of our Rockland County Chapter, on his appointment as Special Placement Assistant to the Rockland County Personnel Office.

Jim Maroon, formerly a member of the Board of Governors of the State Association, has been active in the special education field, particularly with respect to the retarded for several decades. The job will be to work with the staff of the various agencies in educational systems designing or redesigning existing positions to provide enhanced employment opportunities.

What this rational basis is, is not explained by the Court of Appeals at all, except for this bold statement. Some glimmer behind it is the statement of the Court of Appeals in pointing out that assistance to the blind has been recognized as a special category in the field of social services and that the Federal government and other benefits to the blind are not available to other handicapped persons.

On the basis of this thinking, it might be pointed out that the mentally retarded, cerebral palsied and epileptics have a special category in the field of social service because the Federal government under Developmental Disabilities Assistance Act singled them out for special assistance and not the blind or the deaf.

A movement must be made to repeal that part of Section 232 of the Family Court Act that provides for contribution by the parents in these cases.

Mr. Arthur D. Zinberg, with whom the Association has worked closely on this case, has filed a Notice of Appeal to the U.S. Supreme Court.

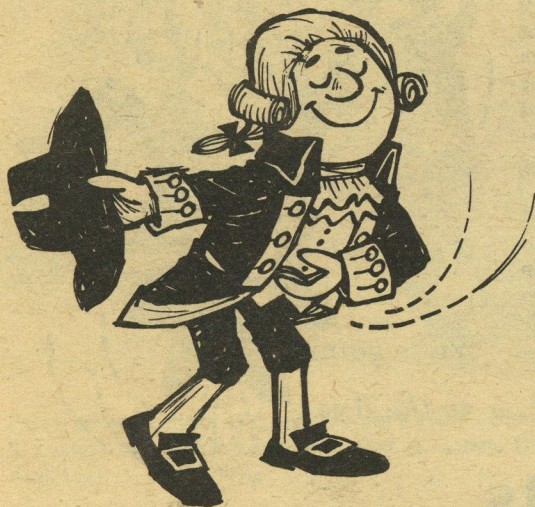
Govs. meet with Ford

Nine governors met recently with President Ford and members of his Cabinet to discuss a long list of concerns the chief state executives have regarding the current federal policies.

The delegation was headed by Governor Robert D. Ray of Iowa. He was joined by Governor Lucey of Wisconsin, Busbee of Georgia, Bowen of Indiana, Bennett of Kansas, Andrus of Idaho, Moore of West Virginia and Noel of Rhode Island.

One of the items discussed was the issue of intermediate care facility regulations. The governors stated the regulations for the mentally retarded were excessively rigid regulations on the Life Safety Code, minimum staffing standards and the four-to-a-room rule.

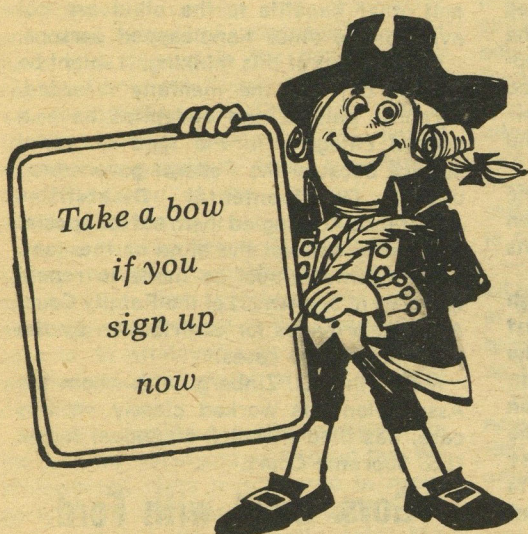
Convention Registration



OCTOBER

7-10

1976



TO: Westchester County A.R.C.

121 Westmoreland Ave.

White Plains, N.Y. 10606

Attn: Mary Kallet

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

Registration	\$ 5 _____
Luncheon — Saturday, Oct. 9	\$ 8 _____
Dinner — Saturday, Oct. 9	\$12 _____
Total	\$25 _____

Name: _____

Address: _____

Phone: _____

TO: Rye Town Hilton Inn

699 Westchester Ave.

Port Chester, N.Y. 10573

Gentlemen:

Please reserve the following accommodations for me for the Convention of the New York State A.R.C. Oct. 1976.

Single at \$39 per day _____

Double/Twin at \$47 per day _____

Date of Arrival _____ Departure _____

Name: _____

Address: _____

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Retarded Children Can Be Helped

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