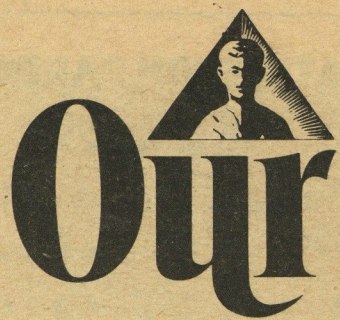


JUN 28 1979



Our Children's Voice

Retarded Children Can Be Helped

Vol. XXXI No. 2

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

June, 1979

ARC responds to Single Source Funding

Equal funding for all, says ARC

In response to the association's demand for "Parity" in funding community services, the Governor has responded in terms of "equality" of funding, merely a proposal for a "Single Source Funding" bill for OMR-DD. In the opinion of the association this is not a real response to equal funding for equal services.

In a memorandum distributed to the legislature, the association has disapproved of the proposed legislation on the following grounds:

1) The purpose of the proposed bill is to latch on to more Federal funds by making the services Medicaid eligible. This is both regressive and unrealistic because the services would have to conform to a medical model, a setback for mental retardation services of more than 50 years. It negates all present day concepts of the developmental model, which may meet or may not meet Medicaid standards.

2) It is unrealistic because it excludes almost all major backup services in the community which are the keystone for the mentally retarded.

Funding lines excluded from the pool are: 89-313 Funds; DD Council Funds; Vocational Rehabilitation; Disabled Children's Program; and 202 Housing (HUD).

3) The bill requires the maintenance of efforts at 1977 levels for all communities. In effect, this mandates not only the counties but the voluntary agencies to maintain this effort, an unrealistic, if not unconstitutional approach.

4) According to a study of Welfare Research, Inc. made at the request of OMR-DD, all previous experiments along this line have failed — the Hartford SITO; Joint Simplification Act (too difficult to obtain assent of all the categorical agencies to the joint funding process) and finally, the Unified Services Act, as a system.

5) The experiment is too expensive. The department's own study states clearly, consolidated funding is not cheap. "It will be an expensive and time-consuming process, etc., etc., etc."

6) The bill confuses services for the deinstitutionalized and the services for those never institutionalized. The former are already funded at 100 percent. The problem is the latter — where the state refuses to see the obvious.

7) The bill speaks of "units of service" for reimbursement emphasizing physical delivery of services instead of the client's needs. Programs, not units of service, must be funded.

8) The department states if the state were to assume 100 per cent of the cost, it will remove the County's incentive to control costs. Nowhere is this substantiated.

The bill is opposed by the Council of Mental Hygiene Directors, The State Association of City Councils and many others.



Senator William T. Conklin receiving beautiful engraved pitcher as token of appreciation from our Madison County Chapter. Jerry Weingold is making the presentation in his office.

Hostel highlights Ups and downs

Saratoga County — Plans for a home for retarded adults in Rexford were cancelled early this year. Saratoga's executive director and the owner of a 19 room Victorian house failed to agree on a price. ARC sought to place eight 25-to-35 year old retarded adults and two staff members in the house. The home, if established, would have been the first of its kind in Saratoga County.

Schoharie — A new community residence in Schoharie County will provide living space for eight adult residents who will be supervised by a staff of three persons. The new residence is the third such facility to be established in Schoharie. An existing hostel will be phased out and will become supervised apartments for the adult retarded, with four such apartments scheduled to be in use. The new residence will be a "beginning place", where residents can begin the progression that will lead to greater self sufficiency and independence.

Dutchess — An attorney who represented the town of Washington in its protest hearing over the location of a group home for retarded there, takes issue with the legal interpretation of the new law given by a counsel for the state Department of Mental Hygiene. Dutchess County plans to establish group homes for eight to 14 retarded adults in several locations in the county. Two of them, Washington included, have gone on record as protesting their location within their

borders. Under Chapter 468 of the 1978 statutes, which became effective in September of 1978, the chapter does not need a town's permission to establish such a group home. The only grounds on which a town can appeal the location of such a facility are that the town is already saturated with a concentration of similar facilities or that it would significantly alter the character of the community or neighborhood. Washington's contention is that the community is inundated with similar facilities and that these facilities serve nearly 10 per cent of the total Washington-Millbrook population. According to a spokesman for the Commissioner of Mental Hygiene, it may be quite a while before a decision comes out of the hearing.

Westchester — Eight institutionalized mentally retarded adults await the day when they will move into a one-family group home located in Yonkers. The wait will be longer because the courts must decide which law, the city's or the state's, governs the establishment of the home. The city has denied a building permit for renovations and the Bureau of Housing and Buildings directed that a special exemption use before the Zoning Board of Appeals be sought. This July, the Westchester Development Services, a state agency sponsoring the group home, has been paying rent for a vacant house that could be a happy home for these adults, who now live at the Wassaic Developmental Center.

Community budget short

State aid frozen at '78 levels

For 96 or more percent of the mentally retarded who have never been institutionalized, the Governor's budget freezes local aid at exactly the same level as 1978, \$18,300,000. In fact, this is a decrease of at least 10 percent in the light of the cost of living increases.

On the other hand, the Governor's budget increases Chapter 620 funding for mentally retarded deinstitutionalized, a small fraction of this number, from \$15,500,000 to \$22,370,000, an increase of almost \$7,000,000.

According to a spokesman for the Association, this is a lopsided approach to the development of Community Services, without which the whole deinstitutionalization program must fail.

The only two real increases in the budget are a) for community residences from 17 million to 25 million (but this is tied in directly with the deinstitutionalization program) and b) 8-1/2 million increase to institutions themselves, at a time when we are supposed to be decreasing the population dramatically.

As an answer to the association's demand for equal funding for community services for all retarded, those deinstitutionalized as well as those never in institutions, the Governor answers with "Single Source Funding" explained in a related article on this page.

The legislature went along with most of what the Governor asked and did not increase funding for community services, at least as of this writing.

Bills have been introduced for 100 per cent funding for mental retardation as well as 75 percent funding for mental retardation and mental illness but these have not as yet moved in committee.

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Be at the convention:
Binghamton-Oct. 18-21

Letters

BETTY PENDLER LAUDED

Edith M. Loveman of the New York State Chapter of the American Association on Mental Deficiency and Bob Thomas of the New York State Council of Exceptional Children wrote jointly to Jerry Weingold expressing their appreciation for the participation of representatives of the New York State Association for Retarded Children in their conference:

On behalf of both organizations, I want to express our appreciation for the participation of representatives of your agency in our 1978 Conference. Not only is there mutual benefit derived from having representatives of the Educational Committee attending and presenting at formal sessions, but the communication and sharing that occurred during Cracker Barrel sessions, informal gatherings and over dinner unquestionably increased levels of sensitivity and understanding. Issues addressed by Betty Pender have been the stimulus for several provocative discussions since the convention.

As you can see, the impact was marked.

CONSULTATION CAN BE CONSOLATION

We want to share with you a very pleasant letter Arthur L. Schwartz, C.S.W., F.R.S.H. Acting Director, Consultation and Education Principal Associate in Psychiatry of Albert Einstein College of Medicine of Yeshiva University.

Dear Jerry:

The January 1979 issue of "Our Children's Voice" really made a very frustrating and tiring day into a rather pleasant one. On page 2 under letters, your publication refers to me as the Acting Director, Consolation and Education. My staff have been teasing me about the new name of our service. We all laughed a bit — and God knows, a laugh now and then can be damn therapeutic.

THANK YOU TO JOHN BERTRAND

From Paul F. DuFlo, Executive Director, Lewis County Chapter of Association for Retarded Children comes this thank you to John Bertrand, Assistant to the Executive Director:

Dear John:

This is just a note to thank you for your assistance to our chapter in securing a loan from the Department of Transportation for the Oneida County ARC bus. Your assistance came at a time when our Van was on its last legs and we really had no place to turn for transportation. Again I thank you for your time and energy spent and want you to know that it is appreciated.

PLAQUE BRINGS THANK YOU

Daniel Donohue, Acting Director, Westchester Developmental Services sends appreciation on behalf of the entire W.D.C. staff for the employee award presented to them.

On behalf of all W.D.C. staff, I would like to thank the N.Y.S. A.R.C. for the very impressive employee award plaque that Mr. Laughery of W.A.R.C. presented to us recently. Our first award winner, Mrs. Alice Bender's name is in place, and we have already installed the plaque in a prominent position.

I want you to know that I think it an exceptionally nice approach that the ARC is taking in identifying worthy staff, since they are the heart of all organizations, yet are so rarely identified.

Many thanks, again.

Live a little. . . .
Learn a lot. . . .
in Binghamton, Oct. 18-21



They dance for retarded

Twenty thousand dollars was raised at a 52 Hour Dance Marathon which was held by Hofstra University's Z.B.T. Fraternity to benefit the Nassau AHRC. It almost seemed like a replay of the 1930's with couples fighting fatigue to finish the three day event, except the beat was different as dancers kept going to the newsest sound including lots of disco and rock.

Major sponsors included the Nassau Ford Dealers and Gus and Clare Garnir of the Ambassador Diner. Along with the dancing and live entertainment there were refreshments, game booths, and an auction. WNEW disk jockey Bob Fitzsimmons served as Master of Ceremonies and Jimmy Cottone, a former president of the Nassau AHRC YOUTH, was co-chairman along with fellow Z.B.T. brother, Jam Sherman.

Book Review

by Mary F. Tomaselli

THE CHILD WITH DOWN'S SYNDROME

By David W. Smith and
Ann Asper Wilson

W. B. Saunders, Phil., PA., 1973

Smith and Wilson have written an excellent book aimed primarily at new parents of Down's syndrome (mongolism) children. The book is divided into four chapters: Genetic factors; Mental, physical and social characteristics; a Photo album; and Adaptation of the family and the Down's syndrome child. New parents will find much that will instruct them in the nature of, help them in their adjustment to, and allay some of their fears about, Down's syndrome.

The chapter on genetic factors discusses the concept of genetic imbalances as a cause of Down's syndrome in full detail but is written simply and clearly enough (with accompanying illustrations) for the intelligent layperson to understand. The authors' discussions of the physical, mental and social characteristics of Down's syndrome are specific and particularly graphic using photographs to augment their descriptions. Forty-five pages of the book are devoted to photographs of Down's syndrome children. They serve to entertain and please the reader as well as give hope to parents who fear the extent of the limitations placed on their child by Down's syndrome. Some new parents will find the final section of the book, which contains personal experiences and comments of other Down's syndrome parents, most helpful.

Although the book has no index (a serious drawback indeed!), I recommend it to new parents, and any persons laboring under the many and varied misconceptions associated with Down's syndrome. It's worth the read!

"Golden carrots"

The state mental health commissioner hopes to improve services offered by state psychiatric centers by offering cash bonuses to directors who meet preset goals.

Dr. James Prevost told a joint legislative finance committee Tuesday the plan will be tested next month with two directors who volunteer to participate without the cash reward. If the pilot is successful, he said, it will be expanded, and cash will be inserted, throughout the state.

However, before it can be put into effect, he noted, the legislature must give its approval, and provide some start-up money to get the bonuses flowing. He said legislation still is being drafted and had no

financial figures to offer at this time.

The principle behind the plan, said Prevost, is to provide rewards for administrators who perform at levels above the objectives set for them. Those objectives would be put in the form of a contract agreed to by the director of the institution and the state's regional mental health director.

"Instead of saying to a director, 'You will do something,' you can get much more positive performance by developing objectives together," said Prevost. In previous years, he said, all directors had to operate within the same guidelines although problems at an institution in Queens, for example, might be different from those at an institution in Utica.

Our Children's Voice
Retarded Children Can Be Helped

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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New York, New York 10010
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ATTENTION PARENTS WANTED:

Parents of moderately or mildly retarded adults willing and able to invest in a group home in Manhattan.

CONTACT:

Joseph T. Weingold
New York State Assn.
For Retarded Children
175 Fifth Avenue
New York, New York 10010

Parisi named to Council

Governor Hugh L. Carey announced the appointments of the Chariman and eight members of the Board of Visitors Advisory Council of the Commission on Quality of Care for Mentally Disabled. Among the nine people appointed was Toni Parisi of Lakeview in Erie County. Toni is President of the West Seneca State School Chapter of the New York Association for Retarded Children. She is also a member of the Board of Visitors of the West Seneca Developmental Center. We congratulate Toni on her challenging new responsibility.



From left to right — Bernice Volaski, President of the Welfare League, George G. Hirsch, former President of the State Association, and Dorothy Gasman, former President of the Welfare League, at a recent functoon at Letchworth Village.

Welfare League Advocacy Project

The Welfare League marked the first year anniversary of its new innovative Advocacy Project with the completion of the **Parent Manual**. The Advocacy Project was undertaken because "we believe that an informed parent or relative is the best protector of his retarded child", says Dorothy Gasman, Advocacy Committee Chairman. Additionally, the Board of Directors is committed to expanding and strengthening the unique Unit Representative Program which Dr. Oleh M. Wolansky, Director of Letchworth Village, invited the Welfare League to initiate six years ago.

According to Bernice Volaski, President, "Over the past 39 years, advocacy has just taken different forms but our efforts are geared to improving and promoting the welfare of all the residents living at Letchworth Village."

The Parent Manual describes in simple language much of the necessary information a parent or relative needs to know when representing his kin at the six month Case Review. The Manual also includes a questionnaire guide which can be used when attending such a meeting. In the section about community placement, another guide is included advising what to look for, what to ask and what needs to be included in a comprehensive placement plan. Definitions and abbreviations of words used at conferences helps the parents get familiar with the "language" of the staff.

Advocacy Project Director, Carol Sussman, M.S.W., has on her staff graduate students from the Schools of Social Work of some of the major universities in the metropolitan area. During the 1977-78 year, Donald Goldstein and James McBrian, two students from Columbia University, were placed with the Welfare League as part of their field work training towards their Master's Degree. Together with the Welfare League, they were pioneers in the first year's work.

The Parent Manual was researched and written by the Project Staff along with Bernice Volaski (President), Dorothy Gasman (Past President and Present Advocacy Chairman), Lou Corbo (Unit Representative Chairman), many Unit Representatives and with the cooperation

of the professional and administrative staff at Letchworth Village. It was well received by the members who filled the auditorium at the Welfare League membership meeting in May 1978. The Welfare League has been receiving requests from other developmental centers and parents organizations around the state for copies of the Manual, available at \$2.00 per copy. This year's Project Staff includes three graduate social work students, Gary Greenberg and Catherine Stern from Columbia and Sanford Rosenberg from Adelphi.

Doctors, take care

A 37 year old New York woman gave birth to a daughter who suffers from Down's syndrome or mongolism. The doctor had not warned her of the risk of the disorder to pregnant older women, she said, and he had not told her of the existence of amniocentesis, a test that can determine if the fetus has Down's syndrome. She sued the doctor. The Court of Appeals, held 5 to 2, that the doctor may not only be held liable for his omissions but he may be required to pay the costs of caring for the retarded child for her entire life.

A person suffering from Down's syndrome could well survive until middle age. If the doctor loses, he could be required to pay as much as \$35,000.00 annually for the care of the child, who is now three and 1/2 years old.

The case, of course, still has to go to trial to convince the jury that the doctor has breached his duty.

In a similar case, although a New York couple won the ruling on the duty of the doctors to warn prospective parents of a possible birth defect, they failed to convince the jury that their own doctors' breached this duty.

Thus, although the courts upheld that the doctor has a duty to warn the prent of the possibility of the risk of giving birth to a defective, parents must still have to prove to a jury that, in fact, he had not performed his duty.

Judge bars segregation of hepatitis carriers

A Federal judge ruled recently against a New York City Board of Education proposal to segregate mentally retarded children who are carriers of hepatitis B from other public school children. The judge contended there was no evidence their presence had or would spread the viral disease.

Judge John R. Bartels, in Brooklyn, held such segregation would violate the retarded children's rights to education in "the least restrictive environment" fitting their needs.

He cited a "potentially devastating impact of the stigma caused by isolating these children" that could cause regression in their development and undermine job and community placement efforts on behalf of retarded persons generally.

The decision said there were "simple prophylactic and classroom management measures which it is in the Board of Education's power to take," and added that neither the Federal Center for Disease Control nor the State Office of Mental Retardation had recommended segregation.

The issue arose out of the efforts under way since 1972 to move retarded patients out of the state's huge Staten Island Developmental Center at Willowbrook.

Judge Bartels said the school board had planned to reassign 48 mentally retarded children identified as hepatitis B carriers into nine special classes, at least one in each borough. He said the board had estimated 60 to 90 more would enter public schools in the near future.

He noted that he had initially enjoined a similar proposal when the plan had drawn objections from Thomas A. Coughlin III, the state's mental retardation commissioner, who is under the court's orders to carry out community placements from Willowbrook.

Judge Bartels said hepatitis B, unlike the more commonly known hepatitis A, "is of limited communicability," although an increased risk may be associated with crowded, unhygienic conditions. Primary transmission, he said, is by blood contact through transfusions or needles, with some belief, he termed not conclusive, that it could be transmitted through such body fluids such as saliva.

Further, the judge said, Dr. Jennifer Howse, associate state mental retardation

commissioner, had testified that since 1975, 130 carriers had been placed in community and family homes without reported infections.

Among a million public-school children, the judge went on, no other group had been tested nor was any action planned against any hepatitis B carriers other than the 48 in the court case.

Voc Ed, at last

The U.S. Office of Education (OE) has issued a position statement urging development of comprehensive vocational education programs at the national, state, and local levels.

Concern with the high percentage of unemployed disabled persons was one of the OE's major reasons for issuing the statement. According to 1970 census data, only 42 per cent of handicapped individuals are employed, compared with 59 per cent of the total population. Handicapped persons have not had adequate access to the education system, the OE reasons, and they have not received a proportionate share of the vocational education that is provided in the public education sector.

Consequently, the Office of Education has taken the position that an appropriate comprehensive vocational education should be available and accessible to every handicapped person, and has set forth five assumptions that form the basis of this position.

It states that 1) Each student must be provided with programs and services that help them form basic skills and make career choices, at the elementary, secondary, and adult education levels; 2) Education and employment sectors must develop cooperative relationships to facilitate the transition from school to work; 3) Sequential instruction appropriate to individual needs and progress should be maintained within vocational education programs; 4) Unemployment among handicapped persons will be reduced when appropriate vocational education programs are provided. Such education also will help employees meet their affirmative action goals; 5) Such programs will provide maximum efficiency in identifying and eliminating attitudinal and environmental barriers.

To implement its position, the Office of Education will assess the educational community's progress in creating such programs and develop program agreements between agencies and departments at the national level, at the same time encouraging similar agreements at the state and local levels. It will also provide for participation by handicapped persons in planning, implementing, and evaluating the programs.

OE states that it will act as a national example in recruiting, hiring, and promoting disabled individuals and designate vocational education for handicapped persons as a priority item for its research and development activities. In addition, it vows to assume leadership in ensuring full protection of civil rights for handicapped individuals in vocational education activities.

Prevention

Researchers at Brooklyn's Afula hospital have worked out a new and less expensive method for accurately determining whether an abnormal thyroid condition in babies born prematurely will lead to mental retardation.

School placement advocacy success

New York City Chapter Education Committee, together with their professional Advocate, Ms. Catlin Donnelly, has started a very successful chain of networks made up of parents whose children are in the public school. They serve as advocates to reach other parents whose children are just entering the school system. These parents maintain a telephone exchange and assist the new parents by going with them to the Committee on the Handicapped to provide moral support.

In addition to their personal help, these parents use all of the reprints the New York State Association Education Committee has been distributing: How to Write Letters to Officials, What to do when you go to your Individual Education Program Conference etc. This is a good reason why each chapter should reproduce this material and distribute it. More important is this personal contact from parent to parent. It is working most successfully in the bureaucratic maze of New York City, so it has to work in your school district.

Won't you try this system with your education committee?

Community Residence Success and frustration

January brought good news and bad news to the Rensselaer County Chapter ARC in their efforts to expand their services in the community residence area. The good news involved the opening of a supervised apartment living program at 2 Prout Ave. in Troy. The bad news involved a decision by Supreme Court Judge Con Cholakis ruling against the ARC's development of a community residence at 147 Pawling Ave. in Troy.

GOOD NEWS

First the good news. The Prout Ave. residence, a three year old apartment house, will allow the Rensselaer ARC to provide a residential option to residents who have made significant progress in group homes, but do not as yet possess sufficient skills to live semi-independently in a supportive living program. The building has six apartments, each with living room, dining room, kitchen, two bedrooms and a bathroom. Two residents will be housed in each of five of the apartments, with ARC staff using the sixth apartment. The residents will be responsible for their own cooking, cleaning, meal planning, shopping etc. Staff will be available to supervise these and other daily living activities and instruct the residents in areas such as use of leisure time, money management and use of public transportation.

The Prout Ave. location is almost ideal for this program, with nearby stores, bus stops, a bank and restaurants etc. As part of the screening process for this residence, each new resident was interviewed by the Residence Screening Committee of the Rensselaer ARC. After telling why they wanted to live in a program like Prout Ave., the resident, staff and committee members identified some goals for the resident to work on.

INTERIOR DECORATED

Residents worked with an interior decorator on the selection of furnishings for each apartment. Classes run by the local Cooperative Extension in areas related to living skills were identified and a number of residents made arrangements to attend. Recreational opportunities and community activities were identified and residents were encouraged to take initiative in the selection of their own leisure time activities. Shopping, planning with future apartment mates, learning more about meal planning and preparation etc. have also been important parts of the transition to the Prout Ave. program for its residents.

BAD NEWS

Now for the bad news. The ruling by Judge Cholakis held that the ARC's residence at 147 Pawling Ave. was a pre-September 1st project and therefore did not come under the new site selection laws. The history of this project is a long and frustrating story of how the rights of mentally retarded people can be denied by wealthy, politically influential people who are biased against the development of a group home. It first started in the spring of 1978 when the Rensselaer ARC, pressed to find an alternate location for a community residence program that was located on the third floor of the YWCA in Troy, found the Pawling Ave. site.

The program at the YWCA is a special project, which is more intensively staffed than the typical community residence. The ARC's search for an alternate site was hampered by the fact that space was needed not only for eight residents but also for five live-in staff. 147 Pawling Ave. provided the needed space for such a program in a very attractive community setting.

In June, the Rensselaer chapter applied to the City Planning Commission for a site plan review of the Pawling Ave. residence. The application was tabled. A few days after the meeting City Planning Commission Chairman Arnold Harris indicated to ARC Executive Director James Flanigan that his commission was opposed to the Pawling Ave. site and would vote against it even if they did not have valid grounds. This was an option available to municipalities that did not wish to cooperate with an agency trying to develop a community residence prior to the enactment of the new site selection law.

Initially, it was not apparent why the Planning Commission was so strongly opposed to the Pawling Ave. site. Subsequently, one of the parties who sued the ARC over the development of the residence was John Sarkis, a former Chairman of the City Planning Commission. Mr. Sarkis served in that capacity during the time when Mr. Harris was hired and served as head of the City Planning Department.

Figuring there was no sense in "fighting city hall", the ARC offered to go through a voluntary site selection process with the City of Troy using the same procedures that would come into effect on September 1st. Plans for the Pawling Ave. residence were dropped and the ARC agreed to work with the city on consideration of alternate sites the city would propose. Despite repeated promises by Mr. Harris and others, no alternate sites were ever proposed. Instead, the ARC was notified in early August that the Planning Commission was going to take up consideration of their tabled application for Pawling Ave.

STRANGE MEETING

In what must go down in history as one of the strangest meetings ever held by a public body, the Planning Commission first refused to allow the ARC to withdraw their application for a special use permit for the Pawling Ave. site. They next refused to give the ARC an interpretation as to whether the project was a single family use, as had been clearly indicated in a Supreme Court ruling in a neighboring community only a few weeks before. Finally, the Planning Commission decided to reject the ARC's request for adjournment of the hearing until the agency had time to obtain legal counsel (the notice of the hearing had only been received two days before and the ARC's attorney was on vacation at the time). The legal advice for these astounding moves came from Deputy Corporation Counsel Michael Roarke, who himself had only recently been involved in unsuccessful efforts to block a black religious group from obtaining property in his own neighborhood. The ARC subsequently expressed strong displeasure at Mr. Roarke's lack of professionalism in his conduct at this hearing to city officials. Seeing that the hearing was going to be a farce, the ARC refused to participate and the application was denied.

By September 1st, the city had still not proposed any alternate sites to the ARC for the Pawling Ave. location, so the ARC filed a letter of intent with the city in accordance with the new site selection regulations. No site was named for the proposed residence, as the ARC had no possibilities at the time. The city did not respond in the 40 day time period allowed. The ARC notified the city they had missed their deadline and was told to be patient. Finally, 80 days after the notification and at least 150 days after first being promised an alternate site by city officials, the ARC representatives met with members of a

site selection committee established by the city.

NO SITES

While the city committee was most sympathetic to the ARC's plight, they had no possible sites in mind and could not come up with a location for the YWCA program within the deadlines faced by the Rensselaer ARC. With this in mind the ARC re-contacted the owners of 147 Pawling Ave. and learned that their house was still for sale. Plans for a purchase by ARC under the new site selection law were initiated.

The bank working with ARC asked for assurances that the agency would be able to obtain a building permit from the city. The ARC applied to the city Director of Code Enforcement, Keith Champagne, for the required permit. After obtaining an opinion letter from the State Attorney General on the case and a letter from Office of Mental Retardation and Developmental Disabilities Commissioner Thomas Coughlin stating the project was a post September 1 project, that came under the new site selection law, and after extensive discussions with City Corporation Counsel Donald Bowes, Mr. Champagne issued the permit.

PERMIT REVOKED

On January 2, 1979 the ARC purchased 147 Pawling Ave. On January 5, 1979 the ARC was served with papers asking that the building permit be revoked and that the ARC not be allowed to do the needed renovation work. The plaintiffs against the ARC, in addition to Mr. Sarkis who is considered to be quite wealthy, were James Browe, who runs the local country club, and Dr. David Tomlinson, a Troy obstetrician. As usual, the opponents assured everybody that they "had nothing against the retarded, but..."

The case was heard before Judge Con Cholakis on January 19th and about two weeks later the judge ruled that the decision of Commissioner Coughlin making this a post September 1 project, was arbitrary and capricious. A number of other issues raised by the ARC were not answered by the judge.

The options available to the ARC appear quite limited. An appeal to the Appellate Division would normally be considered a next step, particularly since a number of attorneys who read the decision agreed that it was very "weak". However, there are problems with this approach, since one of the attorneys in the neighborhood, who was a leader in the opposition to the ARC residence, works as a clerk to one of the Appellate Division judges.

With the political make-up of the City Planning Commission and considering the way the ARC was treated by the commission in the past, going back for a special use permit under the old laws does not appear to be a very attractive alternative.

Of course, the ARC could always consider selling 147 Pawling Ave. However, this would reinforce the idea that wealthy, politically influential people who are prejudiced against mentally retarded people can "buy-up" the rights of retarded people who wish to live in a neighborhood like everyone else and enjoy the same freedoms as everyone else.

As this article went to press, the Rensselaer ARC was closely studying its options. One thing appeared obvious, however, those of us who have been fighting to insure the rights of mentally retarded people still have a long way to go.

Make time now... for your State Convention: Oct. 18-21.



Planning some Northeast Regional activities. (left to right) — Northeast Regional Vice President, Ellen Maroun; State Association Executive Director, Joseph T. Weingold; State President, Ellie Pattison.

AHRC to honor Senator Levy

New York State Senator Norman J. Levy has been designated by the Nassau Chapter of the Association for the Help of Retarded Children as its recipient for the 1979 Humanitarian Award.

Senator Levy, a resident of Merrick, has been a sponsor of legislation which has been helpful to the retarded, particularly in vocational rehabilitation programs, and has served for the past ten years on the Nassau AHRC board of directors. Senator Levy becomes the twentieth recipient of the Humanitarian Award which was instituted by the Nassau AHRC in 1960. Since that time, the award has been presented to leaders in philanthropy and government whose activities have benefited the mentally retarded. Among the recipients was Nelson A. Rockefeller.

The Humanitarian Award will be presented to Senator Levy at AHRC's Thirtieth Anniversary Rose Ball which is to be held on June 16th at the New York Hilton.

Housing Services Act helps retarded

Congress, in the last session, passed a bill signed by the President (PL 95-554) aimed at providing basic support of living services for low-income handicapped and elderly persons. Entitled the Congregate Housing Services Act of 1978, the bill authorizes the Secretary of Housing and Urban Development (HUD) to provide residential shelter coordinated with such services as meals, housekeeping assistance, and help with grooming and personal hygiene.

These disabled persons, residents of public housing projects, or housing financed under HUD Section 202 loan program (group homes for the retarded) the eligible for the services provided by the Act. Eligible residents will apply for the services on the sliding scale adjusted to individual and financial resources.

The bill provides there must be a central dining facility in the residence, and central facilities for preparing meals to be served in the central dining facility. Each Congregate Housing program must provide full-meals program to qualify for funding under this Act.

Further measures of the bill provide that the value of support services which tenants receive under this program, may not be counted as income for purposes of determining eligibility under such state or federal programs as Medicaid, food stamps, or social security insurance.

Congress has authorized funding totaling \$120,000,000 for fiscal years '79 to '82 for this program. \$10,000,000 has been appropriated for the first year.

How New York State develops residences

At a Board of Directors' meeting of the Cattaraugus County Chapter, a policy was unanimously adopted restricting future developments of community residences under the chapter's auspices.

The Board, despite this decision, is extremely interested in cooperating with the State in developing needed community residences and fully recognizes the benefits of residential living in comparison to institutional placements. The Board, however, feels it has no choice but to restrict and limit the extent of continued involvement in this program because of the extreme delays in the funding mechanism causing critical cash flow problems.

CCRC has taken full advantage of the new funding mechanisms; i.e. start-up contracts and program development contracts, which were to provide "up front" monies and thereby eliminate any problems with cash flow.

Communications and assistance from the Western County Service Group was most valuable; however, when materials were forwarded to Audit and Control, Office of Budget and Finance, Attorney General, and any other required offices, the response time was excessive.

This narrative indicates the time sequence and process in developing the residence. This information indicates to date expenses in excess of \$45,000.00 have been incurred in addition to operational expenses for a two month period, before receiving any monies from either the start-up or program development sources.

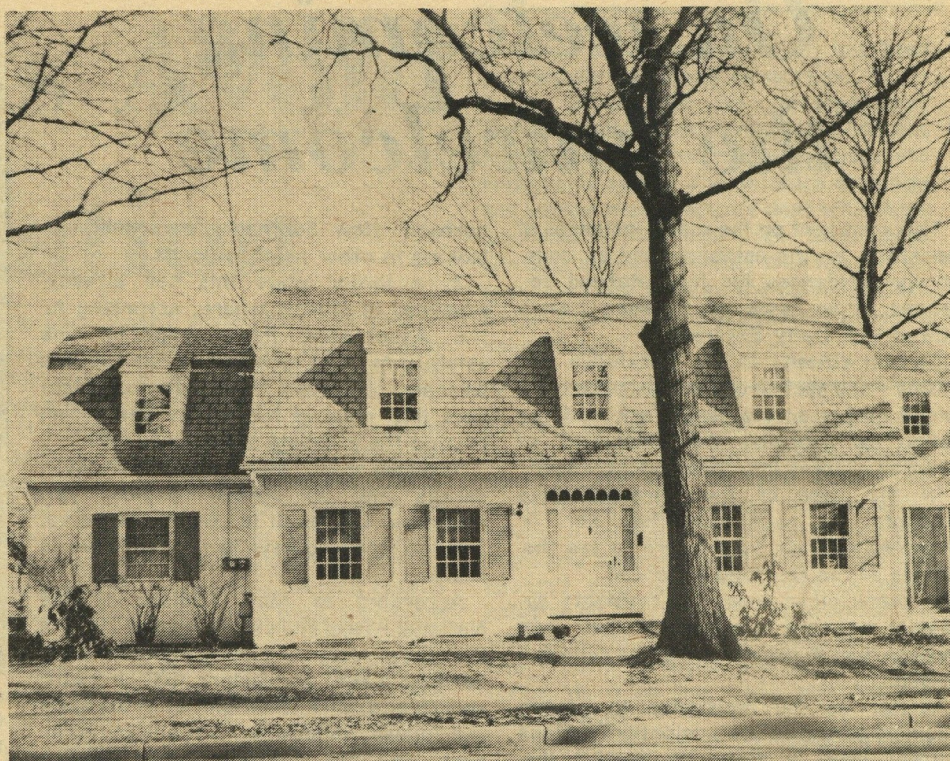
These delays have also caused damage to the reputation and credibility of the agency in light of not being able to pay local vendors for renovation costs, furnishings, and other goods and services.

It is imperative, if community based agencies are being requested to establish these programs, that a funding mechanism be established and put into place that will guarantee "up front" monies in a literal sense and reduce the bureaucratic, legalistic, accounting processes that delay funding up to two, three or four months.

The agency has grown and expanded and wishes to continue to provide needed services, but realistically it must evaluate its position, both programmatically and fiscally. They cannot incur such fiscal obligations on good will statements that monies will be forthcoming.

The harsh realities of community programs are based on deficit funding with intrinsic fiscal limitations. Community residences, with their substantial costs and limited initial funding resources, are an excessive fiscal strain. The establishing of three residences as initially considered would have caused agency-wide financial catastrophes.

Cattaraugus is committed to provide necessary programs and services and is eager and willing to provide input and participate in any discussion that would lead to an amelioration of this financial dilemma.



Nassau's fourth hostel

AHRC's fourth hostel is now open and was formally dedicated on April 1st. The house, which is in Valley Stream, is a two story white and green Dutch Colonial with four bedrooms, in addition to an apartment for the house parents. Nine young women, aged from twenty-five to forty, are currently living in the hostel along with a married couple who serve as house parents. Seven of the women work at the AHRC Vocational Center in Freeport and two are employed at the AHRC Brookville Center as teachers aides. The home was purchased by New York State to be run by the Nassau AHRC and four of the residents have come from the Suffolk Developmental Center. There are some special leisure time activities in which the women have been participating; in the last few weeks they attended a soccer game and also went to New York City to see the Harlem Globetrotters.

Township rejects residence

Rockland township has informed Letchworth Village that it will take "any and every legal action" to forestall location of a community residence for developmentally disabled persons in the township.

The board's action came after reading of a Nov. 9 letter from Letchworth Village notifying the town that Letchworth Village intends to locate the facility there.

"The program is designed," advises the letter, "to facilitate the normalization of 10 to 14 severe to moderate developmentally disabled persons."

"The program will be operated by Letchworth Village Developmental center until a county agency expresses an interest and has the capacity to assume responsibility," states the letter.

Before reading the Letchworth Village letter, Supervisor William Bills described the notification (in the letter) as "a bombshell."

He noted that such action apparently was part of Gov. Hugh Carey's campaign promises of greater effort for the mentally retarded.

Says the town board letter to Letchworth Village:

"We have in the county a Community Service Board. . . A Sullivan County Association for Retarded Children. . . A Planning Committee on Mental Retardation and Development Disabilities. . .

"In discussing this matter with Marc Brandt, executive director of the Sullivan ARC, we were given the information that ARC has presently two group homes open and four more in various stages of preparation. . .

"After their opening ARC will have completed its goal of bringing back to Sullivan County individuals (from

Sullivan) in state facilities due to lack of programming in prior years. . .

"We feel strongly that such proposals should come from (the three county agencies, mentioned above) and (your proposal) does not fit into the existing plans for service to the mentally retarded.

"The Town of Rockland is becoming a highly saturated area for handicapped individuals."

Noting that "We take great pride in ARC," the letter recommends that the state should provide more space at ARC.

The letter concludes with the statement that such a (Letchworth Village) facility should not be operated by the state in the township and that "The town wishes to inform you that it will take any and all legal action against you and other state representatives should it be necessary.

THE REHABILITATION CENTER OF CATTARAUGUS COUNTY

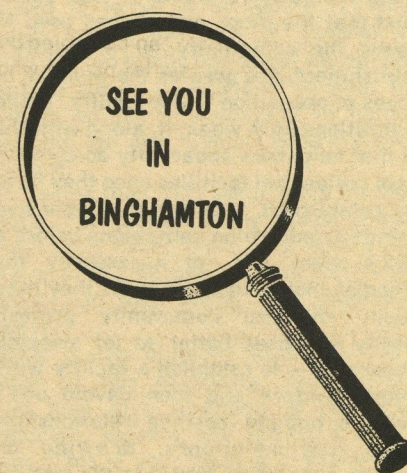
CURSORY OUTLINE OF EVENTS LEADING TO THE OPENING OF COMMUNITY RESIDENCE 913-915 W. STATE, OLEAN, N.Y.

- 10-24-76 — Initial inspection by State Architect
- Numerous letters and correspondence regarding proposal
- 4-26-77 — Agency proposal forwarded to State
- 11-16-77 — Letter from State accepting of proposal
- 1-20-78 — Letter from State — Contract being prepared
- 2-13-78 — Agency applies for operating certificate
- 4-19-78 — Letter from State — "Intent to fund"
- 4-24-78 — Second inspection by State architect
- +7-78 — Renovations begin — \$20,000.00
- 9-1-78 — Formal application — Program Development Grant
- 9-22-78 — Formal application — Start-up Contract
- 10-4-78 — Request from State for additional information regarding operating certificate
- +10-18-78 — Agency purchase — furniture, appliances, etc. — \$14,000.00
- 10-24-78 — Agency sent first voucher for P.O.S — Program Development
- +10-30-78 — Staff hired. Additional program development expenses — \$4,000.00
- 10-30-78 — Agency request information on status of Program Development and Start-up contracts
- 11-10-78 — Agency architect approves structure. Forwards letter to State.
- 11-15-78 — Agency sent first voucher for Start-up contract
- 11-24-78 — Letter from State with Operating Certificate
- 11-27-78 — Hostel opened. Operational expenses \$8,000 - month
- 1-5-79 — Receipt of Program Development Grant (Approx. 75 percent)
- 1-8-79 — Receipt of Operational Contract
- 1-16-79 — Receipt of Start-up monies (approx. 50 percent)
- 1-16-79 — Receipt of Program Development monies
- 1-22-79 — Receipt of Program Development C-151072
- + Expenses incurred.

Reynolds named to Task Force

Governor Carey included Shirley J. Reynolds of Kenmore, a faculty member of the School of Medicine at the State University of Buffalo, as a member of the Task Force on the Transportation of the Disabled. Ms. Reynolds is an instructor in developmental disabilities.

In a letter of congratulations, Joseph Weingold suggested that the deliberations of the Task Force should not exclude the need for transportation of adults to workshops even if they are not physically handicapped.



On welcoming the unwelcome

This comment on the many instances of opposition to the establishment of community residences for the retarded appeared in an issue of Saranac Lake's Adirondack Daily Enterprise.

Certain citizens in the Rockledge and Moody Pond section of Saranac Lake have joined others across New York and the nation in opposing the relocation of retarded citizens into their neighborhood.

In the case of the Saranac Lake residents, the resistance, they say, is prompted entirely by a desire to see the welfare of the retarded enhanced.

In many other areas the residents appear to be more interested in their own welfare than in the welfare of the retarded persons.

Insofar as the resistance to having retarded person as one's neighbors springs entirely from a desire to protect the welfare of the retarded, then some might suppose that there is merit to that resistance. Insofar as the resistance to retarded neighbors partakes of selfishness, then there is no merit.

One test of which impulse is controlling would be the previous or future commitment of the resisters to proper housing for the retarded.

It was instructive that in yesterday's Daily Enterprise there was a story about resistance to the retarded moving into the neighborhood in McHenry, Ill. In that community one Bea Newkirk said, "We have no lack of compassion for the cause. It is just that we want to keep the neighborhood the way it is." Bea Newkirk is willing to be forthright about her prejudices. One hopes that she has been applying the I.Q. standard to her new neighbors for years.

In Saranac Lake, as well, the complaining neighbors said that they are in favor of the de-institutionalizing of the retarded, but that they oppose the use of the particular house chosen to do the job which happened to be in their neigh-

borhood. Now Sunmount personnel are looking in other neighborhoods.

On a larger scale this has already happened in Illinois where, according to the Associated Press reports, the establishment of such homes has run into so many objections from potential neighbors that none of the homes has gotten beyond the planning stage since 1974.

Needless to say, there are differences in details and in stated reasons, yet, somehow, the result is always the same, and the retarded have to go elsewhere to reside.

According to Max Addison of the National Association for Retarded Citizens the type of resistance being experienced in Saranac Lake, and before that in Plattsburgh and other communities in the state and, indeed, nationwide, is really based in part, on "the mistaken belief that a retarded person is a sick, dangerous person."

It is this mistaken belief which apparently led Thomas Norman Sr., of St. Armand to state for publication that the Rockledge citizens are concerned "because they had a bad experience with murder in the past."

The tragedy of mental retardation is compounded by prejudice and that prejudice takes many forms and wears several masks.

It is our hope that all those across the country whose consciousness has been raised by the "threat" of having retarded persons in their community will continue their new interest in the safety and health of the retarded. If that occurs then, after the retarded go elsewhere, the resisters can judge their own motives to be in the best interests of the unwanted and dispossessed whose crime it is to have been born without the requisite intelligence quotient to care deeply about the I.Q.'s of those next to whom they are forced to live.

Group home public ed fosters hostility

Opposition to community-based residential facilities for the handicapped is often grounded in misconceptions and stereotypes. Available evidence lays several bugbears to rest: Such facilities do not appear to result in increases in crime rates, decreases in property values, or alterations of neighborhood lifestyles. Despite initial opposition, neighbors generally become more favorable toward facilities and their residents over time.

In a 1974 survey of residential facilities for the mentally retarded, it was determined that the more approaches used to prepare the community for a facility's establishment, the greater the number of sources of opposition to the facility. While this relationship is weak, it, along with the fact that neighbors apparently do come to accept residential facilities once they have been established, suggests that intensive community education campaigns before a facility opens are not necessarily the method of choice. In some cases they may actually mobilize community protest. Possibly one does better to let sleeping bugbears lie — to establish a facility with minimal fanfare and then devote one's efforts to building positive relationships among new neighbors, drawing on literature suggesting that it is the quality

rather than the quantity of contact between the handicapped and nonhandicapped that is most instrumental in changing negative attitudes. Further research is clearly warranted. On the other hand, empirical ammunition with which to slay bugbears is most helpful in court cases if the die of community opposition has already been cast.



David Lettman, President, Erie County Chapter, speaking to Lancaster Town Board meeting on March 5th, 1979 for proposed barrier-free group home. Also pictured, seated, front row — left to right, Georgeann Redman, Executive Director, Erie County Chapter, Joan Carrithers, Coordinator of Residential Services and Rebecca Mitchell, Consumer Advocate.

Educating the community

Recently, officials of the Erie County Chapter, NYS ARC, presented a plan for a barrier-free group home on Bowen Road to the Lancaster Town Board.

The Chapter proposed a barrier free four bedroom ranch home be built on the site for eight children ranging from 8 to 18 years of age. All of the children would be in wheelchairs or would need walkers. Included would be at least four from the West Seneca D.C.

In response, the Lancaster Town Board approved a recommendation that the Chapter consider four alternate sites.

Representing the Chapter at the meeting were David Lettman, President, Georgeann Redman, Executive Director, and Joan Carrithers, Coordinator of Residential Services.

Mrs. Carrithers said the cost of the home would be paid through the state and Erie County Dept. of Social Services. "The cost would be less than the institution and we would provide a full range of services," she said. "The children would attend

school through the Lancaster school system, probably in the BOCES program or in School 84 in Buffalo."

Dr. David Jerome, chairman of a committee considering alternative sites, said it was not opposed to retarded children, but questioned the Chapter's selection method. Several Bowen Rd. residents expressed concern over drainage problems in the area.

Lancaster Supervisor Stanley Keysa said he and the Town Board were interested in assisting the Chapter in securing the proper facilities for the youngsters. "I personally would have no objection to this group home next door to my house," he said. "But we think that these alternatives should be considered."

Site selection law constitutional

MONROE MAY PROCEED WITH PITTSFORD RESIDENCE (UNLESS APPEALED)

In March of this year, State Supreme Court Justice Robert E. White ruled against the village of Pittsford in Monroe County in its effort to block the establishment of a residential home for retarded adults proposed by the Monroe County Chapter.

Under the Site Selection Law, the Chapter gave notice to the village of Pittsford that they have selected the building at 19 Church Street. Although the village did not, according to the law, come up with alternate sites, it refused to give permission to the Chapter to continue with the project. An appeal was made to Commissioner Coughlin in accordance with the law and, in January of this year, he ruled that the village action violated the law. Thereupon, the village brought an Article 78 proceeding in the Supreme Court to block the implementation of the project.

Mr. Justice White upheld the constitutionality of the law which had been attacked by the village and ruled that there was no "concentration" of residential facilities for retarded people in the area.

The state expects to be back in Court when the Association for Retarded Children, Monroe County Chapter, applies for a certificate of occupancy which the village may refuse on the ground that the building is unsafe.



Joan Carrithers, Coordinator of Residential Services, Erie County Chapter, speaking to Lancaster Town Board meeting on March 5th, 1979.

Patten dies

William D. Patten, a member of the Saratoga County Association for Retarded Children, died early this year. Memorials were made in the form of contributions to the Saratoga County Retarded Children's Association.

Why Soap Operas Avoid Mental Retardation

Reprinted with the permission of Ideal Publishing Company Sherry Amatenstein, Editor TV Dawn to Dusk Magazine.

This article was written by Dorothy Vine. Dorothy Vine is currently a staff writer for CBS Television. She has done extensive free lance writing in the television field (particularly soap operas). She is President of Community League (Wassaic Chapter, New York State Association), writer and editor of the quarterly newsletter and is a former member of the state Board of Governors.

Mental retardation, one of life's cruelest tragedies, strikes all levels of our society — economic, social, ethnic and color. It is not inherited, it is not contagious, but no one is immune. Three percent of the total United States population is mentally retarded, which totals out to more than six million people!

Joseph T. Weingold, Executive Director of the New York State Association for Retarded Children, reports, "The condition affects more than double the number of children than all the other childhood disabilities combined. The figures break down as ten times more mentally retarded people than those afflicted with cerebral palsy; twenty times more than those with muscular dystrophy, twenty times more than those afflicted with blindness!

By 'ripple effect', the number extends to tens of millions in concerned caring family members and friends. Since 20-30 million people reportedly watch soap operas daily, it is safe to assume that many of those watching have a retarded person in their own family circle or among their friends' families.

We had a President of the the United States (John F. Kennedy) who had a retarded sister; a Vice President (Hubert H. Humphrey) who had a retarded granddaughter; a leading film star (Bette Davis) who has a retarded daughter. The list could go on and on of prominent, influential people with beloved retarded children in their families who have openly and sensitively discussed the problem from many angles.

And yet, the soaps continue to avoid the subject.

It seems particularly strange when you realize that in the past ten years soaps have pioneered in dramatizing many formerly 'taboo' subjects, opening the areas for primetime television. Yet primetime television has pioneered in the field of mental retardation by producing several highly praised shows on the subject, including *Teacher, Teacher* (starring David McCallum) and *My Sweet Charly* with Cliff Robertson (later made into a successful feature film). Even daytime (other than soaps) has tackled the subject, such as ABC's fine Afterschool Special *Hewitt's Just Different*.

The soaps have come to grips with every conceivable aspect of the human condition — spiritual, physical and emotional. Consider these subjects which have been graphically portrayed on them: rape (*Young and the Restless* and others); prison gang-rape (*Love of Life*); venereal disease (*One Life to Live*); the right to die (*Ryan's Hope*); abortion (*All My Children*); physical handicap (*Love of Life*, *Secret Storm*).

The list goes on: mastectomy (*Young and the Restless*); alcoholism (*As the World Turns*, *Search for Tomorrow* and others); amnesia (any and all of the soaps); hysterical blindness (*Search for Tomorrow*); hysterical deafness (*As the*

World Turns); emotional breakdown (*Young and the Restless*), blindness (*Guiding Light*, *Edge of Night*).

And still more: child abuse (*All My Children*, *Young and the Restless*); illegitimate children (any and all); political corruption (*Love of Life*); corruption in general (*Edge of Night*); leukemia (*Search for Tomorrow*, *All My Children*); heart attacks (any and all); teenage prostitution (*All My Children*); mistaken parentage (any and all).

This list could go on endlessly and any soap watcher could make his or her own list of even more topics, but it is certain that mental retardation will still be notable by its absence. It seems natural to ask, 'Why?' It also seems natural to ask the question of some of the people who influence the soaps.

Linda Grover, headwriter of *The Doctors*, once wrote a treatise on soap operas in which she stated, "We in daytime have the opportunity to present an undistorted and unhurried view of important social and medical issues which affect the lives of millions of our viewers. We should explore the issues of life in depth — honestly and fairly with sensitivity and insight into each participant's suffering. We can make a statement which deepens understanding of all views."

In a special interview on this subject, Linda further said, "There's still a stigma as well as a shame, attached to mental retardation in many peoples' minds. I think daytime serials would be a wonderful medium in which to explore the subject. It could be a very important, affecting story and we would have a chance to educate and enlighten our audiences."

Linda has not used the subject yet, but "if it was right for a story line for one of my characters, I wouldn't shy away from it. Daytime audiences are becoming more sophisticated, more widely traveled, more aware in all areas. The stories themselves have become more sophisticated and relevant and very real. Any life experience the characters are going through is something you or I might experience and there may be a million going through something very similar. It is important to show that there are other people who have experienced what you or I have and that they're not alone. Lots of people feel isolated with their problems and it's good for them to have the knowledge that there are other people who suffer and feel as they do and can overcome."

Statistics do prove that writer Linda Grover's comments were correct — there are still people who see mental retardation as a disgrace, or deny to themselves that their child is retarded — using euphemisms to becloud the issue. Instead of seeking professional help and giving the child a chance to reach his maximum potential development, they hide the child in their own homes. Broken-hearted, angry, resentful and guilty, they don't know where to turn for help and solace. This has led to broken marriages, alcoholism, abused children and psychological problems for other family members, including the 'normal' siblings.

That the soaps can provide a valuable, educational forum for many problems was illustrated when the venereal disease story line was used on *One Life to Live*. When an informational booklet was made available to the show's viewers, there were countless requests for it. When mastectomy was dramatized on *Young and the Restless*, many women wrote to the show and to the actress playing the role

(Dorothy Green), saying they had gone to have breast examinations, and in some cases early cancer was detected and lives saved because of the show!

It seems safe, therefore, to draw some conclusions here — if viewers were interested and/or helped by the depiction of these far-reaching problems, would it not follow that dramatizing mental retardation and the help available, as well as the seemingly miraculous training results achieved today could be a boon to millions of parents and families? To those without retarded children, it could certainly bring an awareness of the problem they never had before, as well as an understanding and compassion for those who must live with the tragedy.

Agnes Nixon, creator and headwriter of *All My Children*, did use mental retardation on that show, but not as a focus on the subject. It was used as a means to depict the conflict between two characters and was not the thrust of the story line. In early 1977, Ann Tyler (played by actress Judith Barcroft) experienced guilt, love and confusion, as all mothers actually do, when she discovered her child was retarded. It affected her marriage, her health and her life. But the child was never shown, the problems of the retarded were not considered and that catalyst in the story line ended when the baby died suddenly. Had the child lived and its problems, frustrations and maturation been shown authentically at varying stages in its life, it could have been a most dramatic story and of invaluable help and comfort to those watching mothers who feel they are alone with their heartache.

It is the consensus of many members of the Board of Governors of the **New York State Association for Retarded Children** (the largest single volunteer state association in the U.S., with 60 chapters and 32,000 members) that the soaps would be a good forum for the subject. The Public Information and Awareness Committee of the Assn., which functions to educate the public to the needs and the contributions of the retarded, is now directing a major thrust to foster acceptance of community houses and apartments for the retarded, and is particularly anxious to bring its story to as large an audience as possible.

"But," says the Chairman of the committee, "it might be too easy to get maudlin and sentimental and to exaggerate and caricature in order to capture audience interest in a soap. Not only would this be undesirable, it would be harmful to our cause and unfair to retarded people. Dramatizing the problem on a soap would be helpful only if the subject was treated honestly and authentically and done with an expert in the field as consultant. The subject is inherently dramatic and doesn't have to focus entirely on the heartbreak and tragedy; it could be upbeat in showing how research, scientific and technological advances, legislative action and the efforts of parent groups have changed the climate and how retarded people can be helped to reach their greatest potential and, in many cases, return to the community as contributing, tax-paying citizens."

Dr. Joyce Brothers, a psychologist and well-known television personality, identified with soaps because she once portrayed herself in several episodes of *One Life to Live*, also thinks mental retardation is a valid dramatic subject for the soaps. "The value of daytime drama is that it deals with all kinds of behavior and emotions," she said in a special interview for this article. "Although some people in

Almost every 'taboo' subject has been graphically portrayed on daytime TV — from alcoholism to mastectomy; disfigurement to rape; hysterical blindness to hysterical deafness; venereal disease to euthanasia and on and on. Such coverage has helped many viewers deal with these problems in their own lives. Since soaps can be a helpful tool, why then haven't we seen any story lines on the tragedy which has stricken millions of people? Is there a valid reason?

daytime might think the audience would shy away from it, I don't agree. Women have a 'soft spot' in their hearts for children and every woman worries about having a normal child and imagines and fears how it would feel to have a child who couldn't deal with the world as other children do. I think mental retardation is a very important, valuable, poignant topic and I think someone will write a good script, do it on the soaps and make a breakthrough."

It will be interesting, of course, to see if the soaps ever do pick up on mental retardation and turn it into a strong emotional, interest - holding dramatic story line, as Dr. Joyce Brothers predicts. She says, "For years and years, the men who run the networks said women wouldn't listen to, or watch, women on television. Then along came Barbara Walters and Mary Tyler Moore. Not only did women listen and watch, they enjoyed it and learned from it. Someone is going to come along and write about mental retardation and do it sensitively and successfully and everyone will then jump on the bandwagon."

And what about the fans — the important people who watch the soaps? Even network executives admit that the mail and phone reaction of fans to a character or an actor can change the course of a story line.

Questioning a group of fans at a recent soap opera gathering in New York City elicited varied opinions.

Mrs. P.M. of New Rochelle, New York, said, "I feel that if a story on mental retardation was done properly, it would be fine and should be shown because of what soaps are supposed to do; besides entertain, they should bring worthwhile subjects to the attention of people. If a Soap would show a mentally retarded child in a home with other children and show him receiving love and care and attention, I think it would be wonderful. I'd certainly watch it."

On the other hand, Mrs. D. H. of New Haven, Connecticut, said, "Those people who have it in their lives, and there are many, don't want to turn on a soap and see it. We watch soaps to get away from our problems. Most of us would rather watch something that seems a fantasy to us and we can enjoy vicariously — like watching a woman being unfaithful to her husband — anything that gets our minds off our own problems!"

Mrs. D. F. of Brooklyn, New York, said, "It's an unpleasant, frightening subject and one that people would rather forget. But it is so important they must not be allowed to forget it or ignore it. What appalls me is the lack of general information the public has about the subject and they should be educated to what the problem entails — especially in human suffering, but also in hope, determination and love."

It seems then that soaps have avoided mental retardation story lines simply because it's never been done before and they're afraid no one will watch. Public opinion can help swing this judgment, however.

What is your opinion? As a fan, and a reader of this magazine, your opinion could help give direction to networks, producers, writers and sponsors of the soaps. This is your chance to make your opinions known and make them count.

— Dorothy Vine

CHAPTER NEWS *What our chapters*

CLINTON COUNTY CHAPTERS' news seems to be on top of the pile this time, so we'll begin with them, congratulating them upon their handsome newsletter, and mentioning how well their community residence program is growing. At their last open house they had over 100 guests attending. Also, the **CLINTON COUNTY CHAPTER** opened its third community residence. . . At the other end of the State, **SUFFOLK COUNTY** tells us about their 18th Annual Candlelight Ball at which over 340 guests participated in honoring State Senator Bernard C. Smith, for his many years of service to the chapter. . . Right next door at **NASSAU COUNTY**, the chapter is looking forward to its 30th Anniversary and will celebrate with a 26th Annual Rose Ball on Saturday, June 16th. While it has been a time since it took place, we did not have an opportunity to mention the opening of the chapter's Gertrude and Charles Merinoff Vocational Center in Plainview. About 600 guests attended that dedication. Many thanks to the Merinoffs for their years of outstanding support to Nassau County Chapter. . . **WAYNE COUNTY CHAPTER** sent an interesting story called Santa Claus wears swim shorts. An interesting write-up on Lee Thurston of Newark, N.Y. who, together with volunteers in the Wayne - Ontario County area, provide an aquatic program one night every week for 21 handicapped teenagers. Rather surprised to read a story which begins, "Santa Claus wears light blue swim shorts when he arrives at a certain place in Wayne County, N.Y., but the kids are not appalled one bit. He may not have on a traditional red suit and boots but he wears a dark beard and has a big heart!" We agree. . . Speaking of anniversaries, **ORANGE COUNTY CHAPTER** welcomes back its newsletter, "The Torch" after an absence of almost two years. With the agency becoming larger, volunteers just could not keep up with the publication of this sort, so it is now a much more professional job. . . We recently had the opportunity to stop in Ballston Spa, N.Y. and visit the new Helen Hogan Center being operated by **SARATOGA COUNTY ARC**. Over 400 persons attended the dedication ceremonies and open house in November. A portrait of Helen, the long-time leader of the **SARATOGA COUNTY CHAPTER** hangs in the Center, and it was well stated by Chapter, Executive Director, Karl Klein, when he said, "This is an acknowledgement of the life you breathe into this organization." Thanks Helen and congratulations **SARATOGA**. . . Delighted to get the newsletter of **OTSEGO COUNTY CHAPTER** indicating to us that 65 persons are involved in their programs on a daily basis and that by the end of 1979 they anticipate 120-130 persons. 24 children are in their summer school program and their new satellite at Hartwick is humming. . . **ST. LAWRENCE COUNTY ARC** doing a big business in their greeting capsule — this is a process whereby a small wood shaving is provided, on which a person can write a brief message. This is placed in a small wooden capsule, top is fastened together with a mailing tag, and off it goes. The capsules are prepared and packaged at the Chapter's Ogdensburg Center. . . The **JEFFERSON COUNTY CHAPTER** sends the following story about their new community residence for children. The **JEFFERSON COUNTY ARC** opened its original group home for children in October of 1976 on State Street in Watertown, N.Y. The reason for this action was the great need in the community for residential placement for multiply handicapped children, who because of their handicapping conditions, were no longer able to be cared for in their

own homes. All of the children originally placed in the group home were attending and benefitting from programs, either here at the ARC, or through the public school system. In July of 1977, due to the need for more room, these children were moved to 211 Keyes Avenue (a two story dwelling) and a temporary operating certificate was issued for this new site. Within a short time it was evident that the use of a two-story dwelling for a group



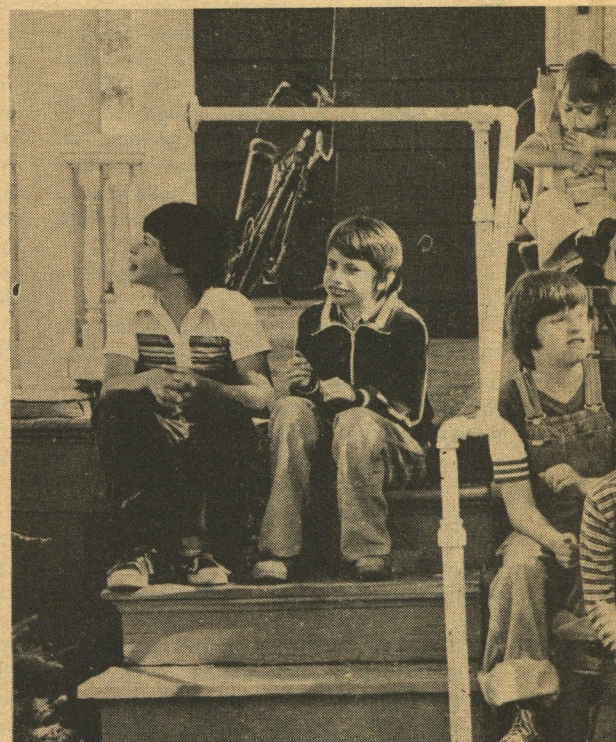
Clinton County Chapter's third community residence.

home was extremely inefficient, as four of the children were non-ambulatory and the other six were ambulatory with help. Therefore, the search for a more appropriate dwelling began. On November 15, 1978, these children were moved to a new one story, barrier-free home at 803 Holcomb Street and a permanent operating certificate was issued for this home. . . **ULSTER COUNTY CHAPTER** very grateful to Harry and Marie Siemsen and their relatives who left a gift of 94 acres of land and buildings to **ULSTER COUNTY CHAPTER**. . . **ESSEX COUNTY CHAPTER**, busy as always, mentioned in their most recent newsletter that their Lake Placid Training Center was turned over to another agency to operate, due to the fact that with the Olympics coming in, they were not able to acquire a permanent community residence for potential clients. They are glad programs will continued to be provided to these clients. There must be a pound of paper in the articles on **YATES COUNTY CHAPTER** and the struggle to acquire a contract with the State through the Yates County Community Services Board, with OMR-DD. However, it all finally gave, when, on February 13th, the County Legislature agreed to let the chapter approach the State directly for funds. Some progress at least. . . **ERIE COUNTY'S** newsletter looking different. Perhaps most interesting, a story about the chapter's demonstration of services. Allentown Industries, the Adult Services arm of the **ERIE COUNTY CHAPTER**, recently rented space for the Renaissance Exposition at the new Buffalo Convention Center and showed some of the services it can provide to Buffalo area businesses. A sizable number of prospective customers signed up for further information on the services Allentown Industries can provide to businesses. . . Who can keep up with **SULLIVAN COUNTY CHAPTER**,

recently opening their second community residence, following that up with organizing a **YOUTH** group, obtaining a second CETA grant, and having themselves a 30th anniversary Champagne Buffet. That's the way to go. . . while our Board is meeting in Albany on April 27th, **ONONDAGA COUNTY CHAPTER** will have had their annual Tennis Tournament, sponsored by Unity Mutual Life Insurance Company, one of the outstanding un-

completed, one member of the group said to them, "Welcome neighbor." Those words really do sound nice, don't they? . . . Delighted to see **TOMPKINS COUNTY**, largely through the work of President Walter Herr, cranking out a newsletter to keep their membership informed. Still looking forward to community residences through the HUD grant. . . **CHENANGO COUNTY**, with their tremendous workshop, writes to say they are in the process of completing a 8500 square foot building addition to provide storage space as well as a modern loading dock to their present community workshop. The addition will bring the total amount of manufacturing program space to slightly under 40,000 square feet. The workshop's satellite operation currently employs 40 individuals in production work tasks. . . President Bernice Volaski, of **WELFARE LEAGUE**, bubbling in the most recent League Letter to indicate that **WELFARE LEAGUE** has been awarded a grant from the New York State Council on Developmental Disabilities for an advocacy program. Very nice. . . Our newest chapter, **SCHUYLER**, working hard to ready their first direct service program, a workshop at the former Padua School in Watkins Glen. Good luck. . . **NIAGARA COUNTY CHAPTER** delighted that Joseph Pillittere was elected to the New York State Assembly. Mr. Pillittere is a board member of **NIAGARA COUNTY CHAPTER**. . . Delighted to see the **SCHENECTADY COUNTY CHAPTER** newsletter indicating that it might be necessary for the chapter to consider alternate methods of funding because their United Way contribution is scarcely reaching one-half of what they request. Never a popular decision, but sometimes the only way to stay alive. . . **CHAUTAUQUA COUNTY CHAPTER** was kind enough to send us their newsletter

dertakings of the year. . . April 22nd was one of the biggest of days in **CORTLAND COUNTY CHAPTER** with the long-awaited open house of their first community residence, the Laura M. Burch House. The residence was brought about through the generous gift of the Laura M. Burch Foundation and the Attorney and Executor of the estate of Mrs. Burch, Mr. Theodore Fenstermacher. The newsletter of the chapter, I must say, is really getting to be a very handsome sheaf. President Bill Ingraham must be printing it at his print shop. . . **CHEMUNG COUNTY CHAPTER** has begun sponsoring a number of programs and projects most recently, a day long conference on Human Rights. . . **PUTNAM COUNTY** raising funds everywhere had a Bike n' Hike, planning a golf tournament, had a '50's dance and is into bingo. Must also mention that they now too have a new newsletter and volume one, number one was very nice. . . **RENSSELAER** out with a clever brochure for their 1979 Capital Fund Drive. A picture of Edison's invention on the front with the statement, Help Us Light Up Their Lives — another of those chapters with a new newsletter format, they have started a new sheet called, "The First Steps". . . Over 300 persons attended a recent open house at the facilities of **ONTARIO COUNTY CHAPTER**. Glad to see us getting so well known in the community. . . **MADISON COUNTY CHAPTER** had their 3rd Annual Dinner - Dance, April 21st. Interesting to note their discussion about their 11 years of existence, compared to some of our old-timers throwing around their 30 years. It was heartening to read their most recent article on community residences which opened up a whole new idea to us. They were talking about a Board of Appeals hearing for one of their community



Children in the first group home at 211 Keyes

Saratoga wins tran

The New York State Council on Developmental Disabilities granted the Saratoga County Chapter New York State Association for Retarded Children \$47,000 for two years to be used for transportation.

In reaching this decision, the Council made their approval contingent upon the Chapters agreement to the following condition: that the service plan be limited

What we are doing and saying for our children and adults

with a notation that we should feel free to use any or all of it in the next issue of OCV. There's too much to use it all, and it's too good to skip any, so we'll just say that **CHAUTAUQUA COUNTY** is really busy and we're delighted to see the numbers of clients receiving services. . . The biggest news in our **MONROE COUNTY CHAPTER** these days, of course, is the change in Executive Directors. After serving since 1963, John Regan will be moving on to play golf in the South. We really cannot express here our deep gratitude for the outstanding work which John has done with **MONROE COUNTY CHAPTER** through the years, we simply will mention that we know he will be very much missed by one and all. . . **FULTON COUNTY CHAPTER** hosted the Northeast Regional Meeting, and we thank them. . . Most interesting conference on legislation was held by **WESTCHESTER COUNTY CHAPTER**. Many dignitaries present with over 100 turning out to support the process of equal 100 per cent funding for all, proposed by the chapter. Excellent legislative form. . . **FRANKLIN COUNTY CHAPTER** writes to say that they are not only very pleased that Ellen Maroun, the chapter founder was elected Northeast Regional Vice President last Fall, but that Mrs. Margaret Nagle, Secretary of the chapter Board will be appointed to the Community Services Board. Closing out this time, with a story on our **COLUMBIA COUNTY CHAPTER** who recently invited members of the business community to come in and familiarize themselves with the chapter's seeking business, which they hope will be useful in their local garment industry. The chapter is planning to triple its power sewing unit and are hoping to enter such areas as institutional upholstery, etc. A good idea by **COLUMBIA COUNTY** and a great way to close this issue of Chapter News.



Assistant Executive Director of the Ogdensburg workshop, Phil Campeau (standing left), looks on as clients and staff work on St. Lawrence County's Greeting Capsules. (advance News Photo)

Rockland protests delay

In this letter to the Director of the Facilities Development Corporation in Albany, M. Carl DeBell, Executive Director of the Rockland County Chapter, protests the kind of state delay which makes the establishment of community residences such a difficult and frustrating undertaking.

The Rockland County Chapter of the Association for Retarded Children has a long history of concern for the retarded citizens of this community. We are now being faced with a situation wherein the rights of these same citizens are being denied by the very governmental system which was established to serve them.

The State of New York has a firmly established deinstitutionalization policy and we all are committed to providing community living experiences in a "least restrictive setting" for our retarded citizens. However, we have been thwarted in that goal time and again due to the necessity of working with Facilities Development Corporation in acquisition of property.

Rockland County has limited property available for lease. After great effort, we have located a few sites which might be considered for community residence development. However, in each case there has been so much delay in obtaining the necessary FDC evaluations, that we are left to consider only those properties which can not for some reason be disposed of elsewhere by the owner.

Chemung declares membership month

The Chemung County Chapter issued a proclamation declaring the month of April as Membership Enrollment Month. The proclamation was signed by Stanley Benjamin, Sr. Chemung County Executive and other chapters are following Chemung County's lead. The text of the proclamation is, WHEREAS, the Chemung County Association for Retarded Children was founded to meet the challenge of a better world for the retarded, and

WHEREAS, The Chemung County Association for Retarded Children has always utilized the resources of energy, courage and confidence borne of achievement, and

WHEREAS, All people who are concerned about promoting a life of usefulness

This month, we lost a house which would have been well suited to our needs when the owner was successful in selling it privately. This house was seen by us on August 23, 1978 and the SLA-1 was submitted by Letchworth Village Developmental Center on August 28, 1978. As of this date, no one from Facilities Development Corporation has seen the house. Unfortunately, this is not a typical situation. Even when a potential community residence is finally seen by the real property specialist, it is weeks before an architect makes an appointment for his review and weeks again before his report arrives.

We cannot establish a community residence program when it takes months for a determination to be made as to whether or not a specific piece of property can even be considered for lease by the State.

It is a sad state of affairs that forces us to petition our own governmental offices that they provide basic services. As a private agency, we have taken on the time and expense of completing necessary preparatory work for the state to assist in the deinstitutionalization process. It is unconscionable that Rockland Association for Retarded Children cannot readily expect the same attention to the development of residences by the appropriate state agencies. We must insist that your good offices see to it that this situation is remedied immediately.

and dignity for citizens who are retarded will find by enrolling as a member in the Chemung County Association for Retarded Children, an opportunity to demonstrate that concern,

NOW, THEREFORE, I, Stanley Benjamin, Sr., Chemung County Executive, do hereby proclaim the month of April, 1979 as

"CHEMUNG COUNTY ASSOCIATION FOR RETARDED CHILDREN MEMBERSHIP ENROLLMENT MONTH" and do hereby call upon persons concerned with the welfare of the retarded to give unto this 1979 membership campaign their full support.

We will have the results of the efforts in the next issue of "Our Children's Voice."

John Regan

To father from son

Dear Readers:

I would like to take a few moments of your time to express a few thoughts concerning your executive director. John Regan is a very good friend of mine and I have known him for over 20 years. Throughout this time, I have grown to respect and honor Mr. Regan in his style of coping with conflicts and the way he enjoys life. Most of you have drawn opinions of this man through your experiences with him while in a professional setting, but I have developed a more diversified viewpoint of Mr. Regan by sitting down and talking with him in many informal and sometimes personal conversations.

No one can truly understand how much devotion John has exemplified unless you are as close to him as myself. He has always taken a "back seat" to others when congratulations were in line. Labeling him as an unsung hero would be an understatement. This letter is to make up for those other times when glory went to "the other guys."

Mr. Regan has always expressed a sincere desire to achieve the finest organization in the mental hygiene field. He has sacrificed family time, recreational activities and many other personal priorities to overcome infinite obstacles that have confronted A.R.C. over his fifteen years. I was around to see the mental anguish eat away at him in times of expansion, reorganization and budget cuts. Yet time after time he answered to any demands, drew all of his powers together and conquered any problems that appeared to threaten the Agency and its staff. Overcoming adversity seemed to be a favorite pastime. Even though he was burdened by problems, he maintained a pleasant, positive and confident attitude. Listening to the problems of others was a keen attribute, though he rarely had enough time for his own. To those of you who haven't had a chance to meet this remarkable gentleman, I can only say it is your loss. To those who do, I hope you appreciate him for his undying desire for perfection to make A.R.C. what it is today.

Bias has played a part in this. A powerful and healthy emotion called love has chosen the words for this letter. My affection and respect for John Regan go beyond any board meeting or budget hearing. He is unparalleled as a professional; peerless as a father. His sincerity, sensitivity and understanding have helped me become that much better an individual. I hope you will take time to thank John Regan for being himself. For me, there is no more perfect dad.

Thanks for listening.

Mark Regan



Keyes Avenue — Jefferson County Chapter.

transportation grant

to one van a year while demonstrating attempts to secure other resources for that purpose. The Director of Community Residences is specifically excluded. The agency must serve the most substantially handicapped than can benefit from this program.

We congratulate Karl Klein, Executive Director, on the approval of this request.



Conflict of interest

State as regulator and servicer

Having terminated a Purchase of Service contract with our Essex County Chapter on February 1, 1979, due to the lack of residences for the Sunmount clients, the state, through the DDSO (Development Disability Services Organization), which is supposed to regulate services in its area out of Sunmount, proceeded to purchase or lease a property for transitional living facility in Franklin County.

Unfortunately, however, the state did not follow its own guideline, but moved 10 of the Essex County Purchase of Service clients into the state operated community residence prior to the building being made ready. There were no eating facilities available, and the clients were expected to be bussed to the Developmental Center (Sunmount) for at least a month in order to be fed. As if this was not bad enough, the fire safety code had not been met. The building is a 100 year old wood frame, oil heated building without the complete fire protection, smoke detection, heat detection system, without central fire alarm bells and stations at all exits and doors as required by the building code.

They installed portable battery operated smoke detectors which cannot be heard throughout the house. Also in violation of the fire safety code construction plans, which called for a closing or sealing off of the second floors by means of fire heated doors on the stairwells, as of February 1, 1979, they were open-banistered with no doors to contain any kind of fire.

At a meeting of the Mental Health

Board, Dr. Francis, the Director of the Sunmount Developmental Center, and also the DDSO Director, stated he had received an operating certificate with waivers, and also stated the fire detection system, although temporary, was adequate. This certificate was not granted by the proper office, but inspection was done by local DDSO personnel and northern county group service personnel, and issued by the Associate Commissioner of the service group.

This is an obvious conflict of interest when the service group has a financial commitment to an agency, as well as a numbers commitment for deinstitutionalization, and at the same time has the authority to waive life safety codes in community residences. According to the opinion of Mr. Paul Kendall, Executive Director of the Franklin County Chapter, who was on the spot, "This is a conflict of interest as well as outright dumping!"

We do not know whether this is also happening elsewhere around the state. Obviously, the inspection agency should not have the right or power to issue certificates to itself in violation of regulations and the law.

Certainly an ARC Chapter, or anybody else, would never, never be able to place clients in a building of that type.

This association has called the attention of the Commissioner over and over again to the fact that the regulatory agencies, as well as the DDSO's, should not have the power to operate.

There is no response.

\$500,000 award for education malpractice

A Queens, N.Y., man, wrongly branded retarded for 12 years by the New York City Board of Education, is entitled to \$500,000 in damages, according to the Appellate Div. of the state court system.

The court ruled 3-2 that Daniel Hoffman, 27, was entitled to the state's first "educational malpractice" award because of the "awesome and devastating effect" the board's actions had on his life.

The judges reduced the original jury award from \$750,000. The case will ultimately be decided by the Court of Appeals, the state's highest court.

Comparing the case to a patient who "had been improperly diagnosed by medical or psychological personnel in a municipal hospital," Judge J. Irwin Shapiro declared that "negligence is negligence."

The case had its origins three months before Hoffman's sixth birthday, when he was in kindergarten in 1957. He was placed in a school for retarded children after he scored 74, one point below the cutoff, on an IQ test administered by a board psychologist.

The negligence, according to Shapiro and a jury two years ago, occurred when the board did not reevaluate Hoffman's intelligence "within a two-year period so that a more accurate estimation of his abilities could be made," as the psychologist had recommended.

Instead, Hoffman was "closeted with mentally retarded children" until 1969 when a second IQ test found Hoffman had

"good intelligence" with "above average intellectual intelligence."

The tragic result, according to psychiatric testimony, which Shapiro incorporated into his opinion, was that Hoffman's family and school personnel "did not provide the stimulation that would otherwise have been given the child" because of "the assumption of the correctness of the school's diagnosis."

This caused Hoffman to accept "his role as retarded," Shapiro said, "on the basis of his serious speech defect. Knowing that he could not speak as well as other children, his self-image was already deflated, making it more likely that he would accept the conclusion that he was retarded."

Sheridan named to Community Board

The Albany County Legislature appointed four new members to the Community Services Board early this year.

Francis Sheridan of Delmar, President of the Albany County Chapter was among those named.

The legislature also plans to appoint three advisory groups of five members each to screen applicants for mental retardation, mental health and drug and alcohol abuse services.

Too soon, too small

Mental retardation and learning disabilities are most common in children and adults who were born too soon or too small, reports The National Foundation March of Dimes.



Dalwin J. Niles

Dalwin J. Niles dies at 62

Former state Senator Dalwin J. Niles, 64, died recently at Wells House after a long illness.

Born in Schenectady, he was a graduate of Scotia High School and Union College. He was a 1937 graduate of Albany Law School and moved to Johnstown that same year.

In 1964, Mr. Niles was elected to the state Senate and, while there, served as Chairman in the Mental Health Committee and Chairman of the Joint Legislative Committee on Mental and Physical Handicapped. He retired from the Senate in 1972.

Mr. Niles is survived by his wife, Mary H. Heagle Niles; two sons, David Niles of Latham and Jeffrey Niles of Caroga Lake; two sisters, Mrs. Robert Hamilton of Fort Lauderdale, Florida, and Mrs. Allan Moseley, Clinton; nieces, nephews, and cousins.

We remember Senator Niles as a gentle man, dedicated to the mentally retarded and other handicapped. He devoted several years of his service in the legislature to a recodification of the Mental Hygiene Law at a time when our Executive Director, Jerry Weingold, served as Director of the Joint Legislative Committee.

The association lost a good friend in the legislature when he retired and all of us grieve his death.

P & A grant for Willowbrook

The Protection and Advocacy System for Developmental Disabilities, Inc. has received a grant from the Department of Mental Hygiene, contracted through the Office of Mental Retardation and Developmental Disabilities, to assess the advocacy needs of Willowbrook class members in the community.

This project will provide advocacy services to ensure that the needs of the community class members are met. A community advocate will be contacting the class members to explain and discuss the project and overall PASDD services. The advocate will identify specific advocacy needs and work closely with the class member to alleviate any problems or deficiencies.

PASDD will be contacting Willowbrook class members living in the community, with whom the New York State Association for Retarded Children may be involved, to inform them of the project and PASDD services. This is in accordance with PASDD's contract with the Office of Mental Retardation and Developmental Disabilities.

O.D. Heck Resettlement protest

Late last year, word was received that 100 additional children and adults were to be resettled into the O.D. Heck Developmental Center by January, 1979. Directives to complete such a resettlement were apparently received by the O. D. Heck administration from the Southeast County Service Group of the Office of Mental Retardation and Developmental Disabilities (OMRDD). The normal staffing ratios in place at state developmental centers would have indicated that over 150 staff would be needed to provide adequate services to the people being resettled, yet only 15 new staff were to be given to O.D. Heck and most of these people were to join the staff after the residents were returned.

Announcement of the plans for the resettlement was met with widespread protest. However, January found the administration of O.D. Heck still trying to develop plans for this massive relocation of people. The O.D. Heck administration was pushed on by comments from top level OMRDD administrators claiming that "O.D. Heck had not done its part of the resettlement job." It is interesting to note that O. D. Heck-Eleanor Roosevelt Developmental Services has established the finest record of resettlement over the past 10 years of any state developmental center. There are more community residences, serving more people, in the O.D. Heck catchment area than in the catchment area of any other developmental center, including the ones in New York City and Long Island serving much larger populations.

It appears that much of the pressure for resettlement comes from efforts of OMRDD to comply with Federal Medicaid mandates. Several years ago officials of the Federal Medicaid program informed New York State that the state would have to spend many millions of dollars to bring the physical plants of state developmental centers up to standards for intermediate care facilities for the mentally retarded (ICF-MR). The state argued that it did not want to spend a lot of money on renovations to institutions that would soon be abandoned as a result of deinstitutionalization efforts. An agreement was worked out between the state and Federal Medicaid officials by which the Federal government would hold off on forcing New York to meet ICF-MR standards if the state would substantially decrease its population in developmental centers. We are now several years into that agreement and the state has not met its resettlement quotas in any year.

O.D. Heck enters the picture when one realizes that it is a newer facility that is certified to serve 320 residents and still meet ICF-MR requirements. As of December, 1978 there were about 180 residents at O.D. Heck.

The Rensselaer ARC joined with a number of other individuals and groups in protesting the manner in which the resettlement was to be conducted. While the ARC did not object to bringing the people back; it was felt that moving such large numbers of clients in such a short period of time, with no thought given to day programming and supportive services and no provision for adequate staffing or staff training, was totally inhumane. In a strongly worded letter to the Board of Visitors of O.D. Heck, the Rensselaer ARC Board of Directors suggested that a long-term injunction and short-term restraining order be sought against the resettlement. The ARC Board also urged that action be taken against O.D. Heck administrators resisting the directives of the Board of Visitors.

From: The First Step Winter 1979 Issue Rensselaer ARC.

Don't Forget: State Convention in Binghamton, Oct. 18-21.

M.D.s protest vaccine test plan

Reject use of retarded subjects.

One of the government's chief health advisors has touched off an angry debate within the medical community by suggesting that retarded children be used as subjects for testing an experimental vaccine made from the diseased blood of Hepatitis victims.

The Hepatitis vaccine has not been licensed by the Food and Drug Administration. A spokesman for its manufacturer, Merck Sharp & Dohme, said testing is in the early stages, and the vaccine has not been proven safe or effective.

Although no researcher has accepted the proposal to test the vaccine on retarded children, there is no SDA ruling against such experiments according to agency spokeswoman Fay Peterson.

The proposal was made by a New York Pediatrician, Saul Krugman, during a workshop on the experimental vaccine two months ago at The National Institute of Mental Health. A distinguished Hepatitis researcher, Krugman is also Chairman of the Vaccine Board from the FDA's Bureau of Biologics, the Chief Federal Advisory Board for reviewing safety and effectiveness of new vaccines to determine whether they should be licensed.

SUGGESTS RETARDED CHILDREN AT HOME FOR TESTS

When questioned in January at a workshop to summarize the material presented he said, "I would like to suggest that there are children throughout the United States who are on a waiting list to be admitted to various institutions for the retarded. . . It would seem to me that this particular group at home, not in the institution, would be the logical group in whom to consider trials with Hepatitis B vaccine."

Medical authorities and government officials vehemently disagree.

Carleen Brigeman, executive director of the Institute for the Study of Medical Ethics in California, called Krugman's proposal "scary" and said, "It's using a captive subject. . . a child. . . unable to give informed consent."

Dr. John Coledge, director of health services at the Georgis Retardation Center, said that "Dr. Krugman's idea is unconscionable. . ." Part of the reason for the angry reaction was Krugman's controversial role in operating a research program at Willowbrook throughout the 1960's that involved infecting healthy retarded children between the ages of 3 and 10 with live Hepatitis.

EXPERIMENTS AT WILLOWBROOK

At that time over the objections of the Association for Retarded Children, parents were permitted to admit their children to Willowbrook Developmental Center (then called "State School") only if they agreed in advance that their children could be subjected to this experiment.

Dr. J. A. Morris, a virus expert who was the only federal official to raise his voice against President Ford's emergency measures in 1976 to inoculate Americans against the Swine-Flu epidemic that never materialized, said "I think that it is absolutely outrageous. I know Saul Krugman, and I know his power. He is the Chief Advisor to the Governor on vaccines. I say that if it is worthy of experimenting on kids, then why not do it with healthy kids. And I would suggest that we start with the children of the Executives of Merck Sharp & Dohme."

LETTER TO CARTER

In a letter to President Carter, our Executive Director, Joseph T. Weingold, protested this gambit by Dr. Krugman as follows:

"Dear President Carter:

Until reading the enclosed *Newsday* article, we had somehow, perhaps naively, begun to believe that though our long history of advocacy and the combined efforts of this agency with our many colleagues, we were at last embarking on a period of what we had hoped was one of "enlightened beginnings" in which the rights of mentally retarded individuals as full citizens, and as human beings worthy of humane treatment, would no longer be questioned.

How distressed we are to read that Dr. Saul Krugman, in alluding to a number of children in the U.S. who are on waiting lists to be admitted to various institutions for the mentally retarded, has indicated that "this particular group at home, not in the institution, would be a logical group on whom we consider trials with hepatitis B. vaccine."

This reprehensible suggestion of Dr. Krugman is unconscionable, at the very least, and gives us occasion to reflect on and to question the ethical intent and practices surrounding research and experimentation in the field of medicine. While it is heartening to note the protest of doctors Morris, Bridgeman, and Coledge toward this heinous recommendation, even the slightest possibility of experimentation on children, especially those who happen to be mentally retarded, strike at the very heart of decent human beings.

With good reason, we are concerned that Dr. Saul Krugman, who occupies a position of immense authority and power within your administration, should even for a moment entertain such an eventuality, let alone advocate its implementation. We, therefore, add our voice of protest to those of the medical profession who have had the decency and courage to respond to this incident which is in effect the beginning of licensing to commit atrocities against a voiceless, innocent group of children to whom fate had already dealt a cruel blow. In conscience, we cannot stand by and permit them to be sacrificed on the altar of Dr. Krugman's ego.

I hope we will receive a response from you in this very grave matter."

Secretary Joseph Califano, the President's Committee on Mental Retardation, Governor Carey, Tom Coughlin, the Commissioner of OMR-DD and Dr. Kevin Cahill were all copied in on this letter dated March 28, 1979, but no one has responded.

Bureaucracy

Since the reorganization there has been a 57 per cent increase, from 154 to 242, in executive management jobs in the new Office of Mental Retardation and Developmental Disability. These assignments pay from \$35,000 to \$45,700 a year.

How about those who serve patients directly? Those jobs have declined by 8 per cent, from 27,160 to 26,931.

Holiday Inn in Binghamton Convention Action — Oct. 18-21.

"PKU" dilemma

For two decades, physicians puzzled over what to do about phenylketonuria. In the middle 1950s scientists came up with the notion of putting PKU children on a synthetic diet that contained essential nutrients but excluded or minimized the dangerous phenylalanine.

So the ailment had been identified, and a presumed treatment was available. The pressure on physicians to give the formula to all PKU children grew sharply with the advent of mass-screening programs for PKU in the 1960s, when Dr. Robert Guthrie of Buffalo developed a reliable and quick blood test for PKU that allowed a single laboratory to test hundreds of samples at one time.

Between 1964 and 1967, more than 40 states passed laws requiring that all newborn infants be tested for PKU with the new Guthrie test. And hundreds of children were placed on the special diet.

There is little question but that a large number of children were saved from early brain damage because of the mass screening and therapy. But such benefits came at a price; later it was discovered that only about half the infants detected in a mass screening program have the "classical" form of PKU that responds to the special diet.

The other half, explains Dr. Leon E. Rosenberg of Yale University, also have excessive phenylalanine in their blood — but with a different genetic defect. Many of these "variant" forms of PKU don't need a restricted diet, he says, and for a few the diet might even be harmful. "In the early days there were surely children who were damaged because we didn't know (how to identify the variant PKU children)," Dr. Rosenberg says.

An increasing number of families, grappling with the emotional problems of the diet and convinced that their children must have outgrown the ailment, simply took their children off the diet.

"Lo and behold, the kids seemed fine," recalls Yale's Dr. Rosenberg. Doctors began to acquiesce in more and more terminations of the special diet. "Most of us in the U.S. have felt comfortable with discontinuing the diet (at school age)," says Dr. Richard Koch of the PKU clinic at Children's Hospital in Los Angeles. "The

feeling has been that the psychosocial benefits were sufficient to justify the risks."

But there has lingered a deep uncertainty about the long-term effects of terminating the diet for PKU children. That concern has been fueled by a medical report from Poland describing IQ drops of up to 20 points in a group of PKU children who had been off the special diet for an average of five years. The children also were said to have developed brain-wave abnormalities and school problems.

"There hasn't been any great hue and cry," says one physician. The Warsaw study wasn't considered conclusive. But many pediatricians began calling in PKU families to tell them about it, and about a similar report from Germany soon to be published. "It's causing some worry and concern among the parents, but we feel we must be honest with them," says Dr. Koch.

Continuing study of 216 children is showing that the diet effectively prevents any severe brain damage, but some slight impairment does occur in many — but not all — PKU children. (Some PKU children have shown an increase in IQ to above normal). But researchers say they will have to follow the children through their teen-age years to determine the full effects of the diet treatment.

Some of the children in the study began reaching school age in the early and mid-1970s, when the question of ending the diet began to surface. As a result, researchers, with the cooperation of the parents, began to randomly remove some children from the diet. Others stayed on it, to form a controlled study of diet termination.

The controlled diet-termination trial is slated to last until the children are well into their teens. But the report from Poland has spurred the collaborative study officials to crank what data is available through the computers to see if there is any difference, so far, between the dieting and non-dieting children. "When we've had a chance to evaluate the data, we'll be able to provide some firm guidance to the parents (on whether to reinstitute the diet)," says Dr. Malcolm L. Williamson who, with Dr. Koch, is a co-director of the study.

Westchester presses for Developmental Center

More than fifteen years ago, as the problem of mental retardation was gaining greater recognition, Westchester chapter realized their ability as a voluntary agency, designed to aid the retarded of Westchester, could not nearly begin to provide all the vitally needed services on their own. A prompt and substantial state effort was the only conceivable answer to the growing County dilemma.

By 1966, the Department of Mental Hygiene and the late Governor Rockefeller agreed completely with the deep concern over the inadequacy of the services then available for the retarded population and a commitment was given to the association by the State to construct a 700-bed state school in the County. This commitment was reiterated over and over again, and is verified by letters repeating these state promises.

NO SITE UNTIL 1970

Despite the commitment, the state did not obtain a site until late in 1970. This site, located on the corner of Bryant Avenue and North Street in the City of White Plains, consists of some 27 acres of lovely land centrally located in the County in a quasi-public area. Bordering or near the

property, are two hospitals renowned for psychiatric care and treatment of the disabled, four churches, the new YWCA, the White Plains High School and some vacant land. The Bryant Avenue - North Street site is in every way ideally suited to the construction of the type of facility that is needed. No finer site is available in southeastern New York State!

In the early '70's, preliminary studies were made by the state for facilities for the care of the retarded and a director was appointed to develop the specific functional needs and to work with the community and local governmental bodies. The plans were abandoned, the director resigned and has only now been replaced and the only activity has been the 1978 authorization of the construction of two hostels for the retarded on a small portion of the site.

Today, at least 675 Westchester residents are scattered in the institutions throughout the State from as far as Rome, New York to the end of Long Island. More than half are considered profoundly retarded and two-thirds of the remainder, severely retarded; and, most of the institutionalized retarded persons also have serious medical and behavioral problems.

Continued on Page 12

Court dismisses parent fee claim

Willowbrook care grossly deficient

The Appellate term of the Supreme Court State of New York has dismissed the state's claim for fees from Murray B. Schneps for services rendered to his daughter at Willowbrook Development Center (now Staten Island Developmental Center).

In granting the Schneps motion for summary judgment to dismiss the complaint, the Court stated, "although the rights and obligations of the parties are governed by the Mental Hygiene Law prior to the amendment relieving the parents of liability, the question remains whether the defendant (Schneps) is obligated to pay the fee claimed by the plaintiff, irrespective of any deficiency in the character of the care and maintenance provided to his daughter."

"In the instant case, the defendant narrates at length the gross deficiency in the care and maintenance provided his child at the Willowbrook School. The Plaintiff's (the State) submission in the court... is totally devoid of proof con-

tracting... the detailed narrative of the inadequacy of the care provided his daughter at the plaintiff's institution."

Finally, the Court said "We must conclude that Lara Schneps received little or no care and grossly inadequate maintenance, and defendant should be absolved of his obligation under the then applicable statute to pay fees to services rendered to his daughter..."

"Even though... defendant's obligation is statutory, rather than contractual, that statutory obligation logically necessarily subsumes, that, at the very least, minimally adequate services were rendered in the first instance."

Legislation, as we all know, is now before the legislature relieving the parents of fees incurred for their children at state institutions before August 5, 1977. Senate bill 910 (Padavan) has passed and is before the Assembly Committee under the Chairmanship of Assemblywoman Elizabeth Connelly.

Welfare League DD grant

Bernice Volaski, President of the Welfare League has just announced that the Welfare League has been awarded a grant by the Developmental Disabilities Council of New York State. This is the first such grant ever awarded an institutional chapter and is based in large measure on the work the Welfare League has been doing in its Unit Rep Program with the aid of the graduate students of social work under the supervision of Carol Sussman, Project Director. The Unit Rep. Program was developed by the Welfare League at the invitation of Dr. Oleh Wolansky seven years ago. The unique advocacy project, now to be funded by the grant, is designed to help strengthen the Unit Rep Program and is an outgrowth of an idea developed by Dorothy Gasman during her presidency.

The money awarded the League will enable us to broaden the scope of our advocacy functions by increasing the number of social workers who will assist us. We shall still continue in our two-fold role: 1. as a Parent Advisory Group for residents without correspondents, and 2. as the consumer advocates for all Letchworth Village residents.

The Chairman of the Advocacy Committee under whom the program will be implemented is Dorothy Gasman. Other members of the Advocacy Committee are Lou Corbo, David Roth, Arthur Scholl, and Henry Siegel.

One of the major goals of the "Com-

munity Assistance Project", as it is called, will be to attempt to define those factors which help to ensure the successful transition of residents being moved into new community living situations. In order to achieve this goal, the Welfare League will now be able to employ two professional social workers who will function as field instructors for up to ten graduate students from the Schools of Social Work in the metropolitan area. The project staff will be looking at such factors as the delivery of therapeutic training programs and community orientation programs provided at Letchworth Village. The staff will also review the placement process and the appropriateness and availability of necessary community residential and support services where required. In addition, the project staff will continue to be available to all parents and relatives who may wish guidance and information on all aspects of residents' welfare. As always, the Welfare League will work cooperatively with Letchworth Village staff in a continuing effort to improve the welfare of all residents.

The Welfare League looks forward to this exciting new venture as an unusual opportunity to expand its services to parents and residents to help assure the rights and the quality of care for all residents living at the institution or being resettled into the community. Each issue of the League Letter will bring further news of the activities of this project.

Westchester Developmental Center

Continued from Page 11

In addition, according to a reliable estimate, there are at least 3,500 moderately or profoundly retarded persons presently in Westchester County. If we take into account those retarded persons now living with their families who either now require services or in the future will require services, the above estimate of 3,500 can be doubled.

The greatest concern is, that in a County of nearly one million, there is almost total lack of centrally located and adequate facilities to provide for the needs of the very large population of profoundly and severely retarded, who can never function independently outside a professionally designed and operated facility.

It is evident that Westchester urgently needs a comprehensive center for the developmentally disabled with a capacity

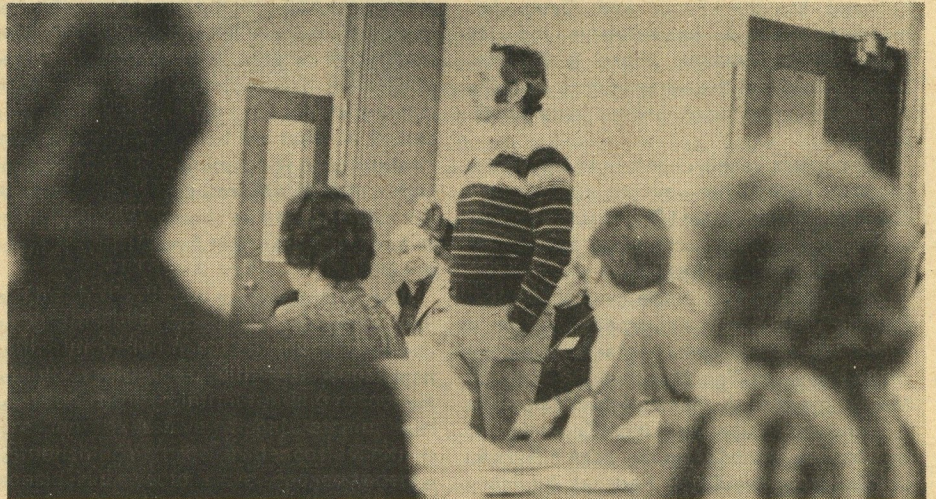
of at least 350 beds. These beds would be used as needed either for long-term residents or for respite care. The facilities needed for services at this center should provide for necessary nursing and psychiatric care, together with medical care for those not requiring hospitalization.

All the reasons that supported the purchase of the Bryant Avenue site and the early planning for its use for the benefit of the mentally retarded are valid today but to a greater degree. The State must renew its commitment and without further delay implement the construction of the proposed facilities on this unique and irreplaceable site.

The Westchester Chapter is irrevocably committed to securing the fulfillment of the State's commitment in this regard and has requested meetings with the Commissioner and his staff.



Ellie Pattison — attentive or critical?

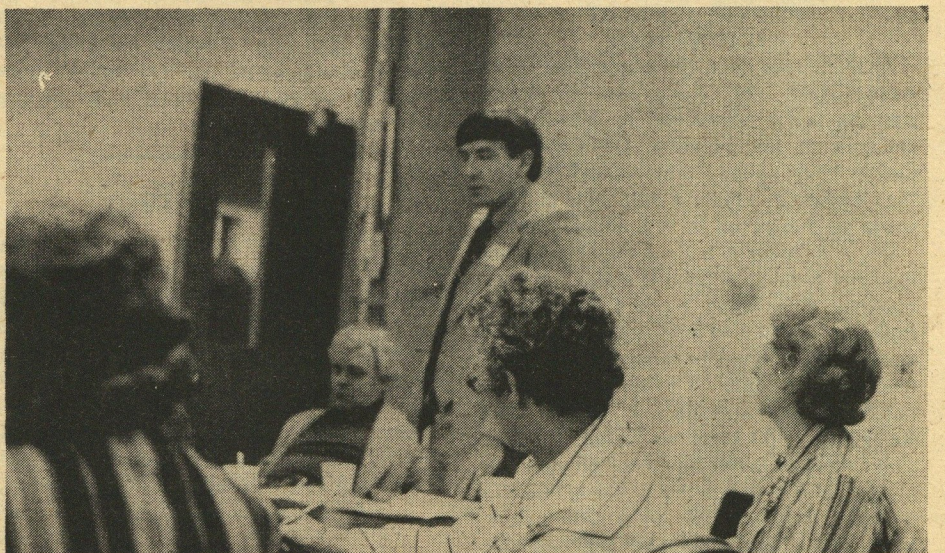


Dr. Irving Caminsky, Assistant Treasurer, making a point.

At the Southeast Regional meeting



Everyone seems to be listening to Mike Goldfarb, Executive Director of our New New York City.



Some are and some aren't listening to Marc Brandt, Executive Director of our Sullivan County Chapter.

OMR/DD medical training

Is procedure typical?

IS MEDICAL CARE AND EMERGENCY PROCEDURE TRAINING TYPICAL?

The Office of Mental Retardation and Developmental Disability is in receipt of about \$1 million dollars from HEW for staff training purposes. The State Association has approached the OMR-DD as well as other agencies for funding to develop training programs for group home personnel. Thus far, the association has met with complete resistance with the attitude of the Office of Mental Retardation being, "We can do it all alone — and better."

Recently, under this program, the New York City - Long Island County Services Group, under the direction of Dr. Jennifer Howse, set up a training program in "medical care and emergency procedure". This program was provided by two registered nurses of the Willowbrook staff who were identified as in-service instructors at the facility

Our New York City Chapter expressed grave concerns with the content of the training seminar, not only as to what they were telling the trainees but the possibility of misinforming community residence staff.

For example, with regard to the Heimlich maneuver, the wrong anatomical landmarks were indicated, the instructor used improper placement of the fist, the specific variations required by children and infants were not taught, and situations in which the Heimlich maneuver should not be used were not discussed.

In addition, mouth-to-mouth resuscitation was taught with an out of date film which does not reflect the current state of the art, etc. etc.

A spokesman for the association commenting on this kind of training said "If this is the kind of training that is going on under this enormous grant, then we wonder what is going to happen with the training of personnel for group homes."

Arbitrator overrules director

The parents of a profoundly retarded child living at the Rome Developmental Center were outraged that an arbitrator saw fit to dispose of an abuse case by a mere reprimand in complete reinstatement of that employee to continue caring for the handicapped. They demanded a re-examination of the arbitration system and the arbitrator in question because of what they considered his irresponsible judgment. In a letter to the Governor's Office of Employee Relations, they asked that the decision made by the arbitrator be appealed.

The situation grew more disturbing when it was discovered that the director of Rome Developmental Center Cornelius R. Walsh, recommended the termination of the employee in question. The judgment of Mr. Walsh was supported by Thomas A. Coughlin III, Commissioner of the Office of Mental Retardation and Developmental Disabilities.

In one of the earlier letters to the Director of the Rome Developmental Center the parents wrote, "This situation is extremely painful to us as James is profoundly retarded and requires total care. He will never walk or talk. These children are particularly vulnerable and are totally at the mercy of those who care for them."

Anyone concerned seemed to be unable to do anything about the arbitrator's decision, the parents wrote in a letter to Our Children's Voice requesting a complete investigation into decisions arbitrators have made in the past in abuse cases concerning the mentally retarded. They asked what steps can be taken to eliminate the arbitration system in the department of Mental Hygiene and replace it with automatic termination of any employee who abuses a patient. They strongly stated that the system of arbitration is unjust and detrimental to the welfare of the mentally retarded.

As a result of this letter, several actions have been taken to investigate the arbitration system in the state.

In Article 33.4 of each of the State CSEA agreements, there is a provision to the effect that the composition of the arbitration panel may be changed by mutual agreement in December of each year. That process of mutual review of the arbitration panel was occurring at the time some of this correspondence was occurring.

The latest information on this situation is that a possible procedure change is

indicated in case assignments where only arbitrators sensitive to client abuse would be utilized. There has been no final resolution to this case. In the meantime, as far as we are aware, the arbitrator who overruled the director is still holding his position.

Hire the retarded? Yes!

Is it really "good business to hire the handicapped" as the media hype puts it?

You bet it is, say Commack engineer Allan Kronenberg, who has the results to prove his point.

A senior communications engineer for Metropolitan Life Insurance Company, Mr. Kronenberg recently turned to the Association for the Help of Retarded Children (AHRC) to fabricate a special interface cable his company needed for its dictaphone machines.

"I learned of the organization through my wife, Janet, a learning disabilities specialist," he said. "The project was ideally suited for them. Larger companies want a huge fee and additional up front work before they agree to take the job," he noted. The AHRC was able to produce the interface cables for about half the cost.

Mr. Kronenberg designed the cables himself, preparing them so that they could be fabricated without the use of a soldering iron, something he felt would be a safety risk.

So pleased was he with the results that he wouldn't hesitate in calling on the AHRC again should the opportunity arise. And the New York office of Metropolitan was so impressed, they used the organization in a special project tying computer terminals into telephone receivers.

"They do a great job," said Mr. Kronenberg. "They don't train the people, they train the job. By tailoring the job around an individual's abilities, it gives him a chance to be self sufficient."

Handicapped Confirmed

Sixty-five mentally retarded youngsters and adults from Brooklyn and Queens received the Sacrament of Confirmation at two recent ceremonies designed for them.

The candidates, all associated with programs and services of Catholic Charities' Officer for the Handicapped, were confirmed by Auxiliary Bishop John J. Snyder. The first group at St. James Cathedral numbered more than 40, the second at the Brooklyn Developmental Center were 22.



Francis Scovel of Jefferson - Lewis County, on his way to the finish line at the 1979 New York State Special Olympics. Delores Wilder and Tim Akin look on.

Everyone a winner in Winter Olympics

Big Vanilla Ski Area, Woodridge, New York — Over 300 Special Olympians gathered at Big Vanilla ski resort for the 4th N.Y.S. Winter Special Olympic games. And what made it so special? Well, the answer was quite evident in the faces of those participating and watching the games.

There was an air of fun and love as competitors whizzed by on inner tubes and toboggans, and demonstrated their newly learned skills in skiing and skating. It

could all be summed up in one competitor's yell, "I did it!" It didn't matter who won or lost, because everyone had lots and lots of fun.

Ron Kutkiewicz, owner of Big Vanilla, put it quite nicely, "I've been to hundreds of competitions all over the country, but never have I seen such a wonderful group of competitors that we could all learn the meaning of competition from."

These athletes will continue practicing in hopes of participating in the upcoming International Special Olympics.

Carey creates ombudsman office

WHAT ABOUT STATE ADVOCATE?

By executive order of Governor Carey, the office of State Ombudsman was established early this year.

The Ombudsman is directed to:

1. Assure that the needs and desires of the citizens of New York State are appropriately considered in the development of governmental programs.
2. Supervise and coordinate existing programs intended to deliver services to citizens.
3. Provide persons seeking information or assistance regarding programs and services with easy access to such information.

The Office of State Ombudsman shall have the following functions, powers and duties:

- a. to advise and assist the Governor and the Lieutenant Governor in developing State programs designed to meet the needs of citizens;
- b. to coordinate existing State programs and activities intended to provide services to citizens;
- c. to cooperate with State agencies to assure that the services to which citizens are entitled are, in fact, provided;
- d. to serve as a clearinghouse for information relating to services to which citizens are entitled;
- e. to refer persons seeking advice, assistance and available services to the appropriate departments and agencies of the State, Federal and local governments or to agencies providing services by contract with such governmental entities;
- f. to investigate specific complaints concerning the delivery of services by State agencies and to report deficiencies to the heads of the agencies involved and, where appropriate, to the Lieutenant Governor and to the Governor;

g. to prepare for submission to the Legislature proposals designed to improve the delivery of services to citizens; and

h. to cooperate with and assist political subdivisions of the State in the development of local Ombudsman programs.

All heads of State agencies and programs are directed to cooperate with the Office of State Ombudsman in carrying out the purposes of this Executive Order. The Office of State Ombudsman shall have access to the heads of State agencies and to other State personnel responsible for establishing policies affecting the delivery of services to citizens.

The Office of State Ombudsman may employ such staff and assistants as may be necessary at a compensation to be fixed by the Lieutenant Governor within the amounts available and subject to the approval of the Director of the Budget.

Retarded save apple crop

Because of the reduced influx of migrant workers, some Michigan apple growers have hired high school children and mentally handicapped adults to harvest a record crop.

The workers, ranging in age from 25 to 67, were put to work on a farm near Williamsburg and were expected to pick 18,000,000 pounds of apples by the end of the harvest season.

"This is the nicest apple harvest I have had in 10 or 12 years," said John Shaw owner of the farm. "It is just a simple fact of life — the people wanted to work. They are meticulous workers. The absenteeism is almost nothing, and I am going to have them back next year."

Meyer Schreiber, Coordinator of our In-Service Training Program for Group Home personnel funded by HEW several years ago, reminds your Executive Director that he (the Executive Director) had proposed this program for New York State Apple Growers some ten years ago.

Live a little. . . .
Learn a lot. . . .
in Binghamton, Oct. 18-21

This year in Binghamton. . .
The Convention — Oct. 18-21

Parents win class action standing

Ask equal funds for non-institutionalized children

A State Supreme Court Justice has granted class action status to a suit on behalf of an estimated 20,000 parents of mentally retarded children in New York City denied state assistance for at-home care because of the lack of previous institutionalization.

Joseph Albert J. Callahan held that the individual plaintiffs — eight Bronx parents — had met the standards in certifying the action in behalf of all such similarly situated parents in the city.

The issues in the case, Sundhelmer vs. Kolb, are two state laws, as well as family care programs, which provide up to \$3,600 a year for the care of retarded children. The assistance goes only to those placed in foster home type surroundings after at least two years of institutionalized care, or to those so certified as the result of a Federal class action on behalf of Willowbrook residents.

Bronx Developmental Center, as a defendant, rejected the assistance request because the plaintiffs' children had never been institutionalized, having been cared for at home.

The defendants claimed that "the plaintiffs' were denied participation in the

family care program because it is contrary to the philosophy of the family care program to place clients in family care in their homes, with the clients' parents as family caretakers."

Permitting this deviation, the Bronx Developmental Center argued, would be contrary to the programs object "to provide an environment which would foster the degree of self-sufficiency necessary for the goal of placing the client in an independent living arrangement."

Justice Callahan ruled, however, that the plaintiffs' claim was sufficient for the granting of class action status and that furthermore, the plaintiffs were aggrieved by the laws and their implementation and that the defendants cease to discriminate against them or classify them differently than other parents and children who are equally needy and equally disabled.

"Insofar as monies are thereby provided to one group, and denied to the other, the

We're all going. . . State Convention, Binghamton, Oct. 18-21.

HEW immunization push

In an effort to eliminate seven of childhood's most dangerous crippling diseases, the federal government has launched a nationwide immunization program.

Of the nation's 52 million children under age 15, more than 20 million have not been immunized against at least one of the diseases, which include measles, polio, rubella (German measles), mumps, diphtheria, pertussis (whooping cough), and tetanus, according to HEW. Its nationwide Childhood Immunization Initiative has two goals: to achieve immunization levels of at least 90 percent of the country's children by October 1979, and to establish a permanent system that assures comprehensive immunization services to the three million children born in the United States each year.

A special effort is being made to eliminate a resurgence of measles. The number of cases in the U.S. increased 62 per cent from 1975 to 1976, and health experts predict greater increases in upcoming years if immunization efforts are not stepped up. In 1977, HEW reports, more than 30 per cent of children under age 14 had not been vaccinated.

The immunization project, therefore, focuses specifically on plans for wiping out measles through vaccination of adolescents and young adults, expanded school immunization programs that include all grade levels, active surveillance systems, and improved outbreak control techniques.

The project planners anticipate that this four-step plan will eliminate measles in the United States by fall 1982.

Apartment must be rented

In 1972, parents with children at the former Willowbrook State School sued New York State in a federal court with hopes of improving conditions at the 6,000 bed institution. One of the plaintiffs in the court suit was Lara Schneps, then a resident of Willowbrook.

The parents' groups eventually received many precedent-setting concessions from the state. Lara Schneps was moved to a group home, but her parents, Vicki and Murray Schneps of Manhattan have continued to fight for the rights of the retarded.

Recently they won more concessions — this time from the owner of an apartment building in Bayside, Queens. The Birchwood Associates had refused to rent an apartment to the Working Organization for Retarded Children (WORC) for three retarded children. Lara Schneps was one of them.

WORC filed a complaint with the State Division for Human Rights and hearings were held in November. The state panel found "the rejection was based on the fact that the tenants were retarded children."

After the finding, the parties agreed to a stipulation under which Birchwood did not admit to a violation of the law, but agreed to rent to WORC and allow the retarded children to live there. The stipulation was signed.

The New York Daily News published an editorial on the subject together with a cartoon about life's chances. The News commented on the suit, saying, "We simply cannot understand how people can hold prejudices against retarded children — and adults. The unfortunate victims of accidents of birth deserve all the help government can give them. And they are helped best in community settings where they can learn to lead more productive lives."

After all, There, but for the grace of God, go you or I."

Simmons, Reville named

Governor Hugh Carey appointed Robert J. Simmons of Watertown to the state Advisory Council on Mental Retardation and Developmental Disabilities. He is a member of the executive committee of the Jefferson County Association for Retarded Children and a former president of that Chapter. His term in the unsalaried post expires March 31, 1980.

Carey also announced the appointment of Frances W. Reville of New York City to the same panel. She is the treasurer of the state Association for Retarded Children.

constitutional attack upon the application of these statutes appeared to be meritorious". The Judge rendered summary judgment to the plaintiffs on this issue of family care support in their own homes for mentally retarded persons who had never been institutionalized.

The broader base for the action, however, is questioning the constitutionality of Chapter 620, whereby the state provides 100 percent funding for community services for deinstitutionalized mentally retarded and only 50 percent funding for those who had never been institutionalized. This issue is not decided by Mr. Justice Callahan, but will be finally decided at a trial.

This may be rendered unnecessary if the legislature passes the bill introduced by Senator Levy of Nassau and Assemblyman Jerry Kremer of Nassau, to provide 100 per cent funding for community services for all retarded as now provided for the deinstitutionalized.

Retardation budget cuts

While the President's proposed budget for fiscal year 1980 cuts Developmental Disability Funds from 59.2 million to 58.5 million, it increases funds to the National Institute of Mental Health by nearly \$30,000,000 and a total of 160.2 million dollars for mental health research in fiscal year 1980.

Alcoholism gets 60 million more in 1980 under the President's recommendation, for a total of \$134,000,000, and the Drug Program is increased by 7 million to a 238 million level.

Mrs. Carter, Chairperson of the President's Mental Health Commission, made a strong appeal before the Human Resources Health Sub-Committee of the Senate of which Senator Edward Kennedy is Chairman.

Unfortunately, however, this commission subsumes mental retardation under mental health, and Mrs. Carter failed to stress the needs of the developmentally disabled in her statement.

We have urged Senator Kennedy to help redress this imbalance to put developmental disability in its proper perspective with increases in proportion to mental health, alcoholism, and drug abuse.

To date, no response.

Carey appoints Council MR under represented

Of the newly appointed members of the Advisory Council on mental retardation and developmental disabilities (which is also taking over the functions of the developmental disabilities council) four, at most, can be said to represent mental retardation. They are Daphne Arindell, Robert J. Hodgson, Francis W. Reville, and Robert J. Simmons of Watertown.

Although Executive Directors of other DD agencies such as epilepsy and cerebral

Handicapped Bill back

Two bills that passed the House of Representatives last year, but failed in the Senate, both aimed at correcting inequities in the Supplemental Security Insurance Law, have been reintroduced.

Congressman Stark has reintroduced a bill (HR 2068) to provide that an individual who applies for supplemental security income benefits on the basis of disability shall be considered presumptively disabled if he or she has received social security or supplemental security income benefits as a disabled individual in the preceding five years.

This corrects a situation where the person on SSI who finds a job, and then loses it, cannot get back on SSI, although the blind can.

The second bill, HR 967, introduced by Congressman Broadhead, was the bill introduced last year by Congresswoman Keyes of California who was reelected, and removed certain work disincentives for the disabled under the SSI program. In effect, this would enable a person on SSI to work and earn \$400 plus dollars a month, as the blind now may, and still be eligible for SSI.

Our members are urged to write their respective Congressman to support these bills.

In addition, Senator Javits has introduced the bill in the Senate (S. 603) to amend the Social Security Act to provide that states may include coverage under Medicaid to individuals who can perform substantial gainful activity despite a severe medical disability.

In a statement accompanying the bill, Senator Javits said that many disabled persons who are employed and earning incomes too high for medicaid eligibility, often these incomes are too low to cover the cost of life sustaining care without which they could not be employed.

"To force an individual to choose between employment and personal attendant care, for example, is unacceptable."

Under this proposal, disabled persons would be subject to state determined state eligibility requirements to medicaid as are, for example, blind and elderly persons.

Correction

In the January issue of *Our Children's Voice*, on page 16, a picture of an Institutions Committee meeting was shown. Michael Styler, an active member of our Institutions Committee was incorrectly named in this picture as Louie Striar. We apologize to Mike for this error.

Deinstitutionalization report

Deinstitutionalization in New York State, an Update from the State Office of Mental Retardation and Developmental Disabilities, is the title of a 30-page paper released this month and available in limited quantities.

The report provides a capsule history of the treatment and care of mentally retarded and developmentally disabled people in New York State and the events

which preceded current efforts to bring people out of the institutions into community settings.

It also provides a description of current goals and the means being used to achieve them.

Copies are available by writing the OMRDD Office of Public Education, 44 Holland Avenue, Albany, N.Y. 12229.

Many women ignore retardation warning

A research study has shown that a significant percentage of pregnant women, warned that they will probably give birth to a mentally retarded child, have the baby anyway.

The same research found that many parents who have been advised to have tests which detect chromosome abnormalities in the early weeks of pregnancy spend many anguished days needlessly fearing bad results. Tests of a mother's amniotic fluid usually find the unborn babies are normal, the researchers said.

The researchers and other experts told the Field News Service that these phenomena raise important questions about counseling programs and other supporting services offered by hospitals and doctors in conjunction with the laboratory tests.

The study, conducted at the New York State Birth Defects Institute in Albany, N.Y., also found a large proportion of potentially retarded fetuses die before birth — apparently bringing new confirmation to the concept that, even for humans, nature has evolved a surprisingly effective natural selection process. The percentage apparently is higher than some doctors have believed.

Researchers led by Dr. Ernest B. Hook found that even when the complicated testing, called amniocentesis, discloses that an unborn child may have nearly total loss of effective intelligence, as well as the slightly less severe brain damage of Down's syndrome, as many as four per cent of the families have the babies. Down's syndrome also is called mongolism.

And when the tests warn of less severe sex chromosome damage, as many as 80 per cent of the parents let the birth go ahead naturally, spurning the opportunity to terminate the pregnancy by abortion. The results came from a sampling of data collected by a nationwide network of specialized medical centers, including Children's Memorial Hospital in Chicago.

Hook concluded that a large majority of all amniotic fluid tests yield normal findings, but frequently not until parents have spent long periods of time worrying about the tests because the laboratory procedure has not been adequately explained.

Spontaneous deaths of the deformed fetuses were as high as 70 per cent for one of the most severe disorders, Hook reported.

Hook's findings were published in the New England Journal of Medicine. Dr. Henry Nadler of Children's Memorial Hospital said the findings demonstrate that counseling programs to make sure parents understand all the implications of

such diagnoses are far less sophisticated than the laboratory work itself at a handful of hospitals across the country.

But Dr. Godfrey P. Oakley Jr. of the federal Center for Disease Control in Atlanta said the findings may demonstrate just the contrary — that a significant minority of parents make a knowing, conscious decision to go ahead with a pregnancy that could produce a severely retarded child. Oakley wrote an editorial also published by the journal.

"What this clearly demonstrates is that people who are having amniocentesis are not going into this with their eyes blind, to have an abortion if there's anything wrong," he said in a telephone interview. "Some parents have been told what the risks are, and they choose to live with them."

Data gathered by Hook on the rare disorders found that two of 47 mothers found to be carrying babies with Down's syndrome gave birth, as well as one of 14 mothers bore children with a more severe brain disorder. And, in the case of two less severe chromosome disorders that frequently do not produce significant retardation, as many as five of nine mothers and four of five mothers gave birth.

Patterning shows no progress

The process of patterning — based on the idea that undamaged brain structures can be stimulated or induced to take on new functions by repeating patterns of development normally associated with other brain centers, was evaluated by the Child Study Center of Yale University.

The center's report was carried in the August, 1978 issue of *Pediatrics*, official journal of the American Academy of Pediatrics.

Dr. G. Timothy Johnson, a syndicated newspaper columnist, gave the following summary of the study and added his own comments, Dr. Johnson said:

"In brief, the study compared the three groups of seriously retarded. One group was treated with patterning.

"The second was treated with a motivational program that did not involve patterning. The third received no special treatment beyond what is normal in a good institution.

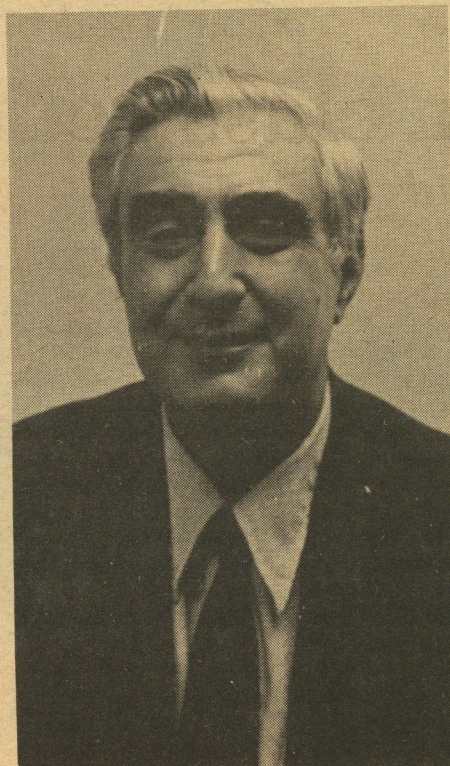
"While the study was complex and subject to some criticism, it was basically a solid, honest attempt to compare patterning with another recognized form of treatment, or with no special treatment.

"It was found that the group that went through patterning made no more progress than the other two. All three groups showed some improvement in performance. Still, no special gains could be attributed to patterning.

"You must realize also that patterning — as typically promoted — requires an enormous commitment of time and energy from the child's parents, family and friends.

"The attention the child receives in the process is undoubtedly healthy. But the overall program may still not be worth the enormous commitment required.

"Before you go too far, I urge you to get and read the article I mentioned. I suggest that you seek some advice from recognized experts in your area before someone makes a commitment to patterning."



Ignacy Goldberg

Goldberg retires

We pay tribute to this splendid individual whom Leopold Lippman has described as the, "sensitive, imaginative, gentle, gracious, thoughtful, considerate", Ignacy Goldberg, an acknowledged, "author, teacher, guide, friend and inspiration". His varied roles in behalf of those called mentally retarded has given new meaning to the term, "expert". Although Dr. Goldberg is taking a well-deserved leave of the field, we know he will never be out of arm's reach as long as those who are mentally retarded have a need.

Throughout his career, Dr. I. Ignacy Goldberg has utilized a wide spectrum of channels to implement his belief and disseminate the view that society can be restructured to provide a more favorable environment for handicapped persons.

Professor of Education in the Department of Special Education at Teachers College, the graduate school of Education of Columbia University, he has trained many educators to lead the way in their communities toward creating more favorable attitudes and programs. As secretary of the International Association for the Scientific Study of Mental Retardation and as an international lecturer and consultant, he has encouraged nations throughout the world to strengthen their services for the handicapped.

As a professional leader — he has served as president of the American Association on Mental Deficiency (1965-66), member of the Executive Board of the Council for Exceptional Children (1961-64), member of the Joint Commission on Mental Retardation of the World Health Organization, member of the New York City Mayor's Committee on Mental Retardation — he has influenced many lay and professional persons to think more positively about the handicapped and to plan more realistically to meet their needs.

Dr. Goldberg is a nationally recognized authority on mental and physical limitations and it was his testimony and depositions in the pioneering litigation in Pennsylvania, Alabama and the District of Columbia which asserted that every child can benefit and every retarded child has a right to education.

As a lecturer of distinction, he has reached the members of many college and university faculties, student bodies and community groups with the message that the handicapped should have as much access to the benefits and responsibilities of American society as any other group.

Above all he is our dear, personal friend.

Herb Katzenberg A tribute

Early this year, the *Herald Statesman* of Yonkers, New York published a tribute to Herb Katzenberg of the Westchester Association for Retarded Citizens. Here are some highlights from the article by Phyllis Riffel.

Herbert Katzenberg of Mamaroneck says he's "not a very interesting character" and certainly not worth doing a feature story about. That remark typifies the modest, self-effacing gentleman who has quietly raised more than \$1 million dollars for the Westchester Association for Retarded Citizens (WARC) and who, at 87 years young, is still going strong as its No. 1 fund-raiser.

Without any prior experience in fund-raising, the soft-spoken man has devoted his time and talents for the past 18 years to WARC, the largest agency in the county providing day training programs for mentally retarded persons. Moreover, he is the first person to serve as a board member and president of the organization without a retarded citizen as a family member.

What is the secret of Katzenberg's success?

"I can only sell what I have confidence in. I learned that many years ago in business. I have confidence in WARC," he said. His advice to other fund-raisers is "accept no for an answer gracefully." It might seem that Katzenberg doesn't receive "no" answers but he notes that, although he has been successful in obtaining funds from smaller foundations, he has yet to crack the big ones, such as the Rockefeller and Ford foundations. One suspects that because of his dogged patience, someday he will.

Katzenberg and his wife of 63 years reside in a five-room house in Mamaroneck they moved to 18 years ago from a larger home in New Rochelle. The couple, who met as teenagers in New York City, have eight grandchildren and one great-grandchild. Katzenberg describes his wife, 85, as an excellent swimmer, talented seamstress and portrait artist and very mechanically-minded. After praising all his wife's accomplishments — which include volunteering in one of WARC's pre-school programs — he did acknowledge his involvement in the concert series at the Emelin Theatre when interviewed. But, as usual, he declined to give himself any credit for his role. After all, he's not a very interesting character — he says.

Westchester wins appeal

Justice William A. Walsh Jr. of State Supreme Court, has found that a proposed group home for eight mentally retarded adults in a residential section of Scarsdale met all the zoning requirements of a "single family" use and was not an institutional use as a group of neighbors had contended.

The decision in a case dating to July 1978 lifted the injunction that had for seven months prevented the Westchester Association for Retarded Citizens from moving the former patients in state institutions into the sprawling, brick home on Foxhall Road.

In rejecting the neighbors' contention, Justice Walsh cited the landmark Court of Appeals decision in a White Plains case establishing such supervised, state-financed residences as identical with single-family homes. He also ruled that the Scarsdale residents and officials were not entitled to prior notification and review of the proposed home because it was established before the September effective date of state legislation requiring a local role.

Weingold resigns from Council

In a letter to Governor Hugh L. Carey, Joseph Weingold, Executive Director New York State Association for Retarded Children, explained his resignation as a member of the Mental Hygiene Planning Council. Weingold wrote, "Although I have found my work with the Council interesting, I find that its focus is too diffuse for my goals and aims, which are particularly with the mentally retarded and developmentally disabled.

I want to thank you for your confidence in having appointed me and assure you I will serve in any capacity you may think I can in the field of mental retardation and developmental disabilities."

Governor Carey accepted Mr. Weingold's resignation with regret.

Our Own Place

The President's Committee on Employment of the Handicapped has published a book of tips for mentally retarded people living in the community. A Place of our Own is written with the needs and expectations of the residents in mind. Printed in bold type and written in clear understandable language, the book features black and white photographs of day to day living situations. Under headings like "jobs we do in our home," "Waking up on time," "making your lunch to take to work," "taking care of how you look," "cleaning your room" and more, the book explains the kinds of things that make up day to day living, working and playing. There's a section on taking care of your money and a list of books on subjects of related interest to community residents, whether they have lived in an institution or at home before.

Copies of A Place of Our Own may be obtained from the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402.

Genetic grants awarded

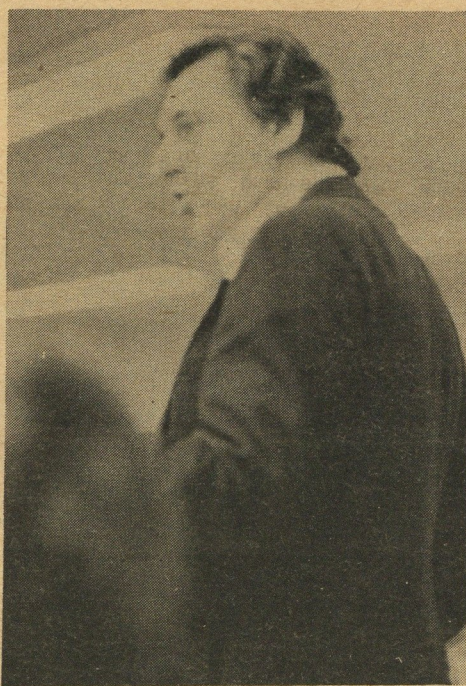
The State Health Department has received a \$325,000 federal grant to coordinate and improve the delivery of genetic screening, counseling and treatment services throughout the State.

The grant, largest of ten awards made to states as part of a \$2.24 million nationwide program, will be distributed to 15 local genetic service centers.

Using these funds, local agencies will be able to purchase new equipment, hire additional staff and generally improve and expand their services to detect birth defects and provide treatment and counseling to those affected.

Dr. Rober C. Herdman, director of the Office of Public Health, who has overall responsibility for implementing the program, said particular emphasis will be placed on improving newborn screening and sickle cell disease counseling services. Dr. Herdman also announced the appointment of Dr. Ian Porter, director of the Department's Birth Defects Institute, as project director and coordinator of the program.

Governor Hugh L. Carey announced the creation and appointment of an advisory council consisting of experts and laypersons involved in the delivery of genetic services and chaired by Dr. Arthur Bloom of Columbia University's Division of Genetics in New York City.



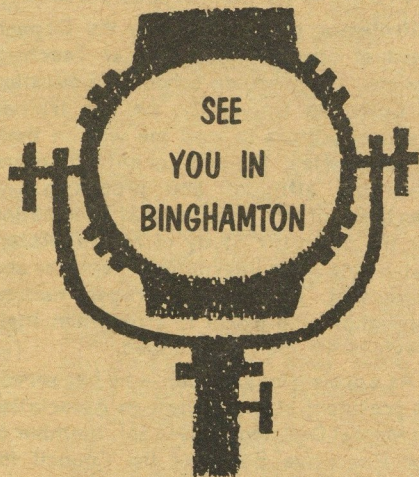
Hy Clurfeld, Senior Vice President, addresses The Parent Education Seminar at the Kennedy Center.

Parent program

The Kennedy Child Study Center, 151 East 67th Street, New York City, conducted a nine week program for parents of infant and preschool handicapped children. The program was sponsored by the New York State Education Department, Office of Education for the Handicapped.

The purpose of the program was to assist parents in understanding and meeting the special needs of their child and families. Materials and information presented were appropriate for parents of children with all types of handicaps.

Evening sessions were throughout May and June and Admission was free. For information, telephone the Parent Program Co-ordinator, weekdays, at (212) 988-9500.



Education Committee

News and Views

We urge you to set up your own education committee to help distribute all the literature that the Education Committee has distributed. As a result of the item in our last column, listing the reprints we have available, the State office was swamped with requests. While we are flattered that so many people read this column so carefully, we agree with Jerry Weingold, that it is the responsibility of each chapter to give this kind of service, whereas the Education Committee continues to supply you — the chapter — with resource material and assistance in workshops etc. Won't you therefore list these reprints in your own newsletter (obtain copies if you haven't got them already), reproduce them and get as wide a distribution of them as possible.

Our April Statewide Education Conference in Albany addressed the concern of parents regarding education for their children.

We held two morning workshops, one very exciting workshop on **Basic Issues, An Introduction to our Child's Rights** — with Georgia Sullivan, Sally Threw and Tom Scholl, all of whom have had experience with committees on the handicapped, appeals procedure, individual education programs and lots more.

The second workshop was concerned with important issues and answers, with a panel of knowledgeable speakers coordinated by Marilyn Wessels, including speakers on legislation, advocacy, state school programs, and commissioner's regulations etc.

The highlight of the conference was an **Indepth Workshop** for the parents — covering what happens when you appear at the Committee on the Handicapped — and what you have to know about the Individual Education Plan. The State Education Department had an excellent presentation covering full details.

There was ample opportunity for questions at all workshops, as well as an opportunity for individual problems to be discussed with all the members of the Education Committee. We will cover the Conference in depth in the next issue of OCV.

HEAD START — Do you have a head start program in your area? If so, contact them and offer to speak to their teachers and their parents to prepare them for the educational procedure they will face when their child enters public school. The Head Staff personnel would welcome input from us as many of them have workshops to sensitize their teachers to deal with children with handicapping conditions. Your offer to help them will increase their knowledge of mental retardation — and may even get you some new members.

EDU-LETTER — The Education Committee is pleased with the success of

our Edu-letter and urge all chapters to advertise this in their respective newsletters. We have had requests from many members of the Committees of the Handicaps, which shows us that not only do they read our excellent "Our Children's Voice" but they really "care" to get further information as to how best to serve our parents. Our requests range from parents, to administrators, psychologists, librarians — so here again, the chapters can push this on a local level and increase distribution of this valuable publication.

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

NAME _____

ADDRESS _____

TEL. NO. _____

CHAPTER AFFILIATION _____

Return to:

Betty Pendler, Chairperson
Education Committee
N.Y. State Association for
Retarded Children

175 Fifth Avenue, N.Y., N.Y. 10010

Hope if you fail I.Q. test

Do you have a low IQ? You do? Well, don't worry about it, because having a high IQ may not be all that great. Psychologists now say that a failing grade on an IQ test just might mean you're more creative than you thought.

Dr. Liam Hudson of Cambridge University claims that most IQ tests leave some aspects of intelligence totally untapped. He suggests that they be replaced with exams that also measure a person's creative ability. "People with high IQ marks are often very UNcreative," says Hudson. He believes that nobody believes any longer that IQ tests measure people's potential intelligence. That's because they don't take into account such things as motivation and guts. Frequently those tests penalize truly gifted people in favor of shallow opponents with a smattering of superficial knowledge.

So if you've flunked an IQ test, you're not a failure after all. You could be a creative genius.

By Jim Aylward,
Albany Times Union

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