

Our Children's Voice

Retarded Children Can Be Helped

Vol. XXXII No. 1

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

January, 1980



From L to R — Ellie Pattison, Tom Coughlin, John Bertrand, Jerry Weingold and Tom's Bust.

Coughlin honored by delegates

The highlight of the Convention Banquet Saturday night, after, of course, the installation of officers and directors by Larry Abrams of Broome-Tioga, was the honor paid to former Commissioner of OMR DD, Thomas A. Coughlin III.

At the time of the Convention Tom had been appointed Acting Commissioner of the Department of Correction (later confirmed) and had left OMR-DD. The Convention honored him for his all too brief, but exciting, and forward looking

tenure as Commissioner. The presentation was a bust of Tom with a suitable inscription.

In his acceptance speech, Tom expressed his relief at being able to go home at night and the absence of parent groups looking over his shoulder. Of course, this was all in good, clean fun, and in the same vein, Jerry Weingold suggested to Tom that this was his opportunity to test out the theory of "least restrictive environment" in Correction.

Resolutions stress community services

In a set of resolutions, covering almost the whole field of Mental Retardation in this state, the delegate assembly highlighted support of the Convention and the Chapters for 100 percent funding of community services by the state for all mentally retarded persons both de-institutionalized and non-institutionalized.

Another resolution of importance to the state was the endorsement of the recommendation of the Public Information Committee that there be a statewide Poster Contest for all public, private and parochial students from Grades 9 through 12.

Other resolutions adopted were:

RESOLVED: That this Association actively seek the introduction and enactment by the New York State Legislature of the Codification of the OMR-DD Services Act proposed and reported by the Task Force appointed by Commissioner Coughlin and headed by Joseph T. Weingold.

RESOLVED: That this Association strongly recommends legislation to protect and safeguard the physical well being of institutional residents and particularly to protect them against sexual exploitation and abuse.

RESOLVED: That the Office of Vocational Rehabilitation be removed from the Department of Education to the Executive Department.

RESOLVED: That this Association supports the restructuring of the Committees on the Handicapped to provide greater parental representation thereon, and calls for the selection of an impartial Hearing Officer by agreement between the parents and School Administrator.

RESOLVED: That this Association opposes Juvenile Delinquent Law, 3915-A, 2944S, passed in the 1979 Legislative session which inappropriately places persons adjudicated as juvenile delinquents and as "incapacitated persons" in a Developmental Disability Center, and that the New York State ARC actively seek the repeal of said law.

RESOLVED: That it is the policy of the State Association to recommend guardianship for all retarded persons, (who require supervision), and with respect to those who have no relative willing to initiate guardianship proceedings to endeavor to assist in that direction, so that each retarded person may have a legal spokesperson whether said retarded person is in the community, a group residence or State Developmental Center.

RESOLVED: That this Association endorses and supports the State-wide project to be known as Mental Retardation Sabbath - Sunday and the Congressional Awareness Program.

Record crowd at Convention

Pattison re-elected president

A record attendance of almost 400 Board Members and Delegates to the State Convention in Binghamton, October 18-20, 1979 made this Convention a resounding success.

Eleanor Pattison, Rensselaer County, was re-elected to a second term as President.

Elected with her were Hy Clurfeld of Nassau, Senior Vice President, representing the Southeast Region, Ellen Maroun of Franklin County, Vice President of the Northeast Region, William Ingraham of Cortland representing the Central Region and Shirley Reynolds of West Seneca representing the Western Region.

Also elected were Marti Smith of Orleans as Secretary, Frances Reville of the Welfare League, Treasurer, Dr. Irving Caminsky of New York City, Assistant Treasurer, and George G. Hirsch, New York City, Immediate Past President.

After many years of service, this Convention saw the absence of Al Cappuccilli of Onondaga County because of private business and matters of health. All of us missed him at the Convention.

Elected to the Executive Committee were Robert Horn of Onondaga, David Essrow of Erie, and Al Turk of Benevolent Society, Willowbrook Chapter.

The Convention was also marked by the enthusiastic meeting of the YOUTH organizations of the State in their own Convention at the same time that the "older" members were meeting.

Resolutions were adopted, the legislative program was approved for 1980, the workshops were enthusiastically received and honors were distributed to Employer of the Year and others.

Much thanks should go to Dick Marcil of Broome-Tioga, Bob Salinkiewicz and the many volunteers who made this Convention so successful.



Ellie Pattison after induction as President.

PRESIDENT'S MESSAGE

As I write this in time to meet printing deadlines, I am still basking in the glow from a most positive and successful convention!

If feedback is any indication, most of you who attended gained useful information from excellent workshops, from interaction with other interested parents, advocates and staff, and even from the often lengthy business meetings.

Our annual "gathering of the flock" is much more than information sharing, however. It is also a time for reflection, re-evaluation and rededication.

The coming year will bring new concerns and directions, as well as traditional crises and trauma. At long last our focus is turning to prevention, as well as delivery of service; for it is hoped that a strong state action plan will evolve from the Symposium in November.

Internal changes within the Association will also be in process, but will not detract us from our goals and purposes. As your president, I, too, rededicate myself to you and the people we serve, for those same dreams are mine.

"Every job is a self-portrait of the person who did it. Autograph your work with excellence".

Ellie Pattison

Introne unanimously confirmed

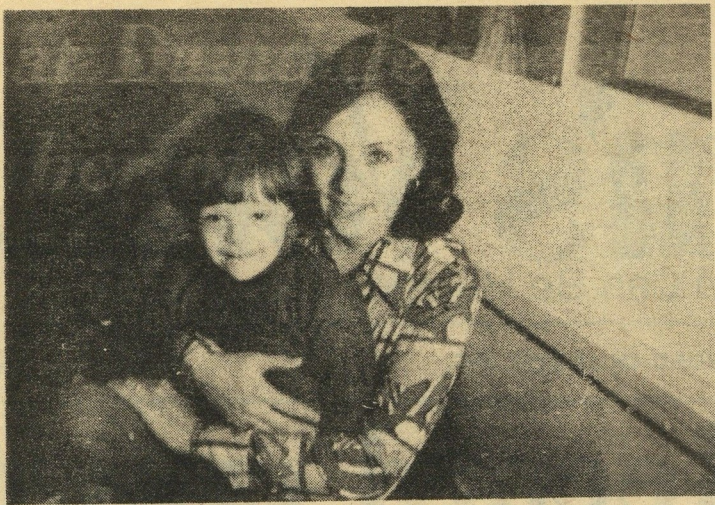
After hearings held by Senator Frank Padavan, Chairman of the Mental Health and Substance Abuse Committee of the Senate, on Friday, November 2nd in Albany, where all testimony was favorable, Jim Introne was unanimously confirmed as Commissioner of the Office Of Mental Retardation and Developmental Disabilities.

All of us here at the Association look forward to a fruitful relationship and congratulate Jim on this appointment.

The waiting period was sweated out in Dr. Jeff Sachs' office in the Capitol where Jeff and Jerry Weingold ate sandwiches but Jim Introne couldn't eat.

Jeff, you will recall, is Program Assistant to the Governor in this area.

A visit by Jeff and Jerry to the Senate later on made it certain that it would be confirmed. And so, our Executive Director drove his chariot back to New York knowing we had a good Commissioner again.



Emily Kingsley and son Jason.

How I became one of "All My Children"

Knowing that if I ever started watching daytime soap operas, I'd be inextricably hooked forever, I never allowed myself to watch them. It came as a complete surprise, therefore, when my son's fiancée told me that one of the characters on ALL MY CHILDREN was undergoing amniocentesis because of a "late-in-life" pregnancy. The producers seemed to be laying the groundwork for a story about birth defects, prenatal diagnosis and/or Down's Syndrome.

Fearing the kind of treatment such a story line might get without current information and attitudes, I phoned the production office of ALL MY CHILDREN and offered to send the latest books and articles so that they could be sure they were presenting the information without being distorted by myth or prejudice.

They were extraordinarily receptive to me. They wanted to know all they could about Down's Syndrome from a personal as well as a scientific basis. When I found out that the producer was an old friend from California, with whom I had worked closely many years ago, I went down to the office in person and spent 2½ hours showing hundreds of pictures of Jason and his friends and telling endless stories, anecdotes and citing facts and figures.

The producer, Jorn Winther, refused to reveal to me whether or not the character was, indeed, going to have a Down's Syndrome baby (they are all sworn to secrecy and will not let anybody know any future plot developments) but I maintained that the period of time when parents are waiting for the results of the amniocentesis is extremely crucial. During that period a couple must decide what they will do if the amniocentesis does diagnose a problem with the baby. Will they terminate the pregnancy or not? This decision must be made very quickly and it is not always made with all of the information or all of the options made clear.

I suggested to Jorn that he might encourage the character, Ruth Martin, to try to get all the latest information on children with Down's Syndrome in an attempt to make the most informed and enlightened decision. I proposed that he might even want to introduce another character... a neighbor, say, who has such a child and let Ruth, and the rest of America, see that it is a manageable situation. I said that they might even want to show the child (a TV soap opera first) and let the world see that a child with Down's Syndrome can be cute and bright and appealing and not a disaster or a nightmare. Two days later Jorn called and said that Agnes Nixon, the owner and creator of ALL MY CHILDREN, was intrigued with the idea and wanted to know if I would be willing to go on with Jason in the role of the neighbor!

I fainted... and then agreed. I did help to prepare the script so that I would be comfortable with the language and the information I'd be giving to Ruth

Martin in her cozy living room set. And the taping was lots of fun. The entire staff, crew and cast were extremely helpful and supportive and Mary Fickett, the actress playing Ruth, made me feel so relaxed, it was like two friends chatting over tea. I'll always be grateful for her warmth and calm easy manner.

Jason handled the taping like a pro, except for one outburst that made it necessary to do the scene in two takes. When we rang the doorbell and Ruth Martin and her son came to let us into the living room, Jason burst into the room, ran to center stage and then, pointing his finger from one side of the set to the other, announced loudly, "CAMERA ONE... CAMERA TWO... CAMERA THREE!!!" The director yelled, "CUT!" and we had to do it over. On the second take, we hustled Jason right over to a large plate of donuts I had requested be on the coffee table. Once up to his ears in very sugary donuts, we no longer had to worry about him counting the cameras!

I am told that 11 million people watch ALL MY CHILDREN every day. That's 11 million people who have now seen a real-live five-year-old boy with Down's Syndrome... a boy who smiles, shakes hands, says "please" and "thank you," is friendly and cooperative and cute. And they've heard me, a mother of a child with Down's Syndrome, say that it's been a most rewarding and enriching experience. I've made it clear that I love my son and am intensely proud of him and that I wouldn't change one thing about him.

In addition to the thousands of relatives of mentally retarded people who may have gotten lots of encouragement from my having come out and said those things, even more important is the fact that these words went to many, many people, housewives, mothers, neighbors, who don't have a retarded child and who don't understand them and continue to fear and avoid them. I hope that we have helped to increase their understanding and acceptance through this exposure.

The other important message the experience with ALL MY CHILDREN taught me was this: if you pick up the phone, if you write a letter, if you open your mouth... things can change. The writers and producers of ALL MY CHILDREN were grateful for the help and information I was able to give them so that they could do the most responsible presentation possible. IF something on television upsets you, write a letter or make a phone call. If we don't do everything we can to change peoples' attitudes, we can't complain when those attitudes remain the same. Don't ever feel that you are too small, too insignificant, to have an impact on the media. They read every letter; they have someone to answer every phone call. All of us must make the commitment to help improve attitudes in the hope that the world that our children are growing up into will be a better one to live in — for them and for everyone.

By: Emily Perl Kingsley

The right to live

The article in this issue on the struggle to establish group homes for the mentally retarded is an indictment of the social system that has so conditioned people with regard to mental retardation as to make them fearful, apprehensive and rejecting.

The Site Selection Law, although with the best of intentions to overcome some of this "neighborly" resistance, fails because it does not really understand fundamental reasons for the establishment of group homes and the basic rights of the mentally retarded.

All those aside, the time has come to state bluntly: **the mentally retarded have the right to live wherever they wish, regardless of neighbors' rejections, the towns' objections, the property values or anything, even proliferation of such group homes.** This right is guaranteed by the United States Constitution with equal protection for all, including the handicapped. Regulation 504 of the Vocational Rehabilitation Act of 1973 bluntly states there can be no discrimination in housing for these people. The Flynn Act prohibits

discrimination in housing for the handicapped, mentally or physically. And finally, court cases themselves upholding these group homes as the equivalent of a family unit meeting the zoning regulation with regard to single family occupancy.

All else is just talk and pandering to blind prejudices that will never be reversed.

We must weigh these prejudices and objections against the unalienable rights of the mentally retarded to live wherever they please.

If we hone this down or diminish this by one iota we are diminishing all our rights and the rights of every minority in every case.

The Site Selection Law is unconstitutional and must be tested once and for all.

No legislative action can change constitutional rights. The horrible conditions under which the discharged mentally ill are living, and their impact on the community, cannot be visited on the mentally retarded. Once and for all, let us stop this nonsense and stand up and fight.

Protection and Advocacy is "Friend to Friend"

What can we do to help the thousands of residents of community and family care homes who have no one to take an individual interest in their well being?

Protection and Advocacy System for Developmental Disabilities, Inc. (PASDD) has developed a unique program called Friend to Friend. A trained volunteer will befriend a developmentally disabled person to help meet social, emotional and practical life needs.

NYSARC in cooperation with PASDD is offering training in methods of implementing "Friend to Friend" programs.

PASDD will also provide technical assistance, sample materials, brochures and additional training programs.

Volunteers need to be recruited and trained in methods of how to meet the developmentally disabled person's special needs. Volunteers will participate in ongoing rap sessions, workshops and additional training programs which focus on the special needs of disabled people.

If you wish to explore the possibility of establishing a 'Friend to Friend' program in your chapter please contact:

Joseph T. Weingold, Executive Director
NYS Association for Retarded Children, Inc.
175 Fifth Avenue
New York, N.Y. 10010

Act Now!

Our Children's Voice

Retarded Children Can Be Helped

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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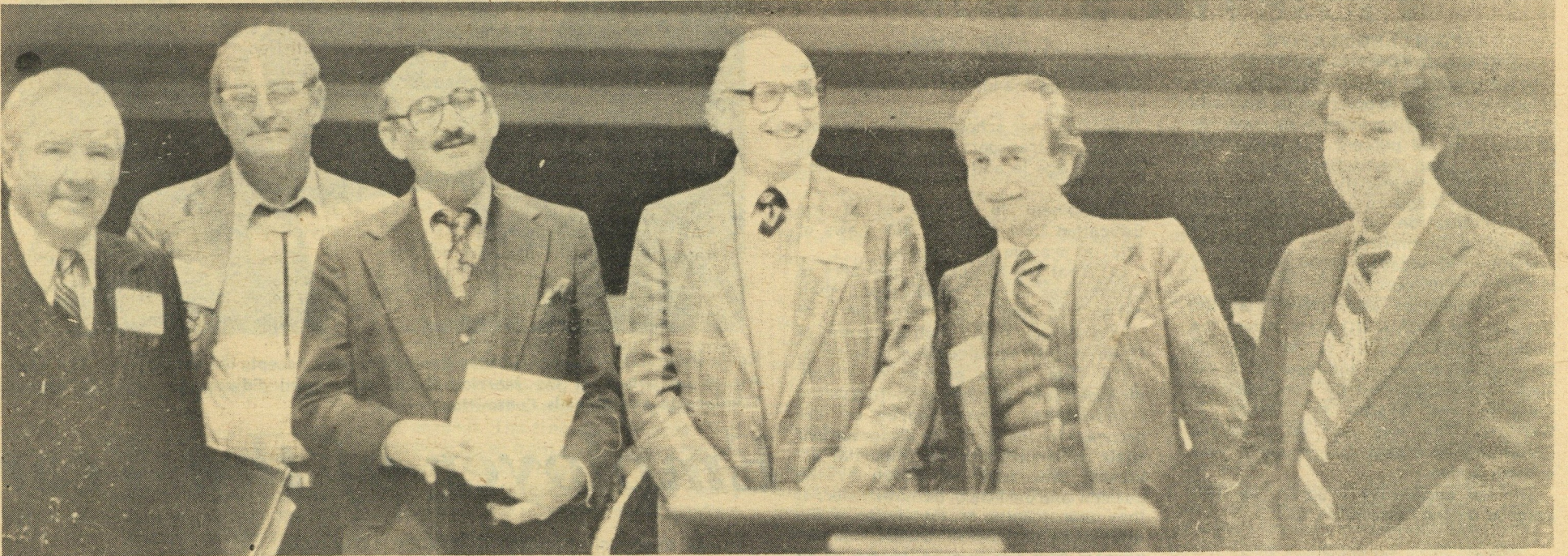
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Prevention Symposium

Rights of birth and development

From left: Sen. William T. Conklin, Dr. Robert Guthrie, Joseph T. Weingold, Dr. Irving Bialer, Dr. Henry Wisniewski, OMR-DD Commissioner James E. Introne.
(Photo by Albert E. Feldman)

Closing the gap between existing knowledge and the timely and effective application of the prevention of mental retardation and developmental disabilities can substantially reduce the incidence of these disabilities. The message heard loud and clear is that what is required now is a far more organized system of medical and social care than we presently possess. Emphasis was placed on improving the delivery of care, not just improving the system of reimbursement for care. It is a sad commentary on our times that too frequently a disproportionate emphasis has been placed on treatment resulting in entrenched disincentives to primary prevention research and application.

A joint funding effort by HEW-RSA — Region II, the New York State Department of Health, and the Office of Mental Retardation and Developmental Disabilities made possible a three-day statewide Symposium on the Prevention of Mental Retardation and Developmental Disabilities, sponsored by the New York State Association for Retarded Children on November 18th-20th, 1979 at the Fallsview Hotel in Ellenville, N.Y.

DR. MARGARET GIANNINI CHAIRS SYMPOSIUM

Dr. Margaret Giannini, Symposium Chairperson, assembled some of the most prestigious individuals in the field to participate in this important event, the main purpose of which was to demonstrate at various levels of community involvement that information and techniques presently exist which when known, disseminated and effectively applied, can substantially reduce the incidence of mental retardation and developmental disabilities. The conference, designed to provide a forum for wide representation from concerned individuals and agencies to plan, collaborate and develop strategies for long-overdue prevention programs, presented an opportunity for those involved in the field to participate in the formulation and implementation of an effective ACTION PLAN for the State of New York.

Keynote speaker, Dr. Robert Cooke, President of the Medical College of Pennsylvania, established a very positive tone for the Symposium with an emphatic affirmative response in answer to the rhetorical question: Mental Retardation — Can More Be Done?

OUTSTANDING FACULTY CONVENES

Outstanding faculty throughout the State and country convened to address a wide range of topics including pre- and perinatal evaluations, high-risk factors and immunizations; the relationship of

nutrition to brain development; metabolic and genetic syndromes; the effects of alcohol and drug syndromes; public health



Two stipend recipients, Shijela and Albert Lundy of St. Lawrence Chapter. Looking on at the real workers, L to R — Lois Alsaker, Secretary to Marc Brandt, Sullivan, Ken Ingber, also of Sullivan and Susan Finelli, registrant.

issues, social and cultural factors influencing approaches to prevention.

The presentors were:

Allen C. Crocker, M.D., Professor of Pediatrics, Harvard Medical School, Public Health Issues; Robert Guthrie, PH.D., M.D., Professor of Pediatrics and Microbiology, State University of New York at Buffalo, Metabolic and Genetic Syndromes; Glenn Haughe, M.D., Deputy Director - Office of Public Health, Albany, N.Y., Model Program for Lead Screening; Mary P. Coleman, M.D., Pediatric Neurologist, Georgetown University School of Medicine, Neurological Evaluation of the Neonate; Brian L. G. Morgan, PH.D., Columbia University College of Physicians and Surgeons, Nutrition to Brain Development; Ralph Colvin, PH.D., Research Scientist, Institute for Basic Research in Mental Retardation, Preventive Techniques from the Laboratory and Clinic; Murry Morgenstern, PH.D., Director of Psychology, Mental Retardation Institute,



Standing, Geraldine Sherwood, Coordinator and Sylvia Weiss, Bookkeeper. Seated, Lynda Russo on loan from OMR-DD.

Early Intervention—Prevention Strategy; Joann Gustafson, Research Analyst, State of Connecticut, Office of Public Health, Rh Factors and Immunization Programs; Lucretia Phillips, M.S.W., Director of Field Work, New York University Graduate School of Social Work, Social and Cultural Factors.

PANEL HIGHLIGHTS FINAL SESSION

The three-day intensive orientation to preventive measures culminated in a final plenary session in which prominent leaders in the field of mental retardation, such as Joseph T. Weingold and Senator Conklin joined a panel of officials representing major provider agencies such as Commissioner James Introne, Office of Mental Retardation and Developmental Disabilities, and Dr. Ian Porter, Assistant Commissioner, Department of Health, to discuss recommendations from participants for future legislative, administrative, and other strategies for the prevention of mental retardation and developmental disabilities on state and local levels.



L to R, Dr. Giannini, Bob Hankin and Ellie Pattison.

The Right To Be Born Well is as important as any other of mankind's inalienable rights. Robert Hankin, the force behind HEW who first approached the Association on sponsoring this Symposium, shared the hopes of our planning committee that this statewide Symposium would be the first-step in formulating a long-overdue Action Plan for Prevention of Mental Retardation and Developmental Disabilities in New York State.

Representatives of United Cerebral Palsy, Epilepsy and Autism joined ARC participants to bring back this message to their communities. OMR-DD plans an action-oriented follow-up, building on the knowledge and recommendations presented at this Symposium.



L to R, J. T. Weingold, Dr. Margaret Giannini, Symposium Chairperson, Dr. Ian Porter, N.Y. State DOH, Dr. Robert E. Cooke, President, Medical College of Pennsylvania and Keynote speaker.



L to R, Dr. Porter and Dr. Allen Crocker, Project Pediatrics, Harvard Medical — who spoke on Public Health Issues of Prevention.



L to R, Robert Guthrie, Developer of Guthrie Test for P.K.U., Dr. Cooke, Peg Giannini and Robert Hankin, Regional Program Specialist RSA, HEW Region II.

Emphasis

Equal funding for all

15 POINT LEGISLATIVE PROGRAM FOR 1980 ADOPTED

In a resounding indictment of the policy of New York State to polarize the mentally retarded by funding those who leave institutions at 100 percent and those who have not been institutionalized at 50 percent in community services, the Convention adopted unanimously the recommendation of the Legal and Legislative Committee that funding of community services for all be on the basis of parity — 100 percent.

The Convention also urged that the Department of OMR-DD place before the Legislature codification of the OMR-DD Services Act proposed and reported by the Task Force appointed by Commissioner Coughlin and headed by Joseph T. Weingold. This has been lying on the Commissioner's desk for almost a year without action.

The full Legislative Program for 1980 adopted by the Convention is:

A. STATE INSTITUTIONS AND SERVICES

1. Continued support of the bill to clarify the provisions of Chapter 777 of the Laws of 1977 by explicitly stating that the abolition of the parental liability for fees in the Mental Hygiene and Social Service Laws is retroactive in effect.
2. It is recommended that a bill be introduced to give the Commissioner of OMR-DD authority, in consultation with an independent body, to make decisions on admissions and discharges to and from developmental centers.

B. COMMUNITY MENTAL HEALTH SERVICES

1. Provision that funding of community services for the non-institutionalized mentally retarded be on a basis of parity with the funding of such services for those de-institutionalized — 100 percent funding by the state.
2. Provision that interest on loans necessarily obtained by voluntary agencies because of failure of the state to make payments on time be reimbursable items included in budget costs.
3. Provision that interest on mortgage loans made by voluntary agencies for acquisition, construction or remodeling of facilities be a reimbursable item.
4. Provision that interest on HFA mortgages be a reimbursable item even when the state has made its 1-3rd contribution towards construction.
5. Provision that the state funding of construction or acquisition of facilities for the mentally retarded by voluntary agencies be on the basis of 2-3rds of the cost, instead of the present 1-3rd, or on parity with facilities for the deinstitutionalized, whichever is greater.

C. EDUCATION

1. Provision that education of the handicapped be mandatory from ages 3 to 21.
2. Provision that school districts be permitted to transport persons over 21 years of age to and from rehabilitation facilities.
3. Amendment to Article 89 of the Education Law (Chapter 853, Laws of 1976) to provide the following:
 - (a) That the number of members of Committees on the Handicapped shall not be less than 7 nor more than 9, of whom no fewer than 3 shall be parents of children with handicapping conditions.
 - (b) That, if the parents of a handicapped child and the Committee on the Handicapped cannot agree on the program for the child, the disagreement shall be resolved by an impartial arbitrator who shall be chosen by the parents and the school administrator; if they cannot agree on the choice of the arbitrator, each shall choose one arbitrator and the two so chosen shall choose a third; in this process of choice, the parents shall have access to the qualifications of the proposed arbitrators.
4. Repeal of that part of the 1977 amendment to Article 89 of the Education Law that removes transportation for children residing in state institutions and attending public school classes.

D. OTHER MATTERS

1. Provision that life insurance companies may not refuse to insure the lives of mentally retarded persons on the sole ground of mental retardation.
2. Provision that parents of non-institutionalized mentally retarded persons may qualify as "family care providers" as well as parents who take their children home from institutions.
3. Provision that the Office of Vocational Rehabilitation be transferred from the Department of Education to the Executive Department.
4. Amendment to the law governing community residences (a) by repealing that portion thereof requiring notice to the municipality of intent to establish a community residence; (b) in the alternative, by an amendment requiring the municipality, if it does not approve the site of the residence, to designate with greater specificity an alternate site of comparable quality, currently available at a comparable price and on comparable terms; (c) by an amendment declaring that restrictive covenants in deeds forbidding the use of the property conveyed for community residences are not enforceable.
5. Introduction of the codification of the OMR-DD Services Act proposed and reported by the Task Force appointed by Commissioner Coughlin and headed by Joseph T. Weingold is also recommended.

HUD awards funds to four chapters

This September, the U.S. Department of Housing and Urban Development announced it had approved the funding requests of four more State Association Chapters. The HUD funding comes under their Section 202-8 Program, which provides both mortgages for the construction or substantial rehabilitation of group homes for mentally retarded adults, as well as a rent supplement to assist in repaying the mortgage.

The Chapters newly approved for this funding are Rensselaer, Rockland, Suffolk, and New York City. The Rensselaer ARC was approved for 6 units (a unit is a bedroom) of rehabilitation at \$210,000. The New York City ARC was approved for 7 units of

new construction at \$265,000. The Suffolk AHRC was approved for 28 units of new construction at \$1,062,625. The New York City AHRC was approved for 12 units of new construction at \$457,120 as well as 18 units of rehabilitation at \$685,680. This makes a total of 71 units at \$2,491,425. Since a unit may be double occupancy, and subtracting the units for houseparents, this year's fund reservations provide the potential of homes for up to 120 mentally retarded adults.

This year's fund reservations bring the total amount of funding HUD has awarded to ARC Chapters during the last four years, for group homes, to a total of approximately \$8,000,000.



Kevin Ryan, (1) President, Clinton County Chapter, accepts the Employer of The Year Award on behalf of the Marriott Corporation from Edward Licence, Chairman, Scholarship and Awards Committee.

Employer of the Year

In one of the closest competitions we have had in years, the Marriott Corporation, nominated by Clinton County Chapter, has edged out Hillside Greenhouses, nominated by Sullivan County Chapter, as our 1979 Employer Of

The Year.

As is our custom, a plaque was given to the winner at our State Convention and an Award Certificate will be provided for every nominee.

Those nominated in 1979 were:

NOMINEE

Marriott Corporation
Hillside Greenhouses
St. Elizabeth's Hospital
Eastern Parkway Price Chopper
Mohawk Data Sciences
Guidepost Association
Keymark
Scott Machine Development Corp.
Corning Glass Works
Sealectro Corporation
Susquehanna Nursing Home
Potters Industries, Inc.
Acco International
N.Y.S. Department of Transportation

CHAPTER

Clinton County Chapter
Sullivan County Chapter
Oneida County Chapter
Schenectady County Chapter
Herkimer Co. Chapter
Putnam County Chapter
Fulton County Chapter
Delaware County Chapter
Steuben County Chapter
Westchester County Chapter
Broome-Tioga County Chapter
St. Lawrence Co. Chapter
St. Lawrence Co. Chapter
Putnam County Chapter

Two awarded \$7 million in malpractice suits

Juries in Manhattan and the Bronx have awarded damages totaling more than \$7.8 million in medical malpractice cases to two Bronx children. They suffered brain damage and were left retarded as a result of admittedly negligent treatment in New York City hospitals.

The awards — \$4,948,000 to a 6-year old boy treated at the now defunct Fordham Hospital in 1974 and \$2,910,000 to an 11-year old girl treated at Harlem Hospital in 1975 — were believed to be the largest ever made for medical malpractice in New York State, and among the highest in the country.

Although the City has not contested liability in either case, it has appealed both verdicts as excessive.

In the first case, the boy was normal at birth, was admitted at the age of 4 months to Fordham Hospital for treatment of bronchiolitis, an inflammation of minor bronchial tubes. Because he had trouble breathing he was placed in a croupette, in which he breathed a mixture of oxygen and air.

Two days later, at the direction of a resident doctor, he was taken from the croupette for X-rays and was away from the oxygen for nearly an hour, when he became unconscious and nearly died. The suit said he suffered irreversible brain damage that led to mental retardation, cerebral palsy, epilepsy and cortical

blindness. Today he is spastic and unable to walk or talk.

The second award was made to a girl who was admitted to Harlem Hospital at the age of 6 with a respiratory ailment. A doctor recommended that a breathing tube be inserted into her trachea to facilitate breathing, but this was not done. For two days, the lawsuit alleged, the girl was left unattended in the ward where she went into respiratory and cardiac arrest and suffered a lack of oxygen in the brain. As a result, she is now retarded.

ARC appointments to Boards of Visitors

Governor Hugh L. Carey has announced the nomination of three members of the ARC to serve on Boards of Visitors of Developmental Centers.

They are Benjamin Aceto of the Welfare League, Letchworth Village Chapter to the Letchworth Village Developmental Center; Robert Sturdevant of Binghamton, founder and past president of Broome County Chapter of the State ARC to the Board of Visitors of Broome Developmental Center; and, Richard D. Gorow, Niagara Falls, a director of Niagara County Association to the West Seneca Developmental Center.

New Hope?

Gene injection cures cell flaw

Successful injection of a single gene into a defective living cell, curing that cell's fatal genetic flaw, has been reported by a team of scientists at the National Institutes of Health and Rockefeller University.

The feat, using the cells of mice, is considered an important early step toward the goal of making the same kind of genetic repairs in human cells. The ultimate purpose of this would be the cure of human genetic diseases by reimplanting a large number of the patient's own cells after they had been repaired.

GENE REGULATION KNOWLEDGE KEY AREA

Vital to this long-range goal and more important for the immediate future, according to the leader of the research team, will be the technique's value for studying how genes are regulated in living cells of animals and humans. The precise mechanisms by which genes are turned on and off and otherwise regulated are largely unknown today and represent one of the key areas of modern research in the chemistry of heredity.

Genes are the basic units of heredity, governing all manner of traits from hair color to the proper functioning of the red cells in the blood. There are several hundred different genetic diseases caused by the failure of one or another specific gene to function properly. The failure of one single gene among the many thousands in human cells can have disastrous effects on the whole person, causing death, mental retardation, physical deformity or other grave defects. Many such diseases are rare and unfamiliar to most people. Others, like the blood disorder sickle cell anemia, are relatively widespread.

GENES INJECTED IN MICE

In the studies, two genes, together with all their necessary regulatory sequences,

were injected together into individual mouse cells growing in laboratory tissue cultures.

One such gene translated by the microinjection technique was one carrying the instructions for making an enzyme called thymidine kinase, which is vital to cell survival. This was injected in mouse cells that had been chosen for the research because they lacked the ability to make that essential enzyme.

The cells that were given injections of the normal gene survived and multiplied, showing that the foreign gene had in fact become a functioning part of the cell and did produce its characteristic product — the enzyme. The transplanted gene itself had been taken from a virus called Herpes simplex type one and could be distinguished chemically from the native mouse gene that served the same function.

HUMAN GENE USED

The other gene injected in the mouse cells was a human beta globin gene — one of the cluster of genes needed for production of hemoglobin, the red, oxygen-carrying pigment of the blood. This gene also functioned to a limited extent. The complete function was not expected because the cells into which the genes were transplanted were not part of the blood-forming system and therefore presumably lacked the precise inner environment needed for the production of a blood product.

The next step in the research, already in progress, is an attempt to "cure" defective mouse blood-forming cells by injecting into them the specific functional gene they lack in their hemoglobin system.

An ultimate objective is to learn enough about cells' natural means of gene regulation so that cells taken from a patient suffering from a genetic disease such as sickle cell anemia can be "cured" of their characteristic abnormality.

Dads also get rap for Down's Syndrome

Thousands of babies are born every year with the mental retardation and physical defects that characterize **Down's Syndrome**.

According to traditional medical wisdom, women in their 30's and 40's have a dramatically higher chance of having such a child — so much so, that some physicians counsel older women against becoming pregnant.

But according to two Tulane University researchers, that's only half the story.

Biologist Dr. Joan Bennet and educator Dr. Kippy Abroms have discovered fathers are almost as likely as mothers to supply the extra chromosome that is the immediate cause of Down's Syndrome. This can have far-reaching implications as more and more men and women decide to become parents past 35.

Bennett, an associate professor of biology, and Abroms, an assistant professor at Tulane's Center for Education, became interested in the question of Down's Syndrome and older parents more than two years ago.

The study of this shows that, although the textbooks talk about the chances of a woman over 38 having a Down's Syndrome child, no data is given for men.

The age of the father at the time of birth of a Down's Syndrome child usually isn't even recorded, and Dr. Abroms attributes that lapse to the persistent medical belief that the abnormality is associated with a

fault in the female egg, not in the male sperm.

The researchers' studies of available Japanese, Danish and American statistics "suggest that paternal age is as strong a predictor variable for Down's Syndrome as is maternal age."

The relative incidence increases slowly for fathers up to age 45 and jumps dramatically past age 55, they note.

Thanks to recent advances in laboratory techniques, Bennett and Abroms have not had to rely solely on statistical analysis: they have been able to "see" markings on the extra chromosome that can indicate which parent contributed it to the genetic makeup of a Down's child.

By taking a karyotype or picture of the 47 chromosomes of a Down's child and by staining the distinctive chromosome trio with a fluorescent substance, a "banding pattern" can be seen. Two of the chromosomes will be banded similarly, Bennett notes, the other will be different.

Then, by karyotyping and staining cells from the child's mother and father, researchers can literally "see" which parents contributed the extra chromosomal material.

After studying reports of more than 300 karyotype and stain procedures involving Down's Syndrome children and their parents, they found that in 115 of the cases, a definite matching pattern could be ob-

Major MR causes still a mystery

In the medical morass called **mental retardation**, causes and treatments are rarely clear.

"Mental retardation is a collection of problems that in many cases have social and economic roots, not just biological ones," says Philip Davidson, director of the University of Rochester's Clinic for Developmental Disorders. "Unfortunately, major research breakthroughs in the field don't exist."

Mentally retarded people make up about 1 to 3 percent of the U.S. population, Davidson says. That covers those who may compete in the Special Olympics, with its eligibility requirement of a 75-or-under I.Q. or enrollment in a special education program. (An I.Q. of 100 is considered normal.)

Someone with a 75 I.Q. can't easily be described, Davidson said. "The person could be wandering around Main Street indistinguishable from anyone else. Of course, the more retarded a person is, the less likely he will be able to cope."

The mental deficit shows up as "difficulty in complex problem solving that requires a higher level of abstract thinking," Davidson added. "But the retarded can learn if you break things down into concrete terms."

The major cause of mental retardation remains the biggest mystery.

Fifty to 75 percent of those called mentally retarded became that way from the catchall cause, environment, Davidson said. "In some cases, retardation follows some devastating disease, like encephalitis or meningitis, that affects the central nervous system," he said. "But most of the time it results from some kind of deprivation, kids living under conditions of neglect, kids that aren't touched enough during infancy or early childhood, kids whose physical and emotional needs are ignored."

Given the social reasons for such retardation, prevention is costly and difficult even though some contributing factors can be identified, he says.

Worldwide studies show that the more severe forms of retardation strike without regard for socioeconomic class, according to Dr. Neal McNabb, chief of pediatrics at Genesee Hospital. "But the proportion of milder cases, which tend to have environmental rather than medical causes, seems greater among the disadvantaged — and that's also true on a worldwide basis."

Genetic defects or misprogrammed chromosomes take the blame for only 5 to 10 percent of the problem, although their effects may be the most visible, says Davidson.

Down's syndrome, the most common of these abnormalities, produces a familiar look, he says. Its prominent features include eyelids with single folds and a flat nasal bridge.

Because its victims were thought to look Asiatic, Down's syndrome became known as "Mongolism" — an unfortunate misnomer. McNabb said. "The term still gets used, but the condition has nothing to do with racial background."

If results instead from a tiny bit of genetic material — a single extra chromosome, he said. Down's syndrome and other genetic defects show up more often in offspring as the mother's age

served. Of those, 30 "extra" chromosomes matched the father's chromosomal material and 85 matched the mother's. Thus, more than a quarter of these were found to be paternally derived. They concluded that the "syndrome is not an exclusively female phenomenon by age or by egg. The conception of a Down's child is an accident of nature and must be shared as a responsibility by both parents."

increases, he said. "Amniocentesis (a test of the fluid surrounding the developing fetus) can detect this and other genetic problems before the child is born," he said.

A drop of a newborn's blood can tell if he or she has a rare enzyme deficiency called phenylketonuria (PKU). A blood test developed in the early 1960s, required by law in New York and most other states, can detect PKU. A special diet begun soon after birth minimizes mental impairment.

New York recently joined a handful of other states requiring the testing of newborns for hypothyroidism. Untreated, the condition causes a form of mental retardation called cretinism, and like PKU, it can be avoided if found and treated early.

There's a growing link between an expectant mother's health and habits and her child's mental development, Davidson said. "There's increasing evidence that drinking, smoking and taking certain drugs during pregnancy may produce mental retardation in offspring," he said.

Best known was the thalidomide tragedy, which produced physical and mental disasters among children whose mother's took the tranquilizer during pregnancy.

"No one knew then that you could rearrange the course of prenatal development," Davidson said. "But now researchers are coming to think that taking any drug that changes an expectant mother's body function can influence the baby's function as well, particularly if taken during the first trimester of pregnancy, when the brain develops. There's some evidence that tranquilizers and drugs to treat depression will affect a developing fetus."

He described fetal alcohol syndrome, the result of a pregnant woman's alcohol abuse on her developing child. Along with mental retardation, "these infants show some similar physical features — such as deep-set eyes — which we think may result from rearranged chromosomes," Davidson said. "If you have similar physical features among children with the same history, you begin to think that something genetic has changed."

McNabb called the connection between alcohol and prenatal development "a clinical hunch," although researchers now seek firmer evidence. "Some people are affected by large amounts of alcohol, and some don't seem affected at all. So we really can't say there's a safe level of intake."

Rubella, or German measles, contracted by a pregnant woman, can lead to physical and mental damage in the child, Davidson said. Injury to a child before or during birth and oxygen deprivation can produce retardation, he said.

"Early medical intervention now saves the lives of many high-risk babies and prevents the severe retardation we used to see in them," McNabb added.

Intelligence quotient, or I.Q. tests, are "an outmoded way" to measure mental retardation, Davidson said. "These are usually paper and pencil tests of ability to reason, create, understand, judge and sometimes organize things in space. All of these are supposedly the components of adequate intellectual behavior."

Those who treat and teach the retarded "are not only interested in this person's ability to add 2 and 4 to get 6, but if he can make functional use of that information," Davidson said. "We're just as concerned about the skills of daily living."

Most mentally retarded people fall into the "mildly" or "moderately" retarded category, he said. "That puts them somewhere around the first grade level in their development. But when you think about it, a first grader is capable of a lot."

Federal Housing Funds: Planning, Renovating and Construction

The Department of Housing and Urban Development (HUD) offers a number of programs to non-profit and profit-motivated sponsors to plan, rehabilitate and construct housing for the low and moderate income population. Housing designated for individuals who have handicaps is generally categorized with housing for the elderly. Continuous efforts are being made to bring the housing needs of adults who have developmental disabilities to the attention of the Housing Authorities in an attempt to increase the availability of Section 8 units and fund reservations.

The following is a synopsis of selected HUD programs currently available to non-profit sponsors:

I. Community Development Block Grants (CDBG). Title I of 1974 Act Public Law 93-383

Mandates local community development programs chosen by local elected officials. A non-profit agency can be sponsored by the local municipality and be the subgrantee in requesting Community Development Block Grant monies.

The CDBG program has two components:

1. Three-year Community Development Program (D) and
2. Local Housing Assistance Plan (HAP). CD funds can be used by eligible units of government who elect to participate in the program. The block grants can be used for, but are not limited to
 - a. acquisition, construction, rehabilitation or installation of neighborhood facilities, parks, playgrounds and other recreational facilities, senior centers and centers for the handicapped.
 - b. removal of architectural and material barriers, and
 - c. payment of administrative costs and charges related to planning and execution of community development and housing activities. (Section 701)

Housing Assistance Plans (HAP) must accompany all applications for CD programs or HUD-subsidized programs. HAP's are required to include the following:

1. Survey of local housing conditions.
2. Determination of local housing needs.
3. Realistic annual goals for providing various kinds of housing assistance to low-income families.
4. Identification of appropriate locations for proposed assisted housing.
5. Provision for citizen participation in the development of the plan.

II. Residential Programs.

A. Mortgage Insurance.

1. Section 231

Housing Act of 1934 - Amended in 1959
Public Law 86-372

Below market interest rate mortgages for the construction or rehabilitation of rental housing for the elderly or handicapped.

Sponsors in this program can be local non-profit advocacy organizations, non-profit and profit investors, developers or housing authorities. Such sponsors need to work through FHA approved lending agencies to participate in the program. Handicapped or elderly individuals who wish to rent housing in these federally financed projects can find out where such projects exist in their communities through the HUD area office.

2. Section 202

Housing Act of 1959 — As amended 1974

Public Law 93-383

Section 202 is a direct forty year loan to non-profit sponsors to finance construction or rehabilitation of projects for individuals who are elderly (62 years of age or older)

and/or handicapped. The sponsor is required to show how the needs of the tenants will be served.

In accompanying provisions, Section 8 subsidies can be used for minimum of 20 percent of all the units within the development. At the time of application, the sponsor may request 106(b) seed monies from HUD to cover preliminary planning costs.

Once the HUD area office issues invitations for applications, the sponsor can obtain an application package from the area office. The package is divided into the following three sections:

1. Project Development Requirements,
2. Submission Requirements for 202 and Fund Reservation, and
3. General Program Requirements and attachments.

These sections relate to the site, physical, legal and programmatic aspects of the development. The "Development Team" is also identified. This "team" is comprised of an architect, general contractor, attorney, consultant (optional) and, of course, the owner. One or more of the Development Team members should be well acquainted or have participated previously in the processing of a HUD application. The process is a long and tedious one that involves intricate paperwork. Someone who has gone through the steps before has a better understanding of HUD forms and has identified some of the key personnel at HUD. A copy of the Handbook is also a helpful guide.

The application will go through the following process:

1. Initial screening
2. Preliminary Evaluation
3. Technical Processing.

In each phase, the documents will be reviewed and approved by the various departments within HUD. If any deficiencies are identified, a certified letter is sent to the Borrower, they are then given ten working days from receipt of the letter to remedy the deficiencies. It is advantageous for the owner to establish a strong working relationship with the HUD staff to assist in the processing.

A minimum capital investment of one-half of one percent (.5 percent) of the total HUD approved loan is required in cash. This investment, which is not to exceed \$10,000, is to be paid by the initial closing date. The money will be placed in an escrow account and held for three years from the date of initial occupancy. After the three-year period, the funds may be used for operating expenses or deficits in the project.

B. New Construction Financing

The financing of housing, new construction renovation, purchase, or rental with private, state or federal agencies proceeds through a sequence of basic steps. The following sequence is used when applying for mortgage loans with HUD and is similar to the process used by state financing agencies.

Step One:

Ascertain feasibility of proposed plan. Visit or contact HUD or a state housing office to procure copies of all forms and requirements for making applications for funding. A formal appointment should be requested after the documents have been studied.

Step Two:

A pre-application conference provides opportunities for the sponsor to present to the governmental agency the nature of the proposed project. In turn, the sponsor receives details of the lender's requirements for specific programs. During the exploratory meeting, sponsors would want to assure the federal or state agency that

1. their proposed plan and number of units requested coincides with their local housing plan;
2. their organization is well established in the community and citizen and board member interest and expertise in housing development exist;
3. a market and need survey has been compiled to assure full occupancy and financial resources to maintain operating expenses;
4. site characteristics are understood; and
5. flexible planning and continuity of the sponsoring organization are identified.

Step Three:

Site Appraisal and Market Analysis (SAMA)

SAMA is the initial stage of the HUD multifamily processing system. During this stage, the sponsor submits an application (FHA Form 2013) requesting mortgage insurance. Included in this application are specifications of the project such as size, number of units and land value estimate, and exhibits such as location map, evidence of site control, transaction price, and request to determine non-profit sponsor eligibility.

Step Four:

Conditional Commitment Application

The issuance of a SAMA letter indicates HUD's initial acceptance of the proposal. At this juncture, the sponsor files for an application (FHA Form 2013) of a conditional commitment visa and approved mortgage. This application identifies the management and an affirmative marketing plan, operating in development expenses, the organization's personal, financial and credit statements and the owner-architect agreement.

Step Five:

Finalized Commitment Application

Application for a firm commitment is required again on FHA Form 2013. This application includes the final architectural drawings, with detailed specifications, cost breakdown and land survey. The issued mortgage loan transaction terms determined by HUD, are established through the firm commitment approval.

Step Six:

Initial Loan Closing

The initial loan closing requires an experienced lawyer and occurs after the firm commitment is made and prior to construction. This legal procedure allows for in-term financing, development advance loans, to defray pre-construction costs.

Step Seven:

Bidding

Bidding is required to assure a cost-plus factor and to avoid challenges or losses regarding personnel and conflict of interest. Bids are based on the plans and specifications of the project and must be accompanied by a bidder's financial statement, a bid bond and performance bond.

Step Eight:

Construction

Construction begins once the initial closing is completed with the awarding of the contract. Periodic inspections will be made by the lending institution's inspector. In the event that changes are needed, a request for change is submitted to HUD by the sponsors' attorney for approval.

Step Nine:

Final Loan Closing

Upon construction, completion and approval, a permanent mortgage loan is closed. After the legal procedure of closing, the loan is disbursed by the lender to the borrower, and repayment of the loan begins. The rent proceeds of the

development, if calculations are accurate, should cover installment payments (principal and interest), taxes, operational costs, etc.).

III Housing Assistance Payments PROGRAM

A. Section 8 Rental Subsidies

Housing Act of 1937 — Amended in 1974
Title II Section 201

Public Law 93-383

Subsidies are given on behalf of lower-income tenants directly to owners of private dwellings or through public housing agencies to make up the difference between Fair Market Rents (as determined by HUD) and the amount the tenant is required to pay. This amount is between fifteen to twenty-five percent, depending on their medical costs, of their annual adjusted income. These funds can also be used by the owner to keep the project operating and can be used with existing, newly constructed or substantially rehabilitated housing or in combination with state housing agency programs.

To apply for funds, individuals or housing sponsors interested in serving individuals whose income does not exceed 80 percent of the median income for the area can contact the area HUD office or the Public Housing agencies (e.g. County, Local Government Affairs). Individuals can apply for a Certificate of Participation. This contract will not exceed three years. With new construction, rehabilitation, etc., the owner can apply for allocation of subsidies with the construction fund reservation.

B. Start-Up Loans

1. Section 106

Housing Act of 1968
Public Law 90-448

Seed money to non-profit sponsors or public housing agencies to cover early planning expenses of developments to house the elderly, handicapped or lower income individuals.

At the discretion of the Secretary of HUD, Section 106 Direct Loan Program exists to provide seed money to defray cost incurred during the planning stage of a housing project. This non-interest loan is designed to allow all housing sponsors to obtain technical assistance relating to construction, rehabilitation and operation of low and moderate income housing. The interest-free loan is available to non-profit sponsors who have an approved fund reservation under Section 202. The loan cannot exceed \$50,000 and is limited to not more than 80 percent of the estimated preliminary cost. The borrower's share of the "seed money" must be put up in cash and cannot be paid in kind. The loan period cannot exceed a two-year term and the owner must spend its share of the money prior to receiving the federal funds.

Planning and pre-construction items may include the following:

1. Preliminary surveys and analysis of the housing market;
2. Preliminary site investigation;
3. Architectural fees for schematic drawings indicated site usability;
4. Land options or purchase;
5. Application and mortgage commitment fees;
6. Construction loan fees; or
7. Administrative overhead.

For further information, contact Ms. Ardyth Anderson Deming, Director of Planning, Ray Graham Institute, 141 Green Valley Drive, Lombard, Illinois 60148, 312 932-9040.

Workshop study results issued

In March of 1979, the U.S. Dept. of Labor (DOL) issued a Volume II of a major study of "Sheltered Workshops Study: Study of Handicapped Clients In Sheltered Workshops and Recommendations of The Secretary".

The study assumes that "sheltered workshops offer severely handicapped individuals an opportunity to reduce their level of social and economic dependence by providing them with rehabilitation services and a chance to work within their own productive capabilities."

The study shows that clients with developmental disabilities (mostly mental retardation, cerebral palsy, and neurological disorders) are the major population in these programs. Most clients had been disabled all their lives.

Mental Retardation represents 61 percent of all sheltered workshops (programs) and 75 percent of all work activities centers.

The typical client was a white, 25-year-old, mentally retarded male who had never married and who lived in a dependent type arrangement. He worked 20 hours a week at subcontract work in a work activity center at an hourly earning of \$0.43, a monthly earning of \$31.00 and supplemented by SSI. Total 1976 earnings of all sheltered programs was \$100-million in wages; these earnings increased 7 percent since 1968 compared to a 44 percent increase in the federal minimum wage rate.

Subcontract work, bench-assembly type, was predominant in 45 percent of the workshops, 2-3rds of the work activities center (WAC) and 1-5th of the training - evaluation programs. Salvage and renovation work was in 20 percent of the workshops but only 6 percent of other programs. Only 6 percent of all clients were involved in custodial work. Almost all clients in all programs do the same job; there is a lack of variety in work experience.

Twelve percent of the clients served annually were placed in competitive

employment; only 11 percent of these placed were not successful and returned to the sheltered environment.

The significant recommendations of the DOL were:

(1) DOL should change their regulations so that subcontracting to workshops can be considered a part of a company's affirmative action program.

(2) Workshops should be used for the training and employment of unemployed persons under the Public Service Employment Program and the possibility of broadening the population which could benefit from the workshop experience should be considered.

(3) A nationally coordinated program should be established to develop and expand industrial markets for workshops.

(4) The effectiveness of federal funds financing workshops, particularly VR and Title XX, should be evaluated.

(5) Workshops should be encouraged to provide or arrange for adult education or compensatory education and education agencies should be encouraged to assist workshops.

(6) The federal government should target financial assistance to workshops serving long-term clients. "This recommendation for funds, if enacted, would deal with the fact that great majority of workshop clients are not candidates for outside employment."

(7) A demonstration program to assist workshops to bid on contracts which might otherwise go to firms outside the U.S. should be developed.

(8) A series of pilot demonstration projects should be conducted nationwide to explore the feasibility of providing wage supplements for those handicapped workers in sheltered workshops who are unable to earn a minimum wage. Funding should be provided by the SSI program.

(9) Worker's Compensation and Old Age, Survivors, and Disability Insurance should be extended to all sheltered workshop client - employees.

No community fund benefits from deinstitutionalization, N.Y. Senate Task Force says

A major State Senate Minority Task Force study on the problems of deinstitutionalization of the mentally handicapped has found that the complaints of local agencies about the lack of financing assistance, poor follow-up care and confusing policies at both state and federal levels, in dealing with the special population, are real problems. Furthermore, the sharp decrease in the institutional population has not meant any reduction in the institutional budget, nor have the funds been shifted to community services.

One of the major findings of the Task Force was that an assumption made early that reduced in-patient populations would free more funds for local assistance programs has not yet proved to be correct.

The Senate Committee noted, that in a 14-year period in which there has been a sharp decline in institution populations, rates for remaining patients have soared from \$7. to \$60.20 per day of care.

From 1969 to 1977 alone, allocations for state institution operations more than doubled to \$670-million, while funding to local programs has barely kept up with the increase in inflation.

The Task Force recommended the state provide 100 percent funding for local programs but, in the light of the past legislative term, it has had to settle for a

bill extending state assumption of local government Social Security Increment matching funds costs for another year.

The report is extremely despondent in tone and we see no encouragement from the administration along the lines suggested.

Census opportunity missed once more

The 1980 Census Information Kit, a copy of which was sent to this office, again misses an opportunity to get information on the physically handicapped or mentally retarded and other handicapped in the country.

In a letter to Mr. James E. Gorman, the Census Promotion Office, Mr. Weingold wrote "In reviewing the questionnaire... I was simply amazed to see not a single question asked about the handicapped, physically or mentally; nor do we see questions on housing for the handicapped."

"I would think this would be a golden opportunity to set some handle on the number of physically handicapped; mentally retarded and developmentally

Open House at Albany Community Home



L to R — Frank Sheridan, President, Albany ARC; Ellie Pattison, State President (with house kitty); Terry Kennedy, Albany ARC Director of Comm. Residences; Henrietta Messier, Chairperson, State Comm. Residence Committee; Les Rivkin, Executive Director, Albany ARC.

(Photo by Teri Bordenave)

Rights violated by home over-regulation

In testimony on a Proposed Regulations, Part 686, "Operations of Community Residences" — on October 24th, 1979 in New York City, Joseph T. Weingold, Executive Director of the State Association protested Over Regulation of Group Homes and the Invasion of the Constitutional Rights of the Retarded to live wherever they please.

"What concerns this Association," he said, "as much as anything, is that the Office of Mental Retardation and Developmental Disabilities feels it necessary to promulgate a 52-page document for the purpose of 'Guiding' Community Providers in establishing and operating Community Residences for Mentally Retarded Persons."

In apparent confusion between a group home for a person discharged from an institution and a group home for persons never in institutions, the Regulations, in fact, put the power to decide whether a person stays, or does not stay, in a group home in the Office of OMR-DD through its DDSO. This is highly objectionable to the Association which takes the stand that the Board of Governors or the Directors of the Providing Agency should be the ones to decide on whether a person is in or out.

Many more details, including the invasion of the privacy and the confidentiality of the clients records, are concerned.

Perhaps one of the most objectionable parts of the Regulation is the mandate that there be a Neighborhood Advisory Committee. What is objected to is the mandate. This should be left up to the Agency because, in effect, a mandate for a Neighborhood Advisory Committee, with the powers given to it, is an invasion of the Rights of the Mentally Retarded to live wherever they please, as long as they are not harmful to themselves or others.

Finally, admitting for the sake of discussion that the Regulations are to better the operation of such group homes, no provision whatsoever is made for richer funding or even adequate funding, a defect that runs through all the proposals of OMR-DD.

Copies of the testimony may be obtained by writing to the New York State Office of the ARC.

Travel training booklet published

A very interesting pamphlet, designed to teach handicapped adolescents to travel independently (including the mentally retarded) on public transportation, has been put out by the New York City Board of Education, Division of Special Education and Pupil Personnel Services and the Bureau for Children with Retarded Mental Development.

Paraprofessional travel training instructors provide individual instruction to each student in the program. Skills such as street crossing, boarding and exiting buses and trains, and requesting assistance are part of the daily activities.

"For many," says the pamphlet, "this is the first opportunity they have had to make a decision." We think everyone should have a copy of this pamphlet to present to their own Boards of Education for possible use. Copies may be obtained from Travel Training for the Handicapped, 8310 — 21st Avenue, Brooklyn, New York 11214.

disabled there are in the country.

- "a) in institutions;
- b) in the community (by age groups);
- c) in education (special classes);
- d) in workshops;
- e) in group housing or other, etc., etc."

Another such opportunity will not come for at least ten years; and we would have hoped something would have been done about it this time out."

Mr. Weingold did receive a telephone call in response to this letter dated September 24th, in which the person was extremely sympathetic with our point of view but nothing, apparently, could be done.

Copies of this letter were sent to Senators Javits, Moynihan, Weicker, Jr., and Congressman Theodore S. Weiss.

HIDDEN WAR

Retarded housing civil rights issue

In response to complaints that Poughkeepsie was rejecting the mentally retarded in its housing program, The Full Citizenship Task Force of the President's Committee on Mental Retardation had a hearing in Poughkeepsie on September 26th.

Calling the de-institutionalization of the mentally ill the largest human tragedy "outside of the boat people", Weingold said that, with adequate programs, the mentally ill would not trouble local communities, but that no federal aid is being given for such programs. As a result, he said, this has rubbed off on the mentally retarded and resistance has grown to their intergration into the community.

"The mentally retarded have the right to live where they want," Weingold said. "This talk of proliferation leaves me cold."

Charles Weatherford, Executive Director of the Dutchess County Chapter of the Association, also complained about the required procedures for the selection of family home sites which has slowed down the selection process unnecessarily.

Only about eight persons, most of whom were affiliated with agencies for the retarded, spoke at the hearing, although the public was also invited.

Mrs. Margaret Tedone, Chairman of the meeting, said she would recommend a state-wide coordinating body to provide more communication between the various public and private bodies which serve the mentally handicapped.

We reprint here, in full, an article by Charles T. Weatherford, Jr., Executive Director, Dutchess County Chapter of the State Association appeared in the Poughkeepsie Journal, Sunday, October 7, 1979.

Calling the Padavan law for site selection unconstitutional, he wrote:

The Dutchess County Association for Retarded Children is presently seeking to open a residence for nine retarded children of Dutchess County at 215 Sheafe Road in the Town of Poughkeepsie.

I find it hard to believe the amount of uproar that is caused by this simple request.

Our laws have singled out the retarded and have made it necessary for them and the agencies serving them to request permission to move into a neighborhood. The same law does not apply to Catholic, blacks, or Zen Buddhist. Presumably they can move in wherever they please, but not the retarded.

The so-called Padavan law for site selection in this respect, I believe, is unconstitutional.

It is disheartening to sit and listen to members of the Sheafe Road community run down their own neighborhood, pointing that the traffic is horrendously dangerous, that the sewerage and drainage in that area is inadequate and fraught with problems, that the police have investigated shootings on the Trap Rock property adjoining the residence site.

As I sit and listen, I begin to wonder why in the world these people aren't packing their goods and moving away from such a dangerous and problem-ridden area. But somehow they want me to believe that these dangers and inconveniences apply only to the retarded.

The article, 'The War Against the Retarded,' in a recent issue of New York Magazine points out that the issue of residences for retarded makes a good political hay for the politicians.

The recent house burnings and beatings associated with the establishment of residences for the mentally retarded hark

back to the days of the Ku Klux Klan, but this time it is not blacks or Jews or American Indians, but the mentally retarded who are having their civil rights taken away from them.

There is not a single scrap of evidence that the mentally retarded are a danger to themselves or anyone else when living in a decent neighborhood where a community residence is erected. The properties are above average as far as their upkeep and looks are concerned.

Once the residence is established in a neighborhood, all of the fears and confusion slowly disappear, and the neighborhood battle standards are rolled up and stored away. Everything goes back to business as usual.

When I testified recently before the President's Full Citizenship Committee for the Mentally Retarded, which was holding hearings in Poughkeepsie, I was asked by one of the members if I thought a massive education campaign might help solve the problem.

I told him frankly that I would like to believe it would, but I am sorely afraid that what we are dealing with is the flames of fear, prejudice and anger, fanned by the political need for issues which will engender support at the polls.

We are fighting a civil rights battle, and education is not the way civil rights battles are won.

I only wish that every member of the community would turn and look deeply into his or her own soul, and honestly ask the question, 'Am I a part of the solution, or am I a part of the problem?'

Will there or will there not be community residences for the mentally retarded? Will the community accept them or will the community not accept them? Who is the community — next door neighbors? Does the Site Selection Law educate the community or merely give the opportunity to the know-nothings to organize?

Across our desks come clippings from all over the state indicating that the questions asked about are not being answered to the satisfaction of this Association.

The mentally retarded are being treated, in too many instances, as pawns to some kind of obscenity game that ignores their fundamental rights under the New York State Laws and the Federal Constitution to equal treatment in all matters including housing.

STATEWIDE REPORTS AGAINST GROUP HOMES

For example — in articles from the New York - Brooklyn Flatbush Life, "Midwood Residents Denounce Home For Retarded."

The article says "at a rowdy public hearing June 12, residents of Midwood bitterly denounced the plan to convert the four-family house on East Second Street into a home for ten mentally retarded adults. But even an hour before the audience stalked out en masse, John Borg, owner of the building at 1479 East Second Street, claimed he would not sell it because of his neighbors fierce objections."

From Dewitt, New York, "ARC Home Draws Protest" because Mary Alice Alexander in East Syracuse said that the new home would block her view: "I'd love to have these people as neighbors but I oppose the house."

From the Knickerbocker News in Albany, "Albany County Seeks to Block Hostel".

FBI probes threats on Staten Island

At least a dozen Staten Island residents have been questioned by the FBI in an ongoing investigation into selection of group home sites for the mentally retarded in the Community Board 2 area.

Federal investigators, acting under special orders from the Justice Department in Washington, have interviewed Islanders for several months to determine if the civil rights of the retarded were violated during the selection of group home sites, and if community residents opposed to certain sites knowingly tried to undermine placement efforts through threats, harassment and incidents of violence, sources said.

The FBI initially denied knowledge of the investigation and later refused to discuss the case.

Among those who have been interviewed by investigators, however, are several Community Board 2 members, officials involved with the selection of sites and community placement of the retarded, community residents and homeowners who attempted to sell their homes to the state for use as group homes.

Investigators began their probe in mid-August, the same time Community Board 2 was engaged in state hearings attempting to prove the board area was "oversaturated" with community-based care facilities.

It is not clear exactly how the FBI became involved in the issue. Sonia Braniff, chairman of the Borough Developmental Services Office said that

his office did not prompt the investigation, adding that the probe "is a surprise to me."

"It could very well be a violation of civil rights, in the sense that the retarded should have the freedom to live where they choose — the same basic right accorded to everyone," she explained.

The group homes are the result of a 1975 court order, the Willowbrook Consent Decree, which calls for residents of the Staten Island Developmental Center to be shifted into community-based facilities as a method of emptying large institutions.

At a public hearing in May attended by 600 people, the group home issue was hotly contested by dozens of homeowners. They said they opposed the sites because they were either located on busy streets, or too near schools, hospitals and other community-based facilities. Some homeowners feared their property values would decline.

In June, Board 2 overwhelmingly rejected five group home sites, but recently, Mental Retardation Commissioner James Introne ruled in favor of the locations.

In the six months between the board's public hearing and Introne's decision, the number of sites has been pared from five to two.

Three homeowners hastily withdrew plans to sell their homes to the state after they allegedly received threats to their lives and property. Several community board members were also repeatedly "pressured" into voting against the sites.

Burning issue continues

And again from Brooklyn, "Dispute heats up over Site of Home for Retarded in Sunset Park Community".

And, from Long Island, Garden City, Newsday — "Building to house Retarded is opposed in East Meadow".

Mr. Frank DeLuca questioned "whether the state has the right to invade tranquility of that community".

And from the Rochester Times Union, "Neighbors Fight Group Homes".

"Village Board Members Last Night reversed their earlier approval of a Main Street residence as the site for the Home of the Mentally Retarded Patients from Newark Developmental Center."

THERE IS ALSO SUCCESS

Of course there are successes as well, as in Manlius where the group home gained court support — when the court carefully distinguished between mentally ill and mentally retarded persons. And, of course, we fight back. For example, the State office of MR and DD has approved fundings for a hostel for retarded adults in Albany in spite of objections from the Albany County Board of Community Services.

And we would also like to report that Johnson City Village officials unanimously endorsed the location of a community residence within village limits which will shelter 8 to 10 mentally retarded persons. This will be run under the auspices of the Broome-Tioga Chapter.

Finally, we should like to summarize all this by quoting from the September 20th issue of the Herald Journal of Syracuse — "The pattern of rejection, then grudging acceptance, ultimately a thriving community interaction with retarded persons living in group homes will be repeated again and again — as long as the need for such homes exist and we try to meet the need."

In Manlius, Onondaga County, where the Association for the Retarded sought to

build a residence for retarded adults, opposition was limited to a vocal well-organized minority whose commitment to block the proposal included bringing suit against the village and ARC when all else failed.

"In state supreme court, the suit failed as Justice William R. Roy ruled the opponents of the home had not proven a variety of charges and assertions that the village board's decision to approve the home was arbitrary and capricious".

Residents of Baldwinsville, also in Onondaga County, many of whom took part in an emotion packed meeting, should heed the experience of those in Manlius who sought to block the home there.

Jefferson leaves

United Fund

The Jefferson County Chapter has offered to withdraw its request for funding from the Jefferson County United Fund.

And the United Fund Board of Directors accepted the offer calling it "a magnanimous gesture."

The move was taken by the ARC board of Directors in an "effort to help (the United Fund) provide for its member agencies."

The United Fund gave \$5,000 to the ARC for this year for what a statement called "needed programs and services." The ARC will seek "alternate sources" for the funding.

The United Fund provides money to 21 member agencies, with a total budget of over \$338,000 last year.

Ronald G. King, president of the United Fund Board, said the ARC is "sympathetic with the financial requirements of member agencies and this unprecedented action is most appreciated."

The association will seek other replacement funds.

Caveats on community operated facilities

The thrust to provide better services for profoundly and severely retarded persons with emotional difficulties or physical problems has received considerable impetus from the availability of some federal money through the mechanism of Intermediate Care Facilities — Mental Retardation.

An Intermediate Care Facility originally was something less than a skilled nursing home but still eligible for Medicaid funding. The addition of Mental Retardation, in effect, originally was to enable the State institutions, by changing the physical plants and programs to qualify for these federal monies otherwise not available to them.

The program of de-institutionalizing, even those who are severely and profoundly retarded, poses considerable problems in the funding because of the different kind of staffing involved and the source of such funding. Hence, the movement on the part of the state to create Intermediate Care Facilities for the mentally retarded in the community and of course, when this happens, the community agencies are involved.

There are a number of questions that still have to be resolved before this becomes clear-cut. For example, will the community agencies be forced into these programs, whether or not appropriate, because the state is not funding what we now know as group homes at an adequate rate; is the community agency ready and able to give the best kind of services to this population which is probably more fitted for a medical than a developmental model? There are many others, of course, but here we list some of the caveats as brought out by surveys in this field.

(1) Medicaid eligible determinations play an important role.

(2) Who sets the rate is critical. In this state, the rate will be set by OMR-DD, but only with the consent of the division of the budget.

(3) What items are in or out of the rate are critical, e.g. day services, surgeries, etc.

(4) Cost controls through audits by defining the difference between "reasonable" and "allowable" costs.

(5) The federal level thrust has been to hold control over the provider by disallowances regarding client eligibility (utilization controls).

OMR combats patient abuse

The state Mental Retardation Office is doubling its confidential investigators to combat patient abuse and improve security in the state's 20 developmental centers for the retarded.

Last year, the Legislature authorized the hiring of eight investigators, but only half the positions have been filled. Now the agency is reviewing resumes to fill the vacancies, an office spokesman said.

Four of the investigators will be based in Albany, and the others will work out of New York City at salaries of \$13,100 to \$15,500.

They will report directly to the Commissioner of Mental Retardation and Developmental Disabilities.

A full complement of investigators is expected to provide Mental Retardation with better ability to safeguard the 14,500 retarded residents of state-run institutions. The developmental centers already have their own staff of safety and security officers.

The confidential investigators, generally former policemen with investigative experience, will work on such problems as a pattern of reported patient abuse or a rash of robberies or break-ins at a particular institution.

(6) Professional Standard Review Organizations (PSRO's) have potential "stop-payment" power.

(7) Independent professional reviews (annual) and utilization reviews (every 6 months internal — every 6 months external) have proved cumbersome.

(8) Local H.S.A. has the right to approve the certificate of need for each ICF proposed.

(9) Finally, institutional specifications regarding life safety requirements are absolutely required for non-ambulatory residents. This may eliminate the group home from the umbrella of the Site Selection Law and make it ineligible under single occupancy zoning laws. In effect, this would probably eliminate most of these as single family utilization houses.

Recently, under a day-treatment program, one of the Chapters of the State Association, which in good conscience provided services for a certain number of persons in a day-treatment program is running the risk of having 40 percent of the clients declared Medicaid ineligible. The charge-back may well ruin the Chapter.

What is most disturbing, in addition to the items listed, is the fact that many of the community agencies may be tempted to go into this program because they cannot receive adequate funding for group homes as we know them and which are, in effect, not ICF-MR's.

Family care community moves limited

In a memorandum dated June 5, 1979, the then commissioner of OMR-DD, Tom Coughlin, issued a directive "effective immediately, no placement from a family-care home to a community residence will be permitted without the written permission of Fred F. Finn, Deputy Commissioner of Program Operations."

In a memorandum issued by Associate Commissioner, Zygmund Slezak, the statement is made that the movement from family-care to group homes does not adhere to the principle of placing clients in the least restrictive setting.

He assumes, in this memorandum, that the movement from family-care to group homes is an "inappropriate movement of clients."

In a sharp criticism of this, Marc Brandt, Executive Director of Sullivan County Chapter, ascribed this memorandum to the growing strength of the family-care providers in the Family-Care Association. He writes, "In fact, the Family-Care Association in our County (Sullivan) is not controlled or monitored by the State, it is the reverse."

He believes that Mr. Coughlin's memorandum was being sent out not because many individuals in family-care were requesting to move into the hostels where "better treatment and less restrictions are usually taking place." — but, because of the tremendous placement goals in the Southeastern Region, many additional family care homes are being certified and are planning to open. The movement into hostels, of course, is a threat to the family care provider, perhaps influenced the Commissioner's directive.

If we are to speak of the free-will of the client, it should not be necessary to have the written consent of the Assistant Commissioner for movement from one community facility to another, especially when such movement is not for the financial benefit of the groups running the group homes.



Mr. Mannie Barsky of the Willowbrook Chapter of the Benevolent Society For Retarded Children helps Ronald Campbell cut the ribbon to officially open the Richmond Hills Vita Course.

Fitness course opens at Richmond Hills

WILLOWBROOK CHAPTER FUNDS THE PROGRAM

A well thought out exercise program is an essential part of the blueprint for achieving and maintaining good physical health. Clients, staff and community members can now find such a program on Staten Island Developmental Center's grounds.

On Saturday, August 18th, two outdoor structured exercise trails, one designed specifically for those confined to wheelchairs, were dedicated at a ceremony held across the street from Building No. 61. Ellen Forman, the project's coordinator, S.I.D.C. director, Elin Howe, Genevieve Camen and Mannie Barsky of the Willowbrook Chapter of the Benevolent Society for Retarded Children participated in the ribbon cutting. The society donated the funds for the course.

The trails are called the Richmond Hills

Vita Course. The approximately 1 3/4 mile ambulatory trail and the shorter wheelchair trail are marked paths that follow natural terrain and are equipped with exercise stations. By following the course and carrying out the exercises posted at each station, the participant gets a complete workout. Progression along the trail is done at one's own pace and instructions for the number of repetitions take into account whether one is a novice or experienced exerciser.

The ambulatory or jogging trail has twenty stations. Calisthenics are performed at ten of the stations and equipment such as rings or parallel bars are utilized at the other ten. The wheelchair course has nine stations.

The Richmond Hills Vita Course will be open for use by clients, staff members and the community during daylight hours seven days a week.

It's not retarded who pose problems

This letter is reprinted from the "Letters to the Editor" in the Syracuse Post-Standard:

Dear Neighbors:

In a recent newspaper article concerning the plan to set up a residence for mentally retarded adults in the village of Camillus, it was noted that the home in question is "across the street from the library." Although I cannot speak for the library trustees, I do not want it to be inferred that, as the director of the library, I am antagonistic to the proposal.

Comparatively speaking, the library has had very little vandalism. There has been, however, abuse of library books and facilities by ostensibly "normal" adults and juveniles, which I do not believe would be done by retarded persons.

In addition, it does not seem to me that such persons would commit the acts of malicious vandalism from which I, as a village resident, have suffered. In less than a year, three side-view mirrors were ripped off my car and smashed on the road in front of my house. In the same period,

the latch on the door of my car was deliberately broken.

As for the "fear" of mentally retarded adults which some village people have expressed, they should be far more disturbed by the discourtesy and foul language of groups of young people who seem to have nothing more constructive to do than hang around the streets.

There is also talk of depreciation of property values because of this particular proposal. From my front sidewalk I can see three properties that have already caused much more depreciation in the neighborhood than I can conceive from the establishment of a home for mentally retarded adults.

In conclusion, unless one has a little crystal ball, it is very difficult to foretell the future. As far as I am concerned, however, I cannot imagine that establishing a home for mentally retarded adults in the village of Camillus will create problems that are remotely as serious and undesirable as some that already exist.

Nina L. Edwards

CHAPTER NEWS *What our chapters*



Erie County Chapter members listen to a candidate at Chapter Headquarters, 470 Franklin Street, Buffalo, September 6, 1979.

As the snow swirls around most of you as you read this issue of OCV, it probably will be hard to remember back to summer. However, we just recently received a full-page newspaper clipping pointing out that **ESSEX COUNTY CHAPTER** held their fourth Annual Picnic at their Maple Knoll Community Residence back in July. Over 200 people attended the event. I don't remember the last time a picnic got a full-page in a newspaper, but it looks like it was such a good one that it certainly deserved it. . . Little **LEWIS COUNTY CHAPTER** got a plug from their local Heart Association because, according to the article we read, Lewis County Chapter was going to be a good neighbor to the heart fund and raise money for them through Bowl-A-Thons, walks, relays, and other activities. Hope they do so well for themselves. . . **ONTARIO COUNTY CHAPTER** sponsored an Open House, October 13th at their training center and community residence. Understand they had quite a turn-out and that it was a most successful event. We always like to thank people for donations and wonder who it was that made the contribution to Ontario County Chapter which they indicated was from the Geneva Appleknockers, Inc. . .

RENSSELAER COUNTY CHAPTER'S newsletter had good news as you looked back at their last two issues. The Spring 1979 newsletter had a headline that their capital drive had reached 46 percent of its goal, and the Fall issue that they had reached 70 percent. I can hardly wait for the next issue which I hope will say, 150 percent. . . Incidentally, the chapter's last Swim-A-Thon raised \$19,200. Nice work Rensselaer. . . **ULSTER COUNTY CHAPTER** managing to keep busy. Among their activities, the 18th consecutive year that the Blanche Moak School of Dance has held an evening of dance on behalf of the chapter for which we thank them. Raised just over \$900 this year. . . On Sunday, October 30th, the **ALBANY COUNTY CHAPTER** held an Open House for its first community residence. Three unique features of this opening were: There was absolutely no opposition from the neighborhood but rather, full support. The eight adult residents are all profoundly retarded, a first for the community. This residence is supplemented by a 620 Outreach Program to insure that each client receives proper services in spite of the normally limited funding available through the 4403 mechanism. . . **CHENANGO COUNTY CHAPTER** had a big Open House Chicken Barbecue on September 8th. Why do we always get notice of those delicious events after the fact? . . . **FRANKLIN COUNTY**

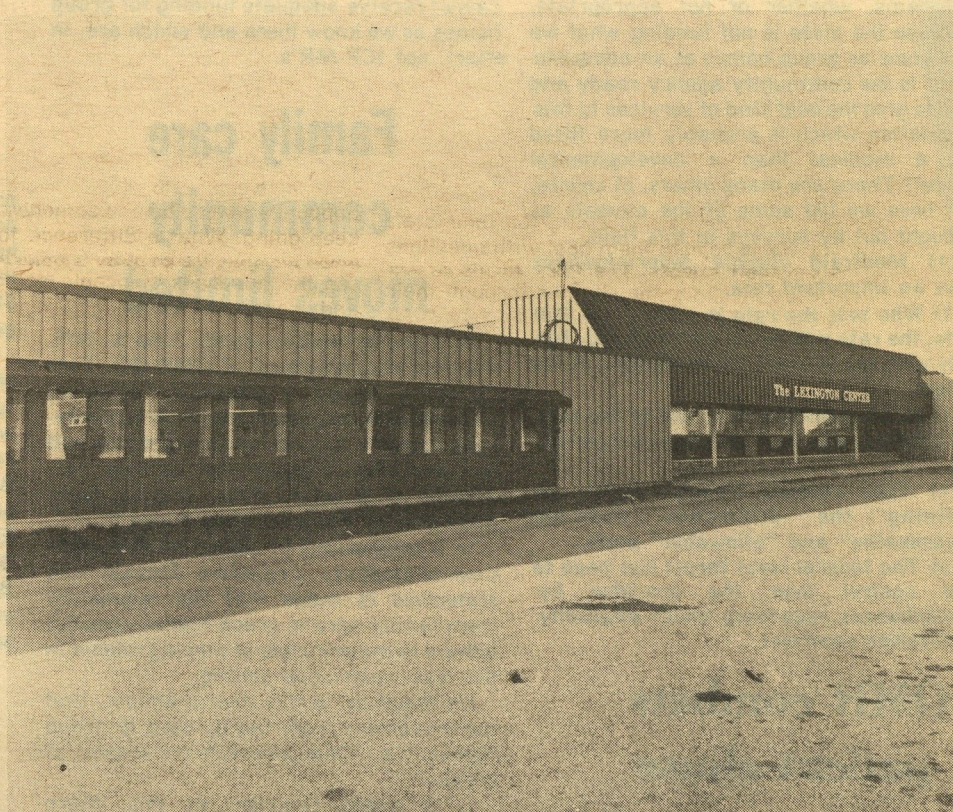
CHAPTER writes to say that they have begun a program of expansion which will enhance its currently existing programs. Along with the recent opening of its third community residence, located in Saranac Lake, the chapter has also received two new grants. From the Developmental Disabilities Assistance Act comes a grant which will triple the size of the currently existing Adult Socialization and Recreation Program. Another grant from the Disabled Children's Program will provide needed ancillary services for their developmentally disabled pre-schoolers. Together, the two grants bring an additional \$75,000 of federal monies to Franklin County. . . **MONROE COUNTY CHAPTER** has officially replaced Executive Director John Regan with his former associate, James Mroczek. An excellent choice in our opinion, and we welcome Jim as "Official Executive Director". Thanks to Monroe for the reprint of several of our book reviews in their excellent newsletter *Monarc*. . . **ONONDAGA COUNTY CHAPTER** looking for good ways to fund-raise, operating a Monte Carlo Night. The highlights are a buffet, beer, a 50-50 raffle, prizes and plenty of games. Looks like a good time to us. . . **ST. LAWRENCE COUNTY**



Woodshop Worker, Paul Lucas, presented an engraved tent stake to Congressman Donald Mitchell, during the Congressman's visit to Oneida County ARC in August, 1979.

CHAPTER very excited about proceeding with a new community residence under the Site Selection Law in Massena, N.Y. Hope it goes more smoothly than it has for some of their sister chapters. . . Speaking of community residences, **STEBEN COUNTY CHAPTER** recently obtained a former convent in Wayland, N.Y. and have begun renovations on this for yet another community residence. . . Thanks to the Broome County Department of Parks and Recreation, who offered a winning program for physically disabled and mentally retarded individuals this Fall. We appreciate that kind of cooperation and we are sure that **BROOME-TIOGA CHAPTER** did too. . . Delighted to see the ad in **CLINTON COUNTY CHAPTER'S** newsletter about their new Greenhouse. Wasn't sure that plants would grow in that cold region, but obviously the chapter knows what it's doing. . . **DUTCHESS COUNTY CHAPTER** sponsored a booth at their County Fair, as do so many of our chapters and used it as an opportunity to promote our ARC Holiday Greeting Cards. Made us very glad that they had chosen to do so. . . Hard to believe, it is the 7th Annual Swim-A-Thon coming up in **HERKIMER COUNTY**, but it is and fund-

CAYUGA COUNTY writes to say that they will soon be offering Day Treatment and Sub Chapter A programs for severely and profoundly retarded adults. Having acquired an ideal facility located in a fashionable section of Auburn, the chapter hopes to deliver services in January, 1980. Contractual agreements have been completed with the Office of MR-DD. Subsequent to the necessary renovations being completed, 35 initial program enrollees will receive services. The structure pictured offers 3,000 square feet of program space on each of 3 levels. In addition to its accessibility to non-ambulatory clients, the structure is equipped with an outdoor-indoor elevator which provides easy access to all program areas. Additionally, the structure is fire-proof; constructed of poured concrete 2½ feet thick in walls and flooring. Concurrently, the chapter, through its holding corporation, recently acquired property adjacent to its main facility for expansion purposes. It intends to raze the existing structure and erect a 12,000 sq. feet standing facility on 1.3 acres of land in order to provide services for more than 75 new clients. The chapter has applied to



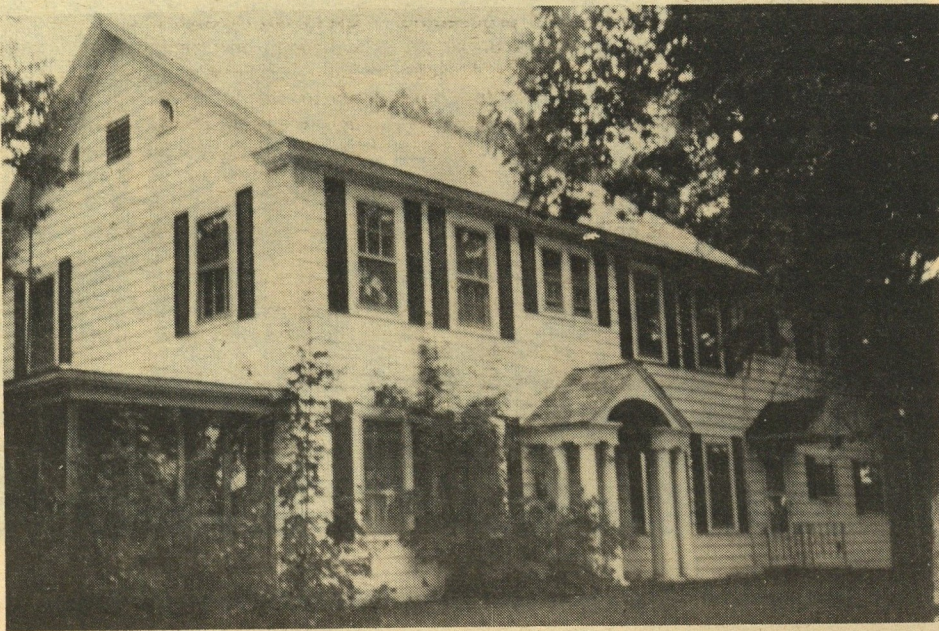
Fulton County ARC's Rehabilitation Center and Sheltered Workshop — The Lexington Center, to which 10,000 additional square feet will be added.

raising Chairwoman, Judy Sprague will, no doubt, come up with another super effort. . . Thanks to the Herkimer County Council of VFW, for their first Annual Old Fashioned Picnic and Chicken Barbecue which they held for the benefit of **ROME D.C.** . . Speaking of donors, we want to thank the Congressman, from the Utica area, Congressman Donald Mitchell for his gift of a flag to the **ONEIDA COUNTY CHAPTER'S** workshop. Some pictures of this very successful event are included here in Chapter News. . . We are delighted to note in **SCHENECTADY COUNTY CHAPTER'S** newsletter that Kirk Lewis has joined the staff in the community residential services. Kirk is a former President of the State Youth Organization, always a very active and interested Youth member and we know that his enthusiasm will do nothing but good within Schenectady Co. Chapter. Interested also to see that Schenectady is speaking about opening their fourth community residence. . . Residences, residences everywhere, together with other program expansions.

both the N.Y.S. Office of MR-DD and the N.Y.S. OVR for the necessary funding. . . Very interesting evening was held by **ERIE COUNTY CHAPTER** recently. On September 6th, the chapter's membership turned out 400 strong to hear candidates for local public offices speak to issues during Candidates Night at the chapter's headquarters. Board of Directors member, Charles Kerrigan served as Master of Ceremonies and kept the evening moving with quips and comments as he introduced each of the candidates to the interested crowd. Many of those in attendance took advantage of the refreshments provided by the Membership Committee to meet informally with the candidates at a social hour which extended past mid-night. . .

JEFFERSON COUNTY CHAPTER held their 25th Anniversary celebration this summer. Fantastic Anniversary Booklet. Sorry we had to miss the occasion. . . Who can keep up with **NASSAU COUNTY CHAPTER**? Just the clippings alone could write a whole column, but to mention a few

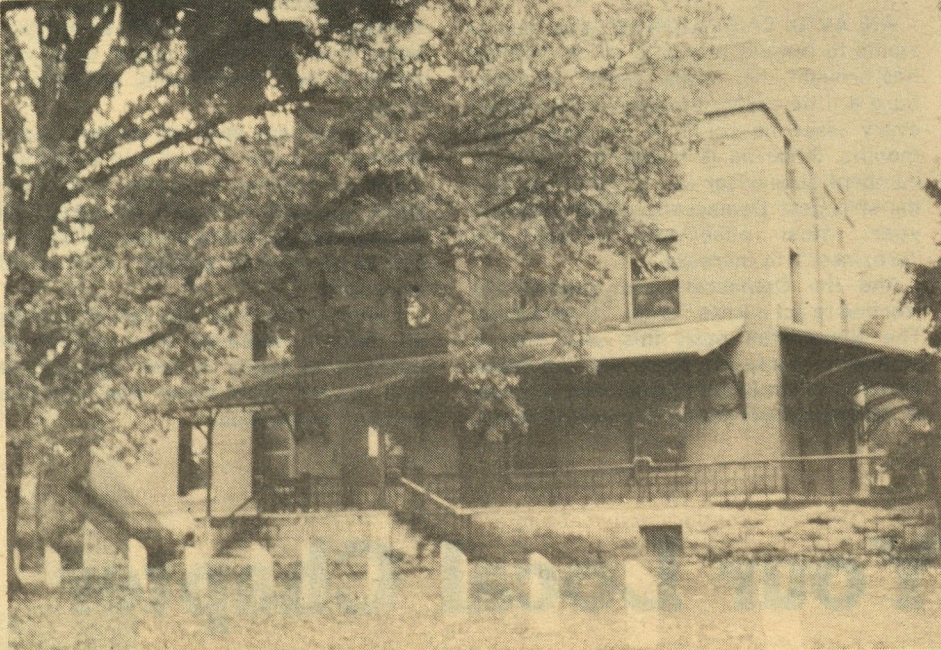
are doing and saying for our children and adults



Albany County Chapter's first community residence at 1457 Western Avenue.

things. Thanks to the students at St. Alden's School who raised \$1500 on their Teen Drive; thanks to the Nassau County PBA who held a picnic for our children during the summer; a horse show was held this summer with a family fun crafts and games area as a side, which also was a good fund-raiser for the chapter; and of course, the Annual Dinner was, as always, a spectacular with Senator Norman J. Levy the recipient of this year's Humanitarian Award. . . . **ORANGE COUNTY CHAPTER** held an interesting forum on death and dying for their staff members to help them deal with questions from their clients. The Port Jervis group raised \$1500 for the chapter through their Swim-A-Thon. . . . **CHAUTAUQUA COUNTY** had a big Founders Day celebration this past summer. . . . Ever expanding, **FULTON COUNTY** sends us this information. Contracts for construction of a 10,000 sq. foot addition to the Fulton Co. ARC's Lexington Center were awarded by the Fulton County Board of Supervisors on October 8th, 1979. The center currently has 28,000 sq. feet. Lexington Center houses the Fulton Co.'s Vocational Rehabilitation Program and Sheltered Workshop. Currently over 240 clients with varying disabilities attend the Lexington Center. The new addition will enable the center to serve up to an additional 50 clients. With the new addition, the center will upgrade and expand its Evaluation Area. A more suitable Activities Center for severely retarded clients will be provided, as will classroom space and individual tutoring areas for the center's Educational Program. — Over 200

people attended the Fulton Co. Chapter's Annual Auction and Bake Sale, which was held on October 6th. This event netted over \$1,600 — Also, the Fulton Co. Chapter's Lexington Tennis Tournament had 50 participants and raised \$200. . . . This next one is called, You Know We're Growing When — I remember my first visit to **MONTGOMERY COUNTY CHAPTER**, when I really was sent to simply throw dirt in the grave of what was thought to be a dead organization. Thanks to a few hard-working people who didn't want to let it happen, we were able to somehow or other keep going. What a difference today and when we open the chapter's newsletter and see the hundreds of people being served and read almost a full-page in the newsletter covering who's who at the ARC with their officers, directors and staff being listed. That's a success story, any day. . . . Astoria Federal Savings and Loan Assn. was presented with plaques from **NEW YORK CITY CHAPTER AHRC** for their 1978-79 Christmas - Chanukah Club Campaign for which the AHRC workshop made special candles and Astoria Federal gave them out with the opening of club accounts. This help, very much appreciated. . . . **NIAGARA COUNTY** celebrated their 12th Annual Award Dinner last summer. Almost 300 people participated in the event at which some 36 deserving people received awards from the chapter. . . . **SUFFOLK COUNTY CHAPTER** bubbling over the Governor's visit to their facility in Behemia, N.Y. If he were going to visit anywhere, Suffolk would be a great place to begin, and with that we bring this issue to an end.



Cayuga County's new Day Treatment addition.

Chautauqua Founders Day

What was begun by the Chautauqua County Medical Auxiliary as a program for 6 young adults whose educational needs were not being met by the public schools now provides services for over 500 adults and children. Recently, approximately 75 officials, guests and friends of the Chautauqua County Chapter, New York State Association for Retarded Children, Inc. gathered to celebrate the 20th Anniversary of the founding of the organization. Tours of the ARC were conducted with an outline of the various services provided. Many of the original founders of the ARC were present at the Dinner and all marvelled at the progress the ARC has made in the last 20 years.

Guest speaker, Dr. Richard Merges, Associate Commissioner of the Office of MR-DD, attributed the success of the agency to the energy and enthusiasm of

Executive Director, Michael Raymond, the cooperation of the Board of Directors and the hard work of the ARC staff, "in making the Chautauqua County ARC the largest agency in Western New York which provides services to the developmentally disabled."

Michael J. Raymond traced the history of the ARC from its inception in 1959 to the present. ARC Board President, Elmer Muench, served as toastmaster. Co-Chairmen, Frederick Hitchcock and Wilbur Dennison thanked the entire Dinner Committee consisting of Freda Eddy, Mary Andrews, Eva Pryde, Virginia Rugg, Lois Gibbs, Betty West, Geraldine Homokay, Walt Gifford, Lucy Zoladz and Cicelia Fisher. They also thanked Nutritionist Carmen Taylor and Cooks Phyllis Allen, Yvonne Leach as well as the other ARC staff who helped prepare and serve the dinner.



The 20th anniversary of the founding of the Chautauqua County Chapter, New York State Association for Retarded Children was celebrated at a dinner recently. From left to right are Dr. Richard Merges, associate commissioner of the office of Mental Retardation and Developmental Disabilities, guest speaker at the dinner; Geraldine Homokay, one of the first founders and member of the Chautauqua County Medical Auxiliary; Michael J. Raymond, executive director of the ARC; Fred Hitchcock, co-chairman of dinner; and Elmer Muench, ARC president. Wilbur Dennison, co-chairman was not present when photo was taken.

Chapters win \$300,00 in Fed transit grants

State transportation Commissioner William C. Hennessy recently announced grants totaling \$1,825,311 in federal funds to 51 private non-profit organizations in the latest federal program to provide transportation for the handicapped.

Six chapters of the ARC have received such grants. They are Herkimer County Chapter, \$45,780 for the purchase of two 20-passenger buses both with wheelchair lifts; Montgomery County Chapter, \$64,680 for two 12-passenger vans and two 20-passenger buses with wheelchair lifts; Fulton County Chapter with \$25,746 for the purchase of a 20-passenger bus with a wheelchair lift; Lewis County Chapter, \$50,862 for two 30-passenger buses, one equipped with a wheelchair lift and one with a two-way radio; Ulster County Chapter, \$49,287 for two 20-passenger buses, one equipped with a wheelchair lift; and Dutchess County Chapter, \$25,746 for one 20-passenger bus with a wheelchair lift.

The funds represent 80 percent of the cost of these vehicles, the other 20 percent put up by the chapters.

This is in addition to the 20 some odd buses obtained through the NYS Association Grant last year and the year before.

ARC pioneers die

We note, with sorrow, the passing of three of the pioneers in the retarded children's movement in this state. They are Ann Gitter of the New York City Chapter, Sidney Finck of the Welfare League, Letchworth Village Chapter and Dominick Manieri, Vice President and Member of the Board of Schenectady County ARC Chapter. All of these were known personally to many of us and will be missed in a movement that surely needs dedicated people.

Services Unlimited

Expansion means 125 jobs

One of the largest industrial employers in the Bath area is planning an expansion that will more than double the size of its work force and will mean over 125 new jobs for county residents.

The firm is Services Unlimited — a sheltered workshop for mentally retarded and developmentally disabled adults.

But the expansion of the Services program cannot be strictly regarded as just another human services project because of its economic impact.

FUNDING FROM STATE AND FEDERAL SOURCES

Joan Mayer, executive director of Steuben County Association for the Retarded, explained funding for the expansion project would come from several state and federal sources, and like other business expansions that will benefit the area economy, will be eligible for a grant through the Appalachian Regional Commission.

The federal grant application is being handled by the Steuben County industrial development agency, Corning Crossroads, Inc.

If the grants sought are approved, it would enable Services to build a 5,000 square foot, barrier-free industrial structure in the Bath Industrial Park, at a projected cost of \$1.5 million.

CENTRAL LOCATION IS PERFECT

Ms. Mayer said as Bath is the perfect location, central to the entire county, the industrial park appears to be an excellent site. Vacant existing structures have been reviewed, she said, and none appear to be suitable for the industrial nature of the workshop.

At present, Services employs about 85 retarded or disabled workers, and about 35 staff members. For the past year it has operated out of the former A & P market building on Liberty Street in Bath.

"What we do is enable people to function as independently as possible, using work as a medium," Ms. Mayer said. Workers, paid on the basis of their productivity, do silk screening, printing, woodworking, collating of materials, and also make upholstery and fabric display books.

"Another important part of what we do is advocating the rights of people who have been labeled 'retarded', or 'developmentally disabled' . . . we attempt to change attitudes," the director said, adding this often means a change on the part of the public as well as in the worker himself.

COUNSELING AND JOB PLACEMENT INCLUDED

Included in the special services provided to the workers is counseling and job placement. "If they become really competitively employable, then we ought to be placing them out elsewhere," Ms. Mayer said, noting Services placement staff has enjoyed success in placing former clients in jobs at the Corning Glass Works and at the Westinghouse plant in Bath.

The building Services rents on Liberty Street would be utilized for a program to get more seriously retarded persons ready to work in the main plant.

The grant applications for the program have won approval of local planning agencies, including the Southern Tier Central Regional Planning and Development Board A-95 review committee and the Finger Lakes Health Systems Agency.

FUNDS SLATED FOR APPROVAL

Ms. Mayer hopes the applications for funding will be approved on the state and federal level, but she cautioned against undue optimism. "It did receive a high priority in the A-95 review, though," she said.

Other funding sources may include a loan from the Small Business Administration, and grants from several other agencies.

"It's exciting that it is being pushed as an economical development for the county . . . because that's just what it is," the director said.

President Carter has signed into law legislation that would permit certain blind and disabled residents of small group living arrangements to participate in the Food Stamp Program.

The new provisions are part of the Food Stamp Amendments of 1979 (P.L. 96-58), an emergency measure to increase the program's spending ceiling and relax certain restrictions on shelter and medical expense deductions set forth in the 1977 amendments to the Act (P.L. 95-113). P.L. 96-58 authorizes food stamps for residents of community facilities, by defining as eligible households:

Disabled or blind recipients of benefits under Title II or Title XVI of the Social Security Act who are resident in a public or private non-profit group living arrangement that is certified by the appropriate state agency or agencies under regulations issued under Section 1615(e) of the Social Security Act, which serves no more than 16 residents.

Under the new Act, blind and disabled persons are eligible on the same basis as elderly persons and alcoholics and drug abusers who are in active treatment programs. All state agencies administering food stamp benefits will be required to implement the new provisions affecting the blind and disabled by July 1, 1980.

Each otherwise eligible blind or disabled person will be treated as an individual household for purposes of determining his eligibility and monthly coupon allotment. In addition to amending the statutory definition of the term "Household", P.L. 96-58 also redefines the term "Food", to mean meals served in small group living arrangements, and "Retail Food Store", to include group living arrangement. This allows some flexibility in the method of administering Food Stamp benefits.

Passage of P.L. 96-58 culminates two and a half years of effort by the Association to gain an exemption from the definition of "institution" for small community residences serving mentally retarded - developmentally disabled persons. Under the Food Stamp Act, residents of institutions who receive meals from the facility are not eligible for benefits. MR-DD Program Directors from the states of New York, Virginia and Vermont played a key role in negotiations with the Department of Agriculture and in the development and passage of the legislation. The amendments were added to a substitute version of the bill in the Senate, upon the request of Senator Robert Stafford (R-VT) and Robert Dole (R-Kansas). Senator George McGovern (D-SD), Chairman of the Senate Committee on Agriculture, lent his support to the amendment as well.

Later, the provisions were included in a final version of the bill reported out by a joint House-Senate conference committee on July 26. The measure was signed into law by the President on August 14.

Once implemented, these amendments should provide Food Stamp coupons, with a value of between \$10 and \$20 per month, to eligible group home residents.

Lest we forget



Remember the rally of concerned citizens for OVR funds? We must do it again.

Sanity (M.R.) in a "crazy time"

This column is reprinted from the Buffalo Courier - Express in pre-election August. It is by Patrick J. Ryan, Courier - Express Staff Reporter.

THERE IS, it seems, a bright spark of sanity burning amidst the darkness of the "crazy times" in Hamburg.

Former Buffalo Mayor Stanley M. Makowski, a man not really known for his glibness, coined that most apt phrase to describe the time leading up to an election.

"See me after the crazy time ends," he would say if you asked him a question about something he considered important. Just before an election was not the time to talk of important things, because everything around had gone crazy.

AND BY ALL the signs, Hamburg has been thrown into a deep dark pit of crazy times.

It's really kind of understandable. The town was a purely Republican preserve until about 1970. There was a time when Democrats moving into the Village of Hamburg, the one-time seat of power in the town, were advised not to let their neighbors know their political persuasion.

That has all changed in the past nine years. The Democrats have knocked over just about every elected office in town, leaving only two in Republican hands.

Last November there was a sign of a possible comeback when Frank J. Warnes shattered an all-Democrat town board by winning one year of an unexpired term from an appointed Democrat.

AN AVID CAMPAIGNER who clearly wants to remain in public office, Warnes has brought the "crazy times" to Hamburg a little early, jumping on just about every issue he could in the past eight months. Since he is trying to unseat incumbent Supervisor Leo J. Fallon, one of the strongest Democratic candidates this year, most observers expect the "craziness" to increase.

And the Democrats are undoubtedly starting to act a little "crazy" themselves. The Republican push this year has a number of party members worried about the three town boards seats, and controls of the board, that are on this year's ballot.

And into the midst of all this craziness walks the Association for **Retarded Children** (ARC) with the announced intention of opening a group home for retarded adults in the town.

IT WAS UNCONCEIVABLE that the issue would not become political in these crazy times.

A group of Clark Street residents had gotten wind of the fact that one of the proposed sites for the group home was in their area.

Irate Clark Street residents were not a new experience to the board, having faced them several years ago over the proposed widening of their street. Nor were the objections to the group home they raised new, since they echoed the opposition voiced about the group home proposal in whatever community they surface.

There was no one at Thursday's special board meeting to point out that existing homes have not lowered property values or the quality of life in other neighborhoods. But there was a lawyer, hired by the residents, threatening the board with "mushrooming opposition" that would "fill the room" with voters opposed to the group home.

THE GROUP CALLED on the board to take action to block the home, since their neighborhood was not "right" for such a facility. The board they said, should pick an alternate site that would be "much more appropriate."

"The question here seems to be whether the board should pick a site or act on the belief that the ARC is better qualified to select a site," Fallon said, alienating the group.

It would have been the perfect time for Warnes to jump in and win a couple of votes by making a motion to block the home. He didn't. In fact he agreed with Fallon that the board should not allow the site to be "kicked around" until no sites were left.

Fallon, Warnes and the rest of the board all deserve applause from anyone who appreciates sanity in this "crazy time." And maybe from those who appreciate human compassion.

Support Your Local Chapter



What made the Convention work — the Registration Desk. L to R, Mikki Lieberman, Ann Hutchings, Sandra Green and Lena Marcil.



An animated group with Commissioner James E. Introne — L to R — Jerry Weingold, Bob Knorr, Schenectady Chapter, Mrs. Introne and the Commissioner.



A relaxed moment with Jonnie Weingold ogling the photographer.



Larry Abrams swearing in Ellie Pattison as President. Looking on L to R — Mrs. Introne, Senior Vice President Hy Clurfeld.



Two former Presidents laughing it up — Bob Hodgson and Elliot Aronin.

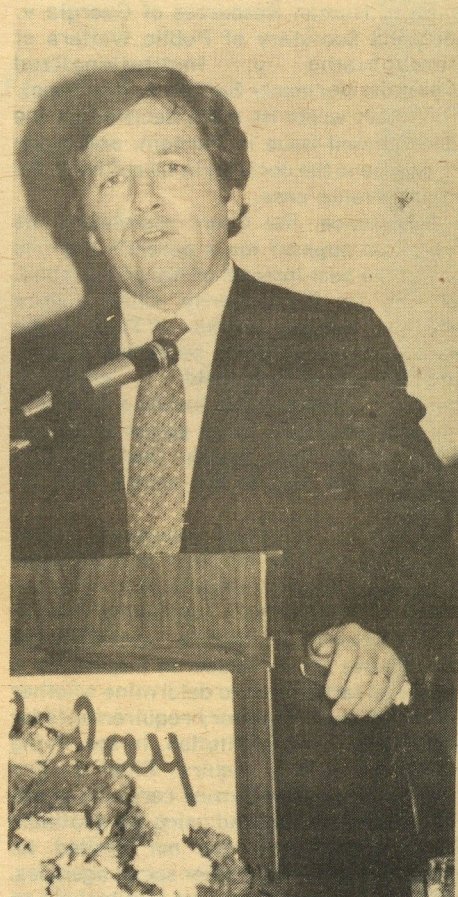


Ellie Pattison holding up miniature gavel presented by Jerry Weingold.

October 18-20, 1979

in Binghamton was a time of unity and re-dedication. This last state convention of the decade could look back on major accomplishments in the 70s... and forward, with hope, to many advances in the future.

Scene at the Convention



Tom Coughlin making his first talk as a civilian — with his appreciative audience.



Not to be resisted — Helen Kaplan explaining membership. Looking on, Dot Ganin of Nassau.

U.S. Supreme Court upholds state commitment laws

The U.S. Supreme Court recently ruled that pre- and post-commitment hearings are not necessary to protect the due process rights of children whose parents voluntarily admit them to mental institutions. In handing down its ruling, the High Court upheld the constitutionality of current commitment laws in Georgia and Pennsylvania and, by extension, key features of similar statutes in some thirty other states.

The two cases before the Supreme Court were *Parham, Commissioner, Department of Human Resources of Georgia v. J.L.* and *Secretary of Public Welfare of Pennsylvania v. Institutionalized Juveniles* (formerly *Bartley v. Kremens*). The Court wrote its main decision on the commitment issue in *Parham*, and made reference to the decision in its ruling in the Pennsylvania case.

In essence, the Court maintained its historical support for a parent's right to act in the best interest of his or her child. Writing for the majority, Chief Justice Warren Burger noted: "That some parents 'may at times be acting against the interests of their child' . . . creates a basis for caution, but is hardly a reason to discard wholesale those pages of human experience that teach that parents generally do act in the child's best interest."

Burger's opinion, however, does recognize the risk inherent in a parental decision to have a mentally ill or retarded child institutionalized, concluding that, at a minimum, a state's commitment procedures must include an inquiry by a "neutral factfinder" to determine whether the child meets statutory requirements for admission to the institution. In specifying the scope of this inquiry, Chief Justice Burger wrote that it must carefully probe the child's background using all available sources, including, but not limited to, parents, schools and other social agencies. Of course, the review must also include an interview with the child.

He went on to say that the decision-maker must have the authority to refuse to admit a child who does not satisfy the medical standards for admission. In addition, a periodic review must be made of the child's need for continued commitment.

In ruling on the Constitutionality of the Georgia and Pennsylvania commitment procedures, the Court found that the "neutral factfinder" does not have to have legal training or be a judicial or administrative officer; nor is it necessary to conduct a formal, adversarial hearing. Instead, the inquiry can be conducted informally by the admitting physician, without violating the child's due process rights.

In reaching this decision, the High Court overturned earlier District Court rulings which held the commitment laws in Georgia and Pennsylvania unconstitutional because they failed to protect adequately the due process rights of children being considered for admission to public institutions. These earlier decisions held that a state's commitment procedures must include the right, after notice, to be heard by an impartial tribunal.

The three Justices (Brennan, Marshall and Stevens) who filed a separate "concurring and dissenting" opinion agreed with the majority that a formal preadmission hearing is not essential to protect the rights of mentally ill and retarded children being considered for institutional admission. However, Justice William

Brennan, writing for the dissenters, argued strongly for mandating a formal postadmission hearing within a reasonable period after the child is admitted to a mental institution.

The dissenters also disagreed with the majority's finding that the due process safeguards applicable to wards of the state need be no more rigorous than those applied to children voluntarily admitted by their natural parents. Justice Brennan wrote that "in the absence of exigent circumstances, juveniles committed upon the recommendation of their social workers are entitled to preadmission hearings."

The decisions in the Georgia and Pennsylvania cases seem to end, at least for the time being, the uncertainty which has surrounded the constitutionality of state mental health commitment statutes since the original, 1975 District Court decision in the case of *Bartley v. Kremens*. When this case originally came before the Supreme Court, the court avoided the question of the constitutionality of the state's commitment statute, choosing instead to remand the case to the District Court for reconsideration of the applicable class under a revised Pennsylvania statute passed in 1976.

Workshop wages earned income

In another ruling (SSR-7823) Social Security has again ruled that wages earned in a sheltered workshop are earned income for the purposes of determining SSI payments.

The significance of this, is that, under earned income in addition to the \$20.00 a month that could be excluded from any income, an additional \$65.00 a month or \$780.00 a year of income plus half the remainder of the rest may be excluded in determining the countable income to be deducted from the SSI benefit. It is important, therefore, whether the income and sheltered income is considered earned or unearned income.

Under the original ruling on which this is based, it was held that where a handicapped individual performed simple services and received token remuneration during a rehabilitation program, such services are not performed as an employee and therefore it is not earned income. On the other hand, however, if such services are performed in a workshop, after he has completed his rehabilitation program, it constitutes employment and he is an employee. As such an employee, his income is earned income.

Meet the Eighties

School district sued for \$5.5 million

A woman who claims her 17 year old daughter was improperly placed in classes for mentally retarded students is suing the Binghamton City School District for \$5.5 million.

Harriet Slawson has formally served school officials with the suit. In February 1979, Slawson filed a notice of claim with the school district, but school officials have not tried to settle that claim said Slawson's lawyer.

Donald G. Sweeney, the school district's lawyer, confirmed the district has received the lawsuit, but was reluctant to discuss the case any further.

"It's premature to indicate what we'll do about it," Sweeney said.

Slawson's suit claims that her daughter spent five years in classes for educable mentally retarded students even though her IQ was above the state standard used to assign children to such classes.

The girl later was enrolled in a special program at the Board of Cooperative Educational Services, but the suit claims that the years spent in classes for mentally retarded students kept her from getting a normal education.

Slawson's lawyer said in an earlier court appearance that the girl cannot keep up with work in classes for normal but slow learners because of her previous placement in mentally retarded classes.

The suit is seeking \$5 million in damages for the girl and \$500,000 for her mother for alleged educational malpractice and negligence.

The girl currently is enrolled in the city school system, and officials are trying to work out a special program for her.

The lawyer said efforts to adapt a suitable educational program for the girl will not affect the lawsuit.

\$1.25 million verdict

A 5 year old boy from Chester, left permanently brain damaged from a 1975 accident at Historic Track, has been awarded \$1.25 million in an out-of-court settlement of a lawsuit.

Dennis Kingley, Jr., son of Mr. and Mrs. Dennis Kingsley, Sr. of Chester, fell 23 feet from the grandstand at Historic Track in Goshen on August 27, 1975. The injuries left him brain damaged.

The defendant in the case was the Orange County Driving Park Association Inc., which operates the track, once owned by the E. Roland Harriman family of Tuxedo Park.

Michael A. Gurda Sr. of Middletown, one of the boy's attorneys, said the case was settled for \$2.35 million five days after the trial began. A co-attorney, John S. McBride of Rock Hill said, "The settlement was so structured that the young man will receive monthly payments for and during the rest of his life."

The accident left him partially paralyzed on one side and the brain damage affected his hearing and speech.

Afterwards, the child received rehabilitative treatment at the Association for the Help of Retarded Children in Middletown.

Medicaid residency rules issued

The new residency criteria replace previous references to "voluntary" residence and define "intent to make a home" in a state separately for institutionalized and non-institutionalized competent and incompetent individuals. These clarifications are intended to provide a uniform definition of "residency" for purposes of determining state responsibility for paying benefits under Title XIX of the Social Security Act.

(1) For any person placed in an institution by a state, the state of residence will be the state making the placement.

(2) For institutionalized blind or disabled persons under age 21 and persons, over 21 who become mentally incapable before 21, the person's residence will be the same as their parent or legal guardian; or, if there is no parent or legal guardian, the state where the person is living.

(3) An individual is considered "mentally incapable" if: (a) his/her I.Q. is 49 or less, or he/she has a mental age of 7 or less,

based on tests acceptable to the mental retardation agency in the state; (b) he/she is judged legally incompetent; or (c) medical documentation, or other documentation acceptable to the state supports a finding that he/she is incapable of indicating intent to maintain residency.

The rules specify that the I.Q. tests used must be acceptable to the state mental retardation agency to ensure that such assessment instruments are professionally acceptable at least within that state. HCFA added this provision in response to comments concerning the disparity between different intelligence tests.

(4) STATE SSI SUPPLEMENTARY PAYMENTS. The final rules provide that, in instances where a Medicaid applicant or recipient is receiving a mandatory or optional state supplementary payment (i.e., in addition to Federal SSI benefits), the state making such a payment will be considered the person's state of residence.

How to evade site selection law

Some group homes for mentally retarded persons with only three occupants have been established without public hearings in an evasion of the law, State Sen. Frank Padavan (R, C-Jamaica Estates) has charged.

The Padavan law, authored by the Queens legislator and adopted last year, imposed requirements for review of proposed group home sites by community boards but defined such homes as those accommodating four to 14 persons. The standard adopted reflected the practice in effect at the time.

Padavan said that he was seeking a conference with James Introne, Commissioner of the Office of Mental Retar-

dation and Developmental Disabilities, on the issue and might offer an amendment to the law to cover smaller groups.

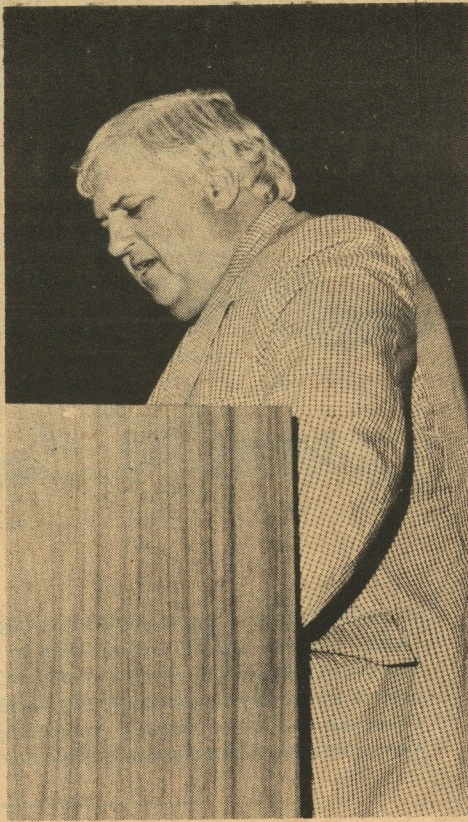
He said that one such home had been established in north Bayside and one in Starrett City, Brooklyn, and that perhaps there were others. He said he had asked Introne to provide a count.

"We find some agencies putting three people into a home with a housekeeper as a way to escape regulation," Padavan declared. "Economically, I don't think it is justifiable."

The smaller homes, although financed and supervised by the disabilities office, are opened without notice to community boards.



Paul R. Dolan, Executive Director of One to One — speaks out on the roles responsibility of the Media at One to One's second Annual Media Awards Ceremony.



Bob Green — Pulitzer Prize Winner of Newsday addressing at the One to One Media Award Ceremony June 19, 1979.

Media Awards

Over 25 newspaper and broadcast journalists were honored recently by One to One for excellence in coverage of conditions of retarded children and adults.

The judging panel was chaired by William B. Arthur, Executive Director of the National News Council and included representatives from the New York Press Club, New Jersey Press Association, New York Chapter of the National Academy of Television Arts and Sciences. The New York State Office of Mental Retardation and Developmental Disabilities and the National Association for Retarded Citizens

also reviewed entries.

The awards were created last year to acknowledge those in the media who have not forgotten the retarded who, according to One to One, "are the most forgotten and powerless people in society." One to One was founded in 1972 to help improve conditions for the mentally retarded. Media Awards Coordinator, Kerry Smith,

noted that "conditions for the retarded in New York, New Jersey and now other states have begun to improve because of the concern of the media."

Act operation criticized

Workshops for severely handicapped penalized

In 1971, the 92nd Congress passed Public Law 92-26, a law that gave priority in the purchase of products and services by the United States Government heretofore, reserved to the Workshops for the blind, to all workshops for the severely handicapped.

The operation of this law, however, has not lived up to its original promise to open up this field to severely handicapped other than the blind. The fact is, in our experience, that workshops could well go broke in their eagerness to obtain these contracts at the "fair market price" established by the Committee On Purchases. An example of this is our Oneida County Workshop which manufactured tent pins for the Department of Defense at 18½ cents a tent pin, at a considerable loss, which could not be negotiated.

The offer was then made to the Workshop to renew this at 24½ cents when the cost of labor and wood as determined by the Workshop is 38 cents. Of course, we turned this down.

How was the 24½ cents reached? It was reached by the granting of a contract at this price to a private manufacturing firm in the south and, therefore, it was established "fair market price".

What lies at the bottom of this is the interpretation of "fair market price" — does this mean the fair market price by a manufacturer underselling everyone to get into Government? Or, is this the fair market price as established by other

sheltered workshops? Interpretation by the Committee on Purchases is the former, a fact that militates strongly against the Workshops for the Mentally Retarded with so many severely handicapped in them.

This situation was protested to Senator Javits in June of 1979, again in July of the same year and finally, in October, 1979, where the following suggestions were made by this Association to remedy this situation.

1. That the section of the law stating that commodities produced and offered for sale by qualified non-profit agencies for the blind shall have priority, should be eliminated. The time has come when all handicapped should be treated equally by the Government.

2. That 'fair market price', as determined by the Committee on Purchases, is almost fatal to workshops dealing with the mentally retarded and the more severely handicapped and that the fair market price should be determined as demonstrated by workshops themselves.

3. Since the intent is to help workshops for the severely handicapped, perhaps there should be a section added to the bill similar to 8A of the Small Business Act where contracts can either be negotiated with the workshops without regard to industrial "fair market price" or where there is a "set aside" for such workshops.

To date, we have heard nothing from Senator Javits' office or from David Morse, his Staff Assistant, who is supposed to be working on this with us.

Services complicated by term confusion

CONFUSION OF MENTAL ILLNESS WITH MENTAL RETARDATION COMPLICATES PROVISION OF SERVICES

A typical example of the confusion that exists between mental illness and mental retardation, in spite of all efforts on a Governmental and voluntary level to inform the public, is the article in the Democrat and Chronicle of Rochester, New York of August 26, headed "Mentally Ill and Retarded Strain Resources of Jail".

Unfortunately, however, although the first sentence states "An overflow of suicidal, psychotic and mentally retarded inmates is behind bars at the Monroe County Jail, primarily because they have

nowhere to go for medical treatment, according to mental health experts and jail officials", this is the only mention of mental retardation in the article. All the rest of the article deals with mentally ill people, the Department of Mental Health, problems of services for the mentally ill in the community, etc., etc.

These are problems which are not typical of mental retardation but are continually confused with mental retardation — in the mind of the community the results that we have all seen in trying to start group homes or other services.

Certainly, someone from Rochester should try to straighten out the Democrat and Chronicle.

National Rehab. Assn. condemns Carter

This resolution was passed by the Delegate Assembly during The National Rehabilitation Association's (NRA) National Conference in Chicago, Illinois, and transmitted to the President and all members of Congress:

WHEREAS, The Rehabilitation, Comprehensive Services and Developmental Disabilities Amendments of 1978 were enacted nearly one year ago, and WHEREAS, Regulations necessary in order to implement such Act have not been issued, and

WHEREAS, The National Institute for Handicapped Research has not been officially established nor a Director appointed by President Jimmy Carter, and

WHEREAS, The Carter Administration has failed to fully support programs for the employment and education of handicapped individuals, and

WHEREAS, The Carter Administration has requested cutbacks in funds for Service Programs for the handicapped carried out by the State rehabilitation agencies, and

WHEREAS, The Carter Administration has requested cutbacks in funds for handicapped research, and

WHEREAS, The Carter Administration has requested cutbacks in funds for handicapped training, and

WHEREAS, The Carter Administration supports attempts by Florida and other states to eliminate Federally mandated programs designed to encourage State support in spite of audits by State and Federal officials which show that handicapped monies have been diverted to other causes, and

WHEREAS, The Carter Administration has consulted but then ignored input from rehabilitation professionals and persons with physical and mental disabilities as to the program and policies that effect their lives; now therefore be it

RESOLVED, That the Delegate Assembly of the National Rehabilitation Association convened here in session this 17th day of September, 1979 condemns the Carter Administration for these actions that represent gross neglect and lack of support of the needs of the handicapped citizens of this nation.

The National Rehabilitation Association urges President Carter and officials of his Administration to move with all due speed to implement fully the provisions of the Rehabilitation Act; appoint competent and dedicated officials; and request adequate monies to carry out the programs and services necessary to provide handicapped citizens with the opportunity to live a full and productive life.

Syracuse Police Department handicapped I. D. program

The Syracuse Police Department has instituted an identification program aimed at the especially vulnerable citizens in the community. The program is strictly voluntary and is designed to expedite identification and medical treatment to those who may not be able to communicate for themselves.

The program involves issuing identification cards and/or laundry labels with the person's name, address, and/or code number. Pertinent medical and emergency information will be available to the street patrol officer via computer, should any emergency arise. In the past, this information has not been readily available to police when an emergency has occurred with a severely handicapped individual having physical, emotional, mental or multiple handicapping conditions of such a serious nature as to

require highly specialized and intensive emergency care which might be vital to this person.

Who qualifies? Severely handicapped children and adults in the Syracuse area, including the following categories: Trainable, severe or profound mental retardation, cerebral palsy, blindness, severe hearing impairment or profound deafness, severe physical handicaps and crippling (such as amputation, spina bifida), severe emotional disturbances, severe neurological - brain impairments (such as strokes, disabilities, brain trauma, seizure disorders), laryngectomy.

To obtain information about starting a similar program in your area, call the Community Relations Section of the Syracuse Police Department at 315-473-3220.

AFTERMATH

Sundheimer vs. Kolb

In the case of Sundheimer V. Kolb, previously reported in OCV, a group of parents in the Bronx, sued the state to force it to fund services in the community for retarded, never institutionalized, in the same way as it funds services for those who have been deinstitutionalized, 100 percent. The judge in that case granted partial summary judgment to the plaintiffs ordering the state to pay parents who kept their children at home the same amount as family care parents as they had been paying parents who took their children out of the institutions.

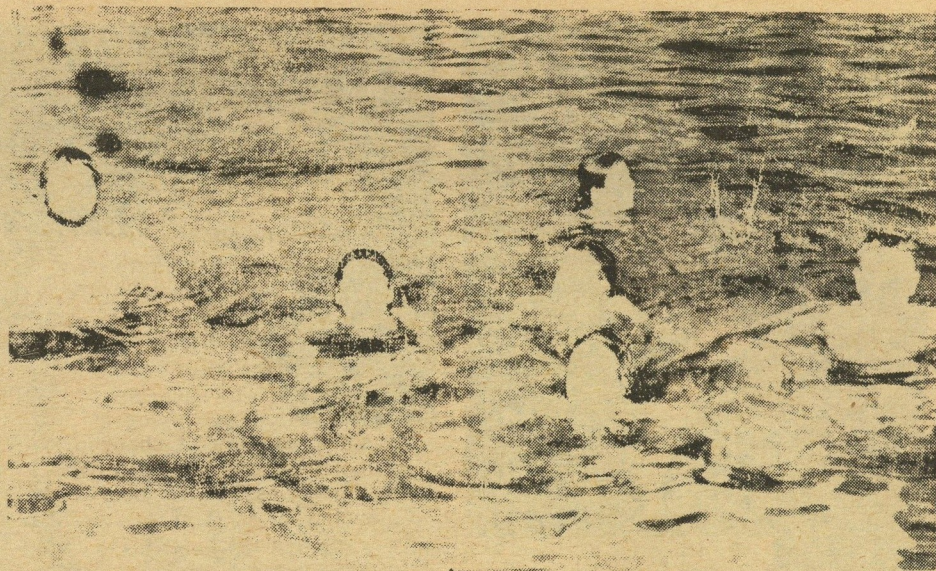
Although the large number of retarded persons in the community, more than 97 percent of all the retarded, would leave one to believe that the limited state resources, should make family care assistance a top priority, "unbelievably", as wrote Dr. Harry H. Gordon, director emeritus of the Rose F. Kennedy Center for Mental Retardation at the Albert Einstein College of Medicine of Yeshiva University, in the New York Times, on September 27, 1979, "the State Office of Mental Retardation, created to help retarded children and their parents, un-

dermined the decision. Instead of following the court's order, the then Commissioner of Mental Retardation, Thomas Coughlin III, closed the family-care program to all natural parents regardless of the severity of their child's retardation or prior institutionalization. Thus, administrative fiat evaded the judge's directive. Under Mr. Coughlin's order, all natural parents are now equally ineligible to receive family-care support."

"The Willowbrook decree" continues, Dr. Gordon, "to stop warehousing the retarded prescribes an equal moral obligation to minimize the need for parents to send their children to distant institutions. The termination of family-care funds for natural parents circumvents the aims of the decree."

"If the state is to provide humane care in the community — a matter of equity and sound economics — the commissioner and the Legislature should first correct the funding imbalance between institutional and community care."

Tricks of this kind will not remove the stigma of "immoral action" from the state that it is acting immorally.



SPLASH DOWN — Local youths participated in the Association for Retarded Children's (ARC) seventh annual swim-a-thon at the Herkimer County Community College pool. The swim-a-thon is conducted each year to raise funds for expansion and development of programs for the developmentally disabled of Herkimer County. Participants included, Christian Celi, Amy Manion, Julie Pickett, Jim Morton, Bob Merhar, and Kerry Shaw. Approximately 600 swimmers took part.

Parent fights to keep child in BOCES

Nicholas Santoro has requested an impartial hearing to have his son Nicholas kept in a class for the multiply handicapped at the BOCES North Rd. facility in Red Hook. The hearing, he said, could cost Red Hook School District \$5,000 or more.

Santoro is fighting the Red Hook School Board's decision to place Nicholas in a class for the trainable mentally retarded at the BOCES Salt Point facility.

The impartial hearing is part of the recourse accorded parents under a federal law dealing with education of handicapped youngsters.

Santoro has been fighting for several months to have his son transferred from the Trainable Mentally Retarded (TMR) class to a class for the multiply handicapped at the BOCES North Rd. facility.

Santoro said that in his son's five years in the TMR class at Salt Point he made no progress and never had the opportunity to learn basic reading and math.

After objecting to the placement before the Committee on the Handicapped and David Machell, director of special services, Santoro presented his case to the Board of Education.

To back up his case, Santoro had Georgia Sullivan, regional coordinator of the Protection and Advocacy System for Developmental Disabilities, a federally funded agency, observe Nicholas.

Santoro said her findings indicated that Nicholas would only regress in that class.

After this, the board placed Nicholas in the multiply handicapped class at North Rd. where Santoro said his son was getting an education and needed therapies in a self-contained classroom.

Santoro said the children in the TMR class at Salt Point were older and that the students change teachers and classrooms for each subject. He said his son was not ready for that environment.

"State and federal governments have ruled that proper educational programs must be provided for the handicapped child by the school district," he said. "The school district, however, uses all its bureaucratic and legal power to fight parents — why?"

Mrs. Jane E. Dubuque, former chairman and present advisor to Advocates for the Education of the Handicapped, also talked of what she termed Santoro's frustrations in dealing with the Committee on the Handicapped and the Board of

Addressing taxpayers, she said: "You are the ones to pay the bill thanks to your district's unwillingness to listen to the parent, teacher, director or other advocates. Whether Santoro wins or loses you still have to pay the bill. And if he loses, he will appeal, and this could cost the district thousands."

District Superintendent Dr. Carl W. Thompson said the matter would be referred to the school's attorney, Douglas Wicks.

Board of Education member Richard Barrett, board liaison for handicapped education, said that the board expected Santoro's request for a hearing. He said, however, he believed the board had made the best possible recommendation.

L.I. gets own M.R. office

The state is establishing an office on Long Island aimed at helping to move the mentally retarded out of large institutions and into community residences.

The plan makes Nassau and Suffolk Counties the office's fifth region. Until now, Long Island and New York City had been considered a single region by the agency, which administers programs for the retarded. Nassau and Suffolk programs were administered from a regional office in Manhattan.

Eddie C. Moore is assistant commissioner and director of the new Long Island region. Moore, 30, currently is director of program operations for the New York City - Long Island region.

The new regional director will work more closely with communities into which the state hopes to move patients from larger mental institutions.

Establishment of facilities in Nassau and Suffolk communities was hampered when objections by residents had to be processed through the New York office. A state law now requires the mental retardation agency to seek approval from local governments before choosing sites for community residences. The Long Island office will report directly to Albany.

Sterilization of retarded person upheld in N.J.

The Superior Court of New Jersey, Chancery Division, has upheld the rights of parents to consent to sterilization of a severely retarded Down's Syndrome girl living at home.

The Court rejected the argument that sterilization can only be performed when necessary to preserve life itself or to prevent irreparable brain damage.

Although the court recognized the right of the retarded person to make a free choice, in a case where the person is incapable of understanding the nature of the sexual function, "reproduction or sterilization and cannot comprehend the nature of these proceedings, hence is incompetent" the parents may make such a decision.

Certain criteria was set up including the above such as a) "that incompetency is in

all likelihood permanent; b) that the incompetent is presumably not infertile and not incapable of procreation; c) that all procedural safeguards have been satisfied, including appointment of a guardian ad litem to act as counsel for the incompetent during court proceedings with full opportunity to present proofs and cross-examine witnesses; d) that the applicants have demonstrated their genuine good faith and that their primary concern is for the best interests of the incompetent rather than their own or the public's convenience." The court warned that the decision was not to be interpreted as authorizing parents to consent to sterilization of incompetent persons absent authorization by a court of competent jurisdiction. "Each application must be decided on its own merits" says the court.

New drugs to help retarded

A new manual on the use of psychotherapeutic and antiepileptic drugs for mentally retarded and developmentally disabled individuals, the first ever produced specifically for that purpose, is being distributed to physicians at New York State Office of Mental Retardation and Developmental Disabilities facilities.

The "Manual of Psychotherapeutic and Anti-epileptic Drugs" was developed by the agency's Committee on Therapeutics, chaired by Dr. Judith H. Rettig, director of the Office of Health Services.

The manual will provide each physician at a state developmental center with correct dosages of the drugs for various age groups and with rules for prescribing these drugs. It spells out the very specialized use of psychotropic and antiepileptic drugs, possible adverse reactions

to them, and potential undesirable interactions when used in combination with other medications.

The manual will be used in conjunction with a computerized drug ordering and exception system, which will begin functioning in the New York City area soon and should be fully implemented at all state developmental centers by year's end.

The main computer for the system is located at the Rockland Research Institute's Sciences Division, which originated the system. When used together, the manual and system will serve to set standards for and monitor the ordering of the drugs for mentally retarded and developmentally disabled persons of all ages in state developmental centers.



HAPPY NEW YEAR!

OMR/DD plan fails

Programs under funded over regulated

In Testimony on November 7, 1979, on behalf of the State Association, the Executive Director, Joseph T. Weingold, pointed out that the update (1980) of the OMR-DD five-year plan (1974-1984) does not come to grips with the under-funding of services.

Although the statement is made that the "existing funding mechanisms cannot maintain current services, much less support expansion of services," no remedy is offered except the vague proposal of "Single Source" funding, and idea which we believe has already been discredited.

The ARC again proposed a 100 percent funding for all Community Services whether for clients coming out of the institutions or those never in institutions. "We just don't understand the opposition to this except for the money involved. But, if California, Michigan, Minnesota,

Illinois, and Pennsylvania can fund at 90 percent, where, then, does this state fail in its ability?" said Mr. Weingold in his statement.

The state update, furthermore, is defective in that it does not provide for at least 40,000 more persons who may come into the program if the definition of Developmental Disabilities is changed to conform to the federal definition, eliminating categories. This can be a fatal error in planning for services.

The Association also objected, in this testimony, to the power given to the DDSO to operate facilities — goes even so far as to give them the power to create a new agency where they feel there is no agency around to do the job.

Copy of the testimony may be obtained by writing to the State office, 175 Fifth Avenue, New York, New York 10010.

"Senior Companions"

Adult residents of 16 of the Office of Mental Retardation and Developmental Disabilities' 20 statewide developmental centers will soon experience the kind of loving attention which has helped so many of the younger residents there, it was announced by James E. Introne, Commissioner.

"The Senior Companions, as the program is called, will provide services similar to the state's very successful Foster Grandparents Program," Mr. Introne stated. "It will especially seek to help clients over the age of 21 make the transition to community living."

The State is providing \$300,000 to fund a total of 175 Senior Companions to serve at Broome, Craig, J.N. Adam, Letchworth Village, Manhattan, O.D. Heck, Rome, Staten Island, Suffolk, Sunmount, Syracuse, Wassaic, Westchester, West Seneca, and Wilton Developmental Centers, Mr. Introne explained. There will be from five to fifteen at each facility.

The Senior Companions, like the Foster Grandparents, are persons over 60 who meet certain income requirements. Many are retired. They are paid a modest \$1.60 an hour for their efforts, an amount that is not taxable and will not affect retirement income. They are also provided transportation to their assignment, a daily meal, and an annual physical.

"Senior Companion programs have been funded by the Federal ACTION program in other states," Mr. Introne said. "New York's is the first to be entirely state supported." The Office's Foster

Grandparents are ACTION funded.

According to Mr. Introne, the new effort will not only be applied to an older group of clients, but will also have the specific assignment of aiding the community placement program. "Senior Companions are being educated concerning our placement efforts," he said, "and provided with skills that are geared to helping individual clients make the transition to community life."

Mr. Introne said the Companions may work with small groups as well as individuals. Foster Grandparents are always one-to-one. "Two basic approaches will be used to meet two goals," he explained. "Some Companions will be assigned to adults preparing to leave a center for a community residential setting. They will be friends and advisors to their retarded companions, helping them to learn the living skills and make other needed preparations for the move."

This group will often follow their assigned Companions from the facility into the community and remain with them, providing a familiar friend during a difficult adjustment.

Others are being assigned to clients in community residences, day programs, family care, and sheltered workshops. In all cases, they are working to provide encouragement in dealing with the day-to-day demands of community living. "The goal is to make each placement a successful one," Mr. Introne said.

Initial training sessions have been conducted and assignments are now being made.

Weicker pushes discrimination law

U.S. Sen. Lowell P. Weicker has called on Congress to enact laws making it illegal to discriminate against persons who are mentally or physically handicapped.

Testifying before the Senate Labor and Human Resources Committee, Weicker said anti-discrimination legislation protecting handicapped persons was an "unfortunate omission" from the Civil Rights Act of 1964.

Measures outlined in the Rehabilitation Act of 1973, which bar employment discrimination for the handicapped in federal agencies, should be broadened to include employment in the private sector, said Weicker.

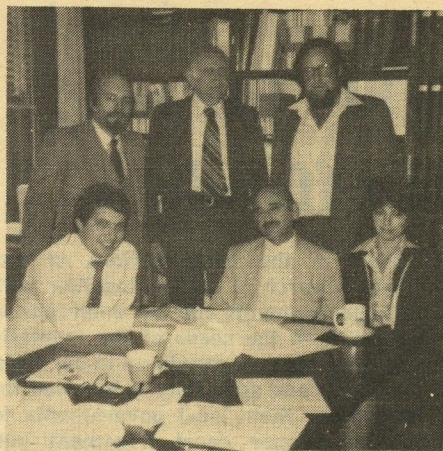
Legislation currently before the Labor

and Human Resources Committee would expand that coverage into the private sector.

Weicker said existing law "does not go far enough" because "it restricts the types of organizations and agencies affected and its intent is both general and vague."

Citing a recent Supreme Court decision against a handicapped person seeking nursing training, Weicker stressed the need to close loopholes in the present law with more comprehensive legislation.

"What this bill seeks to insure is that their path to contribution is not blocked, that they, like other minorities, have as their partisan the law of this nation," Weicker stated.



We discuss ICF/MR's

Seated L to R, Commissioner Introne, Jerry Weingold and Anne Marie Vadney, of Commissioner Introne's staff. Standing L to R, Bob Norris of OMR-DD, Dr. Goralick and Mike Goldfarb, New York City Chapter ARC. Story on page 9.

Debate ends; hostel approved

Months of public debates and private arguments ended late last year when the State Department of Mental Hygiene indicated it was going ahead with plans to open a hostel for the mentally retarded in Commack. The proposal had drawn mixed opposition from the community, the most vociferous complaints coming from homeowners living near the proposed site at 1 Mayfair Terrace who contended its location adjacent to busy Jericho Turnpike could pose a safety hazard to its occupants. The building, once the home and office of a now deceased physician, had been on the market for several years and had been earlier rejected by the Smithtown Town Board for conversion into law offices, despite support from neighboring property owners. The State indicated the rambling split level was ideal for the handful of trainable adult retarded who would live there as a family unit under the wing of a set of house parents. Though the Town formally opposed the plan, final authority rested with the State agency. "We expect the hostel to open within the next four months," predicted a State Mental Hygiene official recently. The hostel will be operated by the Association For The Help Of Retarded Children which will either buy the building outright or lease it from the State.

New director for Rome D.C.

Keith A. Hoffman, deputy director for institution administration at the Rome Developmental Center since October 1976, has been named the center's acting director. He succeeds Cornelius R. Walsh, who died recently.

Hoffman's appointment was announced by James E. Introne, commissioner of the state Office of Mental Retardation and Developmental Disabilities.

Before joining the staff at Rome, Hoffman was deputy director for institution administration at Marcy Psychiatric Center. From 1973-74, he was chief of the bureau of institution administrative services within the state Department of Mental Hygiene.

A native of Florida, Hoffman attended Clark University in Worcester, Mass.,

SSI-SSDI bills passed

In September, 1979, the House of Representatives passed two key bills of income maintenance legislation and sent them to the Senate for initial consideration by the Senate Finance Committee.

SUPPLEMENTAL SECURITY INCOME — On June 6th, the House approved a bill (H.R. 3464) that would remove certain work disincentives for disabled persons under the Supplemental Security Income program (Title XVI of the Social Security Act). This legislation would: (1) increase the substantial gainful activity test (SGA) to the "phaseout" point — the level of countable earnings at which a recipient loses SSI eligibility. This practice is currently followed for blind and aged SSI applicants — recipients but not for the disabled; (2) disregard certain work-related expenses; (3) disregard certain impairment-related expenses, including the cost of attendant care; (4) permit an SSI recipient to retain disability status under SSI for 12 months after termination of benefits due to his/her earnings level and allow an additional four years of presumptive disability; (5) make certain changes in the appeals process; (6) make it clear that parental liability would only apply for children under age 18; (7) allow SSI recipients who medically recover from their disability to continue to receive benefits if enrolled in an approved vocational rehabilitation program; and (8) permit states to elect to have the disability determination process turned over to the federal government. The bill passed with little debate and was sent out of the State Senate Finance Committee which held hearings in October the result of which we have not yet heard.

At the same time, the Committee was also to consider an SSI work disincentive bill (S. 591), introduced by Senator Robert Dole (R-Kan.). The Dole bill would not allow an earnings phase-out for disabled workers, similar to H.R. 3464, but instead would provide for: (1) presumptive disability; (2) counting income from sheltered workshops as earned, rather than unearned income; (3) allowing an extension of cash payments to handicapped persons under SSI even after they reach the SGA level; (4) extending Medicaid after the break-even point when it can be shown that, without medical assistance, the person would be unable to continue working; and (5) disregarding the cost of attendant care in determining the SGA level.

graduating in 1966 with a degree in economics. He holds a master of business administration degree in hospital administration from Xavier University, Cincinnati, Ohio.

Hoffman has also served as assistant business officer and chief administrative and fiscal officer at Sagamore Children's Center on Long Island, and as assistant business officer at Utica State Hospital.

He and his wife, Denise, live in Alder Creek.

William Knowlton, an office of mental retardation spokesman, said Hoffman will be eligible for a director's salary in the \$46,000 range after serving as acting director for 60 days. He currently earns about \$42,000, the spokesman said.

Membership Counts

United Church of Christ

Program for rights for m.r. alleged criminal offenders

As long as sixty years ago a medical doctor who served also as the director of the Municipal Court in Boston, Mass., wrote, in pleading for more protection for the rights of the mentally retarded who are brought into the courts throughout our nation: "The mentally retarded possibly form the most important single group of which our courts need to take cognizance."

Yet, even in the present day, mentally retarded alleged criminal offenders — as distinguished from the mentally ill — continue to be victimized by our courts and criminal laws.

The mentally retarded are frequently judged by the courts to be competent to stand trial even when they are not competent in understanding what is going on. In their lack of understanding, they are easily persuaded, because of their wish to please the authorities, to sign confessions when they have not committed the crime to which they confess. And, then, judged guilty, they are subject to an imprisonment in which they must frequently suffer cruel persecution from the more intelligent prisoners.

It is for these reasons the United Church of Christ asked its members last year, as part of the 1979 "Neighbors in Need" offering, to contribute to a program for "Rights for Mentally Retarded Alleged Criminal Offenders."

The program will seek to:

- sensitize the congregations of our United Church of Christ, together with local governments and law enforcement agencies, to the needs of the mentally retarded who are caught up in our legal system — and especially to the need for pressuring their local governments to provide proper court treatment and social services for them.
- hold workshops to train judges, attorneys, police, parole and probation officers in recognizing the signs — and the needs — of the mentally retarded alleged criminal offenders.
- provide a model for use in special training and rehabilitation, as well as care and custody, for mental defectives over sixteen years of age who are charged with, arraigned for, or convicted of criminal offenses.
- organize parents of retarded delinquents and friends of retarded adults to seek proper legal defense by identifying those lawyers trained or sensitized to the plight of the mentally retarded offenders.

The program will be administered by the Commission for Racial Justice of the United Church of Christ, in cooperation with the Office for Church in Society and the United Church Board for Homeland Ministries.

Hiring freeze deplored by ARC

President Ellie Pattison, in a telegram to Governor Carey, with copies to the Legislative Leadership as well as to Jim Introne, protested most strongly the hiring freeze announced by the Division of the Budget across the state and especially in OMR-DD.

Although the bulletin from Dr. Howard Miller, Director of the Budget is dated November 1, 1979, this was not called to our attention until two weeks later, and, indirectly, although it affects children that we serve most strongly.

The directive calls for a "complete freeze on hiring. . . all permanent and temporary positions funded from State Purposes — Regular and related offset appropriations."

Again, we are confronted, says the Governor, with a very stringent budget period in 1980 and 1981 but we don't know the basis for this.

It is interesting to note that the directives states "this is the only distribution of this bulletin. Please supply copies to all interested officials and employees in your department or agency at all appropriate locations." It fails, however, to understand that the parents of the retarded in the institutions are the most concerned, not just the officials and employees.

This is the complete text of Ellie Pattison's telegram to the Governor:

"A hiring freeze across the state has just been brought to our attention. Whatever the fiscal condition of the state, we cannot believe that curtailment of services to the most vulnerable, the mentally disabled in our institutions, is an acceptable price to pay to redress for a money shortfall. The quality of care in our institutions and backup community services must suffer. What price standards and expressions of regard? We ask you to lift this freeze as it applies to the mentally disabled — in the name of humanity."

Fight!

OMR/DD introduces puppets



L to R — Puppet with Kate Klein, Co-Chairperson ARC Public Information Committee.

School children across the state will soon be able to meet the "Kids on the Block", a troupe of handicapped and non-handicapped puppets, that is part of OMR-DD's newest public education program. The puppet show, designed to teach children what it is like to be handicapped, will be brought to the New York State public elementary schools this Fall. New York is the first state to institute the program.

Five troupes, assigned to the Albany, Buffalo, New York City, Rochester and Syracuse areas will be trained and coordinated by public education in association with the advertising firm of Porter and Novelli Associates.

Barbara Aiello, a former teacher of handicapped children and national special education consultant and writer, is the creator of the "Kids on the Block." Aiello writes all of the scripts which are developed from concerns and questions voiced by non-disabled children and all script material is critiqued by disabled children, adults and parents of disabled children.

The "Kids on the Block" are child size puppets, who wear real children's clothing and real children's shoes.

The puppets include "Mark," who is a cerebral palsied puppet in a wheelchair; "Mandy," who is deaf and through whom children are taught some basic sign language; "Ellen Jane," who is an 18 year old Down's Syndrome retarded puppet, and Renaldo who is blind. There are two nondisabled puppets, "Melody," who wears glasses, and "Brenda," who is a bit overweight.

There are two important goals for the "Kids on the Block." "First, I want to teach children about handicaps in a non-threatening and 'Unpreachy' fashion, and second, I want to show non-handicapped children how to develop positive relationships with their handicapped peers," Aiello says.

The puppets were constructed by professional puppeteer, Ingrid Crepeau, who has won two regional awards for design of puppets on a Washington, D.C. children's television show, Sneakers. She, or puppeteer Kathleen McArdle, who is a trained special educator with experience in the education of young handicapped children, assist Aiello during the show.

Commission ends MR-DD accreditation program

The eleven member organizations of the Accreditation Council for Services for the Mentally Retarded and Other Developmentally Disabled Persons (AC-MR-DD) voted recently to terminate the Council's decade-long affiliation with the Joint Commission on the Accreditation of Hospitals.

The history of the disaffiliation process began in mid-1978 when the JCAH Board of Commissioners voted to dissolve five existing accreditation councils, effective June 30, 1979, and put into effect a reorganizational plan to improve the commission's management structure. As reported in the November, 1978 issue of *New Directions*, the reorganization plan called for replacing each council with a professional technical and advisory committee. In addition, an overall Policy Advisory Committee was to be established to advise the JCAH Board of Commissioners on policy and coordinate various agency functions.

Even before the plan was finally approved by the Board, the member organizations of several councils voiced concern about its impact. AC-MR-DD appointed a task force to study alternative methods of continuing its accreditation program. The task force's findings resulted in a recommendation that AC-MR-DD disaffiliate from JCAH and establish an independent, non-profit corporation.

Finally, on May 18, 1979 member organizations of the council met in special session to consider the proposal. The vote was 8-3 in favor of the task force's recommendation. Major reasons cited for the disaffiliation decision were:

- the need to preserve consumer participation;
- the need to retain the development model upon which the current AC-MR-DD standards are based;
- the importance of strengthening the interdisciplinary provision of services; and
- the need to protect the autonomous decision-making role of member organizations.

Currently, JCAH is working with members of the Council to promote a smooth transition and assure the continuity of the MR-DD accreditation program. On June 15, the Council met to discuss possible strategies and timelines for resumption of normal MR-DD activities. One of the critical, unresolved questions is the future organizational focus of the program. The pros and cons of several alternative locations were explored in a special report prepared for the Council in April by Human Services Research Institute, a non-profit Washington-based policy research firm. But, thus far, no final decisions have been reached.

During the transition phase, current accreditation status of all agencies will remain in force and all prior accreditation decisions made by JHAC will be honored.

Win!

Lutherans aid retarded

The newly formed Lutheran Association for the Developmentally Disabled (LADD) is advocating programs for these special children and adults to assure them of more productive lives.

The dream of the 23 member board of LADD to create a \$500,000 endowment fund was recognized at a special ceremony.

A proclamation was signed by Erie County Executive Edward J. Rutkowski proclaiming last July and August as "Lutherans Aiding Developmentally Disabled Months" in Erie County in recognition of the fine contributions this organization is making for the cause.

Richard P. Wulf, a layman at the First Trinity Lutheran Church, Tonawanda, a founder of LADD, notes the group was formed to give mentally handicapped persons the experiences automatically afforded the rank and file of people and to assure parents that their children will be cared for when they are no longer living.

The Wulfs' mentally handicapped son, Douglas, 20, was the subject of the specially created filmstrip, "My Name is Doug." The filmstrip was used in Sunday Schools throughout the area.

LADD, together with the Eastern District of the Lutheran Church - Missouri Synod, of which Dr. Arnold E. Kromphardt of North Tonawanda is president, recently engaged a full-time executive.

The Rev. James Hallman, who presently serves the Lutheran parish in Benner Springs, Kansas, took over his new duties this past August.

The Rev. Mr. Hallman's work will be funded by men's, women's and children's organizations throughout the area and will serve all denominations. The Mr. Rev. Hallman, father of a mentally handicapped child, will have the responsibility of helping churches set up programs to aid developmentally disabled and their parents. Formation of a counseling service for parents will be one of his major projects.

Another look at David Jenkins consumer member of D.D. Board



DAVID JENKINS

David S. Jenkins, Gov. Hugh L. Carey's recent appointment to an advisory council in a state agency with a \$500 million budget, often begins answers with the observation, "Now, that's a difficult question."

He then proceeds to give at least two sides of the question, laying the answer adroitly between the rock of controversy and the hard place of boredom.

It is a neat trick, illustrating a facility many other gubernatorial appointees envy. But Jenkins, who is 25 and a Troy native, is not a typical appointee and the council he will serve on during the next three years is uncommon.

Although its title, the Advisory Council on Mental Retardation and Developmental Disabilities of the state Office of Mental Retardation and Developmental Disabilities, is bureaucrat-talk, at least half the members must be from outside the bureaucracy — either former residents of state mental hygiene institutions or parents of residents. The council has a say in how and where the state office of mental retardation spends its huge budget. Jenkins, a slight, soft-speaking man, spent 18 years, nearly his entire childhood, in the Rome Developmental Center.

"Are you retarded?" he was asked during a recent interview.

"Now, that's a difficult question," he said. "Some people say I am, and others say I'm not."

Jenkins was placed at Rome when he was two years old. He was extremely sick from birth, and he required care his family in Troy could not provide. He grew up at Rome, taking courses equivalent to a grammar school education, and sitting on a board advising the center's director.

In 1973, Jenkins underwent open-heart surgery at Albany Medical Center Hospital. He spent months recuperating, both in the hospital and in the O.D. Heck Developmental Center in Schenectady. Four years ago, Jenkins left the institutions and moved into a hostel for the mentally retarded and developmentally disabled in Troy. He began taking adult education courses and has since moved to another partment in Troy. He lives with eight people, including a counselor.

"We live on an independent basis with other people," Jenkins said. "It's something we never had at Rome. Someone always told you when to get up. We have responsibilities, and we're going to get more."

Jenkins works at the Legislative Messenger Service. He is a familiar figure in the corridors of the Empire State Mall. He's known for his affection for the Kennedys and his passion for sports.

"I was very flattered when the governor appointed me to the council," Jenkins said. James Flanagan, an official of the Rensselaer County Association for Retarded Children, suggested to state officials that Jenkins be appointed to the advisory council.

At council meetings, Jenkins said he will concentrate on education and sports for the handicapped. He believes much more can be done in both these areas. He also intends to talk to mentally retarded persons and counselors in Troy about their views. "I want to know what the council can do to help," he said.

Towards the end of the interview, Jenkins was asked about the controversial practice of transferring thousands of persons from state institutions to local residences such as hostels.

"That's a very, very touchy subject for me," Jenkins said. "Since I was in them. I think there are other ways of helping. Parents have more choices now than they did 20 or 30 years ago. A lot of people," he said in an even tone, "shouldn't have been there."

Take a Break

"Take-A-Break" is a respite care service for handicapped children in Syracuse and Onondaga County. It's available for children who are mentally retarded or developmentally disabled — persons with cerebral palsy, autism, epilepsy or other neurological impairments. The service is also available on a limited basis to individuals 21 years old and under, with other physical, mental or emotional disabilities (visual or hearing impairments, multiple sclerosis, muscular dystrophy, spina bifida).

"Take-A-Break" provides short-term temporary care of the handicapped child in his or her home. Specially trained and screened sitters and companions give parents that needed "time away that will refresh them."

For County residents, "Take-A-Break" works very simply:

Call Director Barbara Weinstein at 425-5360 or 425-5355.

REGISTER to use the service. This means filling out a form providing specific information about the handicapped person.

INFORM the director of the specific time (well in advance, please!) for which you would like the respite.

"Take-A-Break" will do the rest — link the appropriate sitter companion with your family.

The actual payments of the sitter companion (\$1.50 per hour, three hours minimum — weekend rates are \$30 for Friday evening through Sunday evening) is made by the family. There is a limited fund available for families in need of partial or full financial assistance.

"Take-A-Break" is sponsored by the Parents' Information Group for Exceptional Children and funded by the Onondaga County Department of Mental Health. It began in May, 1978 and also provides many of its services for handicapped adults.

Empire State Enterprises

Empire State Enterprises for the Handicapped is now operating from the Empire Plaza in Albany, N.Y. This new organization was developed from the initiative of several members of the Capital District Coalition of Executive Directors from the Albany area. Prior to incorporation, monthly meetings were conducted by a task force of individuals from the private and public sector who serve the handicapped of New York State, representatives of the New York State Department of Commerce and the New York State Office of General Services, and experts from the business community. The group considered the need for providing adequate retail training sites for clients and for developing marketing outlets for handcrafted goods made by the handicapped of New York State. It was apparent that the sheltered workshop did not provide the proper environment to train clients in the field of retailing and that current efforts to market clients' handcrafted goods were inadequate. It appeared the newly developed Nelson A. Rockefeller Empire State Plaza in Albany could provide the ideal setting to accomplish both of these goals.

Although the task force originally addressed itself only to the needs of clients from the Capital District, it was eventually decided to extend the service of the project to the entire state. This helped to assure success of the project as a training effort and as a business venture. It is anticipated that, in time, the project will be extended to other large cities in the state.

The Enterprises operate under the direction of a President, a Board of Directors and a part-time volunteer project coordinator. The General Manager of the J. C. Penney Company is President of the Board of Directors.

The purpose of the Empire State Enterprises for the Handicapped is to establish a first-rate retail marketing outlet to be located in the Rockefeller Plaza for goods made by disabled people from throughout New York State and to develop a retail outlet model for goods made by disabled individuals which can be copied in other locations across New York State.

Initially, the retail outlet staff will consist of a manager-trainer, a clerk-trainer and a part-time assistant.

Application has already been made to the Office of Vocational Rehabilitation for funding. It is anticipated that the Albany project will become self-sustaining within a year.

We will be reporting on the business progress of this new enterprise in future issues of Our Children's Voice.

A boy in no-man's land

The state Department of Mental Hygiene didn't want him, and neither did the city, so for 13 long months Larry Salter, a 13 year old with a history of mental and emotional problems, was confined to a city hospital ward — a forced stay that cost taxpayers a needless \$85,000.

The youth was brought to City Hospital Center at Elmhurst, Queen's on July 4, 1978, by his distraught mother because he was no longer controllable. In one emotional outburst, he had broken windows and furniture in the family's Far Rockaway home and Mattie Salter injured her back trying to restrain him. She made the difficult decision to place her son in some sort of mental facility.

The real tragedy came when Mrs. Salter and hospital officials sought out the proper government agency. The youth suffers from dual problems of being mentally retarded and emotionally disturbed. The state apparently was willing to treat mental illness, but not emotional disturbance, and the city, emotional problems,

but not mental retardation.

So while government agencies pondered the situation, the youth remained in the hospital ward, with hospital officials able to stabilize his behavior for only brief periods of time.

Lorraine Pokart Levy, senior supervisor of social work services, child and adolescent psychiatry department at the hospital, said the youth soon regressed.

Finally, the state Department of Mental Retardation and Developmental Disabilities agreed to place Larry in a Queens "developmental center," where he is now.

The youth's mother visits him on weekends and reports that she can see progress.

"When you send out applications, review case histories and hold conferences on an individual that's one thing," Levy said. "When you have such an individual in a ward, in all consciousness you must do everything you can."

National infant screening program

A bill known as the **National Infants Screening Act of 1979** has been introduced by Congressman C. W. Burgener of California with numerous co-sponsors. The bill provides that the Public Health Services Act should be amended so the Secretary of HEW can make grants to public and private entities "to acquire the automated equipment, supplies, and personnel required to conduct multiple screening of blood specimens routinely collected from newborn infants for metabolic disorders."

The bill further provides that no plan

shall be approved unless it includes follow-up and management of detected cases of treatable metabolic disorders; that it provides for phenylketonuria, hypothyroidism, galactosemia, and other conditions as may be required by the Secretary.

It is noteworthy that New York State is far ahead of this program in its mandate for screening not only in these conditions, but others as well. The bill is now in the Committee on Interstate and Foreign Commerce.

Chapter Tips

Have you ever wished you could sit down with the members of your local Committee on the Handicapped in your local school and have a good rap session with them about ARC?

You can. As a chapter project — get a list of the names of the people on your local committee from the school superintendent and see that they receive a copy of OCV.

This list of names will change each year in July but it is easy to keep it up to date.

— Kate Klein,
Co-Chairman Public Information

N.J. Racing Day nets over \$400,000

In 1977, the New Jersey Legislature passed a law permitting racing tracks to have an extra day with the state's take to go to the agencies servicing the developmentally disabled.

The money went to the Disabilities Council and was distributed on the basis of: A) A weighted scale, the amount of importance of variety of services rendered to clients by each local unit and B) The number of disabled in that category.

Finally, on August 2nd, approximately three weeks after the first half of the scheduled 1979 Charity Racing Season had been completed, \$422,369 was slated for distribution and a little over \$300,000 went to the New Jersey Association For Retarded Citizens.

The law covers all flat as well as harness runs throughout the Season.

For two years, the New York State Association has urged the Legislature to pass a similar bill, but without success. In commenting on this, our President, Ellie Pattison said, "We often wonder why other states show so much more sensitivity to the needs of the developmentally disabled than New York State that prides itself on being first, when, of course, it isn't. Let us hope for the best this coming year".

ARC community home position supported

We were very pleased indeed, to receive this letter from our friend Pat Carroll, Executive Director of the Cattaraugus County Chapter of the ARC supporting the ARC's position paper on the regulations for the Operations of Community Residences.

"Dear Jerry:

I read with delight your prepared statement on "Operations of Community Residences. Both myself and staff related to residences were ecstatic and agree wholeheartedly with positions you took and questions you raised. They are identical to our concerns voiced in this area of New York State.

It is getting to the point where I consider it a required condition that all community-based programs attain a sixth sense called "healthy paranoia" in dealing with the State. At one point I foolishly thought the State had an interest in developing community-based programs. More recently, in our area, J.N. Adam is duplicating services to the extent of establishing residences and work activities centers with little, if any, input from the community. However, all of our proposals must go through N.J. Adam, which is the local DDSO process.

I don't mean to bother you with details, but again was delighted in your presentation and thought I would pass on my comments.

Sincerely,
Patrick J. Carroll
Executive Director"

News and Views from the Education Committee

Betty Pendler, Chairperson

"The Mountain Comes To Mohammed"! On Friday, October 12th, a high official of the State Education Department of the Office of the Children with Handicapping Conditions, Mr. Robert Guarino, took a three-hour train ride into our New York office to meet with our Executive Director, Mr. Joseph T. Weingold, and members of the Education Committee to discuss new procedures regarding their position paper called "Special Education Classification and Standards Project". Mr. Neal Rosenberg, Legal Representative for the State Education Department, was also in attendance, as was our very concerned and interested President, Ellie Pattison.

The significant outcome of this meeting was the recognition that the State Education Department is seeking our input, and wants to have a cooperative relationship with us. Mr. Guarino promised that our state office will have full input into any changes in the regulations prior to their submission for approval.

We all agreed to do away with the nebulous term "Least restrictive environment" and replace it with "Most Ameliorative Environment" so that our children would be placed in the environment which will make it possible for them to function at their highest ability at the moment, and encourage them to go beyond.

More and more, the role of the individual chapters will be to advocate for quality programming within the public school system, and, like Schoharie County Chapter, who recently discontinued their program for school age children, all chapters will be called upon to work with parents and the school system. We hope, therefore, each chapter will have in place an active Education Committee to assist those parents and get involved in being fully informed of due process procedures, etc., to help your members get through the educational system. The Education Committee stands ready to assist chapters in workshops and literature.

How impartial are the "Impartial Hearing Officers?"

Kindly share your experiences with us. The Education Committee is seeking information on how impartial hearing officers are selected in your district.

What is "Appropriate Transportation?" as stated in Section 4405 of the State Education Law? The Education Committee wants to present a position paper regarding transportation services to the Office of Children with Handicapping Conditions. Won't you send us your experiences — with problems in transportation; i.e., types of vehicles used,

services provided, length of time spent on buses, safety practices, etc.

Why not set up a joint workshop with BOCES, Schools of Education — State Education Department as Joan Fiala of Broome-Tioga Chapter did recently, inviting representatives of BOCES, Broome Developmental Center, SUNY at Binghamton, representatives of the State Education Department, and Thomas



L to R Georgia Sullivan, Neal Rosenberg, State Education Dept., and Robert Guarino consulting at meeting at State office.



At the same meeting — L to R — Tom Scholl, Marilyn Wessels and Chairperson of State Education Committee Betty Pendler.

Scholl, our Regional Committee Member, all of whom gave the audience lots of information.

Please contact the Members of the ARC Education Committee in your region if you have any specific concerns or wish to receive additional information regarding Education.

William Albertin, RD No. 2, Amsterdam, New York 12010

Joan Fiala, 19 Exeter Drive, Endicott, New York 13760

Dr. James Johnson, 30 Morrison Ave., Plattsburgh, N.Y. 12901

Betty Pendler, 267 W. 70th St., New York, N.Y. 10023

Shirley Reynolds, 864 Colvin Blvd., Kenmore, N.Y. 14217

Thomas Scholl, 7528 Moon Valley Drive, Liverpool, N.Y. 13088

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Sally Threw, Box No. 12, Brant Lake, New York 12815

Marilyn Wessels, 160 Clayton Road, Schenectady, N.Y. 12304

Donald Boudov, Executive Director, Onondaga County Chapter, ARC 600 South Wilbur Avenue, Syracuse, New York 13204.

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

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

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CHAPTER AFFILIATION

Return to:

Betty Pendler, Chairperson
Education Committee

N.Y. State Association for
Retarded Children

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