

Our Children's Voice

Retarded Children Can Be Helped

VOL. XXXIII NO. 2

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

SEPTEMBER 1981



Irene L. Platt, president of the New York City Association for the Help of Retarded Children, presents the group's Humanitarian Award to Gov. Hugh L. Carey, who was guest of honor at the organizations 32nd Annual Dinner-dance held at the Sheraton Centre Hotel in Manhattan. More than 1,000 attended the affair. WCBS-TV news reporter Arnold Diaz served as Master of Ceremonies and comedian Nipsey Russell entertained at the event held on May 16. Carey was honored for his deep interest, friendship, support and dedication to the mentally retarded.

Sherwood promoted Westervelt hired

With the movement of John Bertrand to the position of Executive Director, effective December 1, 1980, there were some additional changes in the A.R.C. State staff.

Geraldine Sherwood, who had been employed in the position of Program Co-ordinator since December, 1975, was named Assistant Executive Director, effective January 2, 1981.

Donald Westervelt was hired, effective March 30, 1981, in the position of Field Representative, replacing that of Program Co-ordinator.

Mrs. Sherwood, or "Gerry" as so many of us know her, earned her Bachelor degree at Dominican College, where she majored in history and had a minor in Sociology. She received her Master of Science degree in Special Education at Yeshiva University where she is continuing post graduate studies in Administration. She also received Montessori Teacher Training at Fairleigh-Dickinson University and interned at the Montessori School of Early Learning. Her teaching experience includes both regular and special education classes. No stranger to ARC by background, Mrs. Sherwood had been employed for four years by the Rockland County Chapter as the Director of Children's Services. During her years there, areas of Language Development

and Physical Education were developed and an Early Intervention Program was started.

After leaving Rockland County Chapter, Mrs. Sherwood stayed active in the field, working as a Coordinator of Staff Training for the Homemaker - Upjohn Program, where she designed and implemented an orientation program for paraprofessionals working with a multi-handicapped population. A member of the AAMD and CEC, Gerry has already made her mark within the Association, and her appointment was greeted with enthusiasm by many Chapters.

Don Westervelt was one of six excellent finalists considered for the Field Representative position. A native of New York City, he grew up on Long Island. Don attended C. W. Post College and graduated magna cum laude from New York Tech. He has had advanced studies in Hofstra and Cornell Management Programs.

A veteran of four years in the Air Force, Don spent twenty successful years in business before coming to the A.R.C. He was the plant manager for several business firms in Long Island, and dealt with personnel, inventory, production and other phases of business. In 1978 he decided to try the world of Social Services and was hired as Manager of Operations by the Oneida County A.R.C.

Legislative Review

by Joseph T. Weingold

Although not actively involved in the legislative process this year, I have reviewed the 1981 legislation that may affect the mentally retarded and other developmentally disabled in N.Y.S. State.

Such a review is a most disheartening experience. As of this writing, about two-weeks before the end of the Legislative Session, almost nothing of real significance, with the exception of one bill, has passed the Legislature.

This is Chapter 253 of the Laws of 1981 introduced by Assemblyman Haren Berg (A-7245). It amends the Insurance Law to continue health insurance coverage for unmarried children, (covered under a non-profit group health policy,) incapable of self-sustaining employment by reason of mental illness or developmental disabilities. Note this is a group policy only, not an individual policy, and has to be a non-profit group health policy. It is of extremely limited value, but represents some advance.

We are also informed that A-663-A (Hevesi), an omnibus Civil Rights Bill for the disabled that amends the Civil Rights Law, Executive Law, Labor Law, Education Law and Insurance Law (to prohibit discriminatory practices with regards to civil rights, housing, admission to college, employment, including admission to labor organizations and life insurance), may have passed at this time. We are waiting further word and a copy of this bill. If it has passed, and if it prohibits discrimination in writing life insurance solely by reason of the mental retardation of the insured, it will cover one of the other bills we have been pushing for several years. It will also confirm the civil-rights of the mentally retarded and other developmentally disabled.

Although there are probably dozens of bills that have been introduced that may affect the welfare and lives of the mentally retarded, I am going to list here those I have culled from the Legislative Index and I consider of paramount importance at this time.

These were sent out in a Legislative Bulletin and are listed not necessarily in the order of their importance and the Association's stand on the measures:

(1) A bill to include interest accrued and paid after August 1, 1981 on obligations issued by the State Housing Finance Agency to finance community and mental health or community and mental retardation service projects as part of an operating cost.

This is a very limited bill in time and scope and applies, probably, to five projects in the state involved with building facilities through community mental retardation service companies. (S-4378, Levy; A-6054, Kremer). (S-4860A, Padavan; A-7895A, Connelly). This Padavan-Connelly bill was passed June 23, 1981.

Although the Association approves this bill, it has urged (in the past) that legislation be introduced to include interest on all loans obtained by Chapters to help finance operations when funds are not forthcoming on contracts with the State.

Such legislation, to my knowledge, has not been introduced.

(2) A Fee-For-Service Bill, whereby the State will pay fees to providers of services for sheltered workshop activities and day-training services. In effect, this is our 100 percent bill of previous years and supplements the law passed last year on Fee-For-Service for community residences.

We are certainly in favor of this bill. (A-8538 at the request of Elizabeth Connelly and others). At this point, the bill rests in the Mental Health Committee in the Assembly. There is no Senate bill.

(3) A bill that provides Not-For-Profit corporations having no salary or compensated officers shall not be required to be brought within the coverage of the Workers Compensation Law except as they wish to file a form electing to do so. (S-4966, Pisani; A-4509, Robach). The Association is heartily in favor of this bill because the Workers Compensation has penalized many of our Chapters by rating the handicapped workers very highly and not taking experience into consideration. We are still covered by liability although this is not as complete as Workers Compensation where no negligence has to be proved. Nevertheless, it may save the Association's Chapters many thousands of

(Continued on Page 12)

Convention to be held in Albany

Looking back — moving forward.

That's the theme for the 1981 New York State ARC Convention, to be held at the Best Western Turf Inn in Albany, New York from October 15th to 18th.

The 1981 State Convention promises to be a very interesting and informative weekend, as we examine a number of issues of vital importance to the future of Mentally Retarded Citizens of our State.

The impact of Federal budget cuts, the implementation of a new fee-for-service funding system for Community Residences, the ability of our Chapters to continue to provide quality services at a time when funding for human services is decreasing, the choice between Community Residences and Intermediate Care Facilities for the Mentally Retarded; these are but a few of the topics to be examined at the 1981 State Convention.

This year's Convention will be a cooperative effort with Representatives from the Rensselaer, Albany and Schenectady County Chapters already meeting together to plan this important event. Further details on the Convention will be sent to all Chapters as this group continues its work.

For now, be sure to mark your calendar for the weekend of October 15 to 18 and plan to spend three days "looking back and moving forward".

CONVENTION — ALBANY — OCTOBER 15-18

A Letter to share

In our last 1980 issue of OCV, there was an article entitled Parents Become Professionals that had a misprint in the first paragraph. The paragraph read: "Does a Professional really know what its like to live with a **regarded** (instead of retarded) child?"

Picking this up, an old friend wrote to Mr. Joseph T. Weingold, then Executive Director of the Association, and we share her letter in full.

Dear Jerry:

I am Patty James's sister (Helen James is our mother) and I wanted to write you, to tell you how much I enjoy reading **Our Children's Voice** each time it comes. It has so much news in it and interesting articles that are informative to me. It seems to me to get better all the time.

I have worked over the last ten years as an editor and writer and I guess, though I really have progressed way beyond it, I'll never stop proofreading. I loved the enclosed typographical error from the last issue because I thought it was inspired. The typesetter substituted a "G" for a "t" in retarded making it a "regarded" child, which I think is perfect since being regarded, as people with needs and feelings, is one of the biggest hurdles we face in living with and loving a retarded person. I just couldn't resist pointing it out to you because I thought it was a wonderful slip that was meaningful to me.

Someday I want to write the story of what's happened to Patty in the last 18 months — which would have to, of course, incorporate the last 40 years as well — but it is a miracle that says more about small home group care than words can even describe. In fact, even though I'm a writer, I find myself at a loss for words every time I leave her after a visit. She has truly found an adult home and she is overcoming so many problems and behavioral difficulties with the loving support of the wonderful people she lives with who see her as a total human being. They are more accepting than even we, her family, at times and, as a result, she has more self-esteem and confidence in herself than she's had in years. To think, she was only inches away from Creedmore and we as a family were more desperate than we'd ever been just two years ago. If we hadn't found Weigand Farm and Finnegan House in Milton, New Jersey, we all would be going through God knows what — and especially Patty. I'm still too overwhelmed by the whole thing to write about it. Everytime I do, my eyes fill as they are now and I can't see the typewriter keys!!!

We all hope that all goes well with you. Keep up the good work!

Warm wishes,
Shirley J. Longshare

One letter to the Editor

Dear John:

Congratulations to you on being cited in the May 1981 issue of "Personnel Practices and Labor Relations" for their references to "Our Children's Voice" as being an outstanding publication at the state level for non-profit organizations.

Our ARC really captured the honors in that issue with the Livingston - Wyoming Chapter being cited also as having an outstanding newsletter at the local level.

Be sure you include both citations in the next OCV and keep up the good work.

Sincerely,
Shirley J. Reynolds,
Education Director
United Cerebral Palsy
Association of Western
New York, Inc.

(Now that we have a new editor to this paper, we're wondering if we'll be able to keep up this kind of honor. We hope so.)



Equal rights for handicapped

Hempstead Town Presiding Supervisor Thomas S. Gulotta (left) proclaims Bill of Rights for the Handicapped Week in recognition of the 1973 state resolution guaranteeing all people with handicapping conditions the same rights and privileges enjoyed by their fellow residents. Joining Presiding Supervisor Gulotta for the Town Hall ceremony are (L-R) Town Clerk Daniel Fisher; Linda Leaf, director of Open Island Program of the Human Rights Commission; Don Dreyer (receiving proclamation), director of the Office of the Physically Handicapped of the Physically Handicapped; James V. Denon, commissioner of Open Island Program; Harry Schweitzer of the Nassau County Dept. of Health's Physically Handicapped Children's Program with Ed Webb of the American Heart Association, Inc.

Raymond named to Task Force

Michael J. Raymond, Executive Director of the Chautauqua County ARC has been appointed by the Office of Governor Hugh Carey to a State Task Force examining independent living programs in New York State. Mr. Raymond was appointed because of his demonstrated interest in services to the disabled. The purpose of the Task Force is to determine the possibility of expanding independent living programs through improved coordination and utilization of existing federal programs.

Under a recent federal initiative up to 15 states will be selected to receive \$80 million of additional independent living program resources from seven core federal programs. Participation of states will be determined on the basis of the content of letters of intent, submitted by a task force, describing independent living resources within their respective states.

The Task Force is composed of disabled consumers and advocates and representatives of state agencies responsible for administering available federal programs.

If New York State is selected to participate in the federal initiative, the Task Force's responsibilities will expand. It will solicit project proposals from community organizations interested in developing or expanding independent living projects; review and rank proposals according to project merit, and forward for federal review; serve as a coordinating mechanism for the delivery of state-pass-through federal services to local projects; ensure smooth implementation of this initiative at the state and local levels; and provide necessary technical assistance to the projects.

Mr. Raymond was appointed by Irving H. Freeman, Assistant Secretary to the Governor for Education and by Jeffrey A. Sochs, DDS, Assistant Secretary to the Governor for Human Resources.

Operation Horseshoe

On Sunday, February 8, 1981, nine people affiliated with the Wayne County Chapter traveled to Niagara Falls to participate in "Operation Horseshoe".

The Participants included four clients: Geraldine Kirbis and Loretta Garrison from the Day Activities Training Program, Charles Gravino from the Vocational Rehabilitation Center and the Clyde Community Residence, and Jim Cusimano from the Lyons Community Residence. The volunteer staff attending were Patty McKinny, Joan Muoio and Shirley McNaney from the D.A.T.P., Joe DeMarco from the V.R.C. and Albert McNaney, a representative from the N.D.C. Board of Visitors.

"Operation Horseshoe" was the first event to celebrate the United Nations year for the Disabled Person. A human Horseshoe made up of over 12,000 people stretching from Goat Island, New York, across the Rainbow Bridge to Table Rock Point, Ontario assembled to emphasize the theme "Disability Knows No Borders". Despite the blowing snow and below freezing temperatures, most people in the horseshoe stood outside for two hours until the signal was given to raise their phosphorous lit candles. Following the symbolic lighting, fireworks were set off over the falls.

All participants were invited to a party at the Niagara Falls Convention Center after the ceremony was over. Refreshments were served and several ethnic groups provided entertainment.

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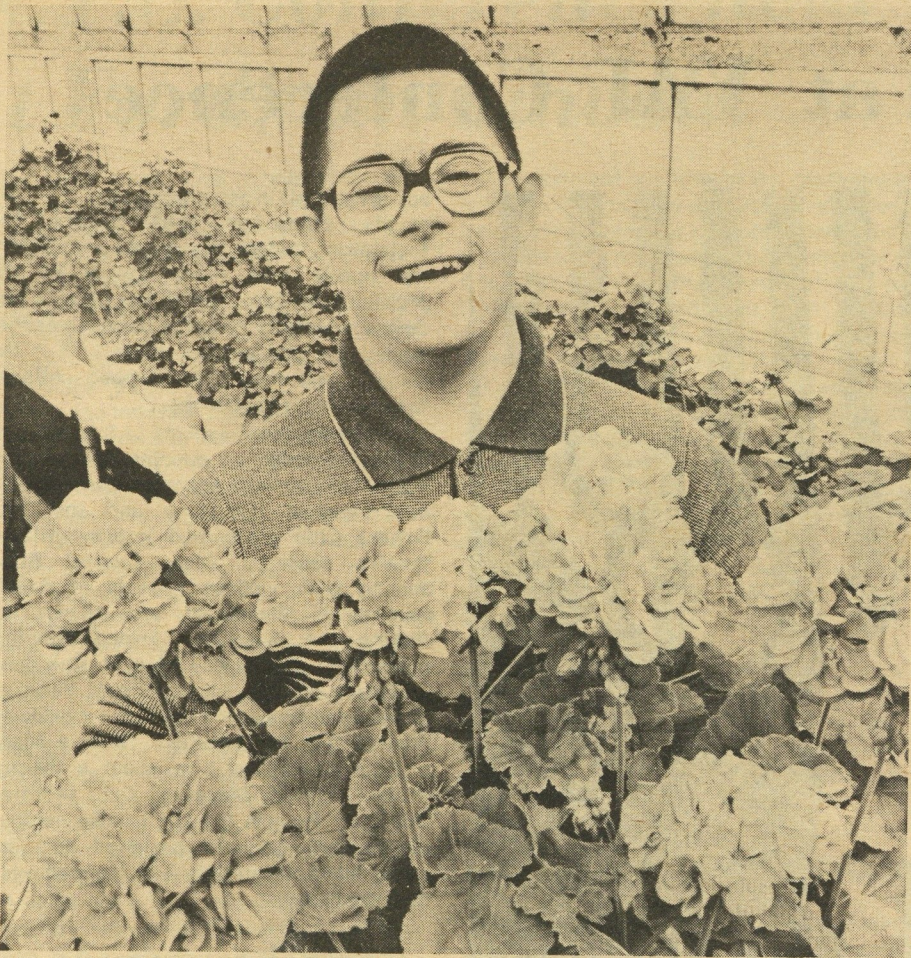
NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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Everything came up geraniums at the Nassau Association For The Help of Retarded Children this spring. Thirteen men work in the horticultural program and while the activities are year-round the high point is the AHRC Famous Geranium Sale which last year saw nearly 10-thousand plants sold to the public. This year should even surpass that record. The sale ends around early June when the greenhouse starts to concentrate its efforts on the large vegetable plot. The assembly of holiday decorations starts with the fall.

Rome D.C., Onondaga, Schyler ARC membership pacesetters

In a year when chapter membership in the Association seems to be sagging, ten of the Association's chapters have done an outstanding job with membership, surpassing goals set for them for this year and in some cases almost doubling previous memberships.

Three of our most outstanding efforts were turned in by Onondaga County Chapter where Mary Carol Fisher was membership Chairperson, Rome Developmental Chapter where Ethel Lombard was membership Chairperson and Schuyler County where Mrs. Thomas Brown led the way.

Onondaga, which slumped badly last year to a final membership of 181, has reached one of its highest membership totals yet, submitting 562 names. At Rome Developmental Center, Ms. Lombard more than doubled last year's membership total. Struggling with the shrinking membership as the institution itself grows smaller, Rome D.C. had last year turned in a membership of 158, which was an increase of 28 from the prior year. Proving, however, that enthusiasm goes a long way. Ethel Lombard set out this year to surpass the Association's goal of 175 memberships for the chapter and did so

with a resounding explosion. With a few more memberships still anticipated as forthcoming, the chapter has already submitted 318 memberships, more than doubling their previous year's total.

The Schuyler County effort was also an outstanding one. A relatively new chapter, Schuyler has turned to membership from its earlier days, obviously being willing to show other chapters what you can do even in a small county. In 1980-81 the chapter has gathered a total of 224 memberships and their goal for this year had been set at 260, on the incorrect assumption that they had perhaps located just about every potential member in the county. Proving to us how wrong we could be, Mrs. Brown has turned in a record 391 memberships from Schuyler county. Both Schuyler County and Rome Developmental Center will have an additional representative to the Board of Governors this fall because of their membership efforts, as will Delaware County which also went over the 300 mark this year. Our congratulations to those who did such fine work.

The ten chapters which have already surpassed their goals, and their membership chairpersons are:

YOUR LOSS CAN BE BIG GAIN FOR PERSONS WITH M.R.

The chapters of the New York State ARC have entered into the State Lottery Commissions cash-back competition for collecting losing lottery tickets for the benefit of the organization. This is a program set up by the State Lottery Commission for non-profit organizations and there really is no trick to it. Individuals simply submit their losing "instant winnings" tickets to their local chapter and they in turn submit them to the State Association. We are entering the tickets with the Lottery Commission on behalf of all chapters. The competition is being run in four quarterly segments from April 1981 through March 1982. Each calendar quarter the group in the state collecting the most losing tickets will receive \$5,000, the second group \$2,500 and the third prize 1000 tickets. There will be 5 consolation prizes of 500 instant winning tickets and 22 honorable mention prizes of 100 instant winning tickets. The State Association will be dividing any prizes won on a pro-rata basis with all participating chapters, and individual chapters will receive one cent each for every losing ticket turned in.

What can you do to help? If you participate in the State Instant Winnings

Lottery (Green tickets) you can save any losing tickets that you have. These can be given from time to time to your local ARC Chapter for submission to the Association or, if you have no active lottery chairperson in your chapter, you can send the tickets directly to the State Association and we will be glad to credit them to your chapter for any benefits that we may obtain.

As of the end of May 1981, the Association stood in third place in the State in terms of numbers of tickets collected. It is our hope that we can be the first place winner in each calendar quarter and for the year as a whole. Your losing tickets could help the mentally retarded win much needed funding. Won't you please participate?

The following chapters have designated specific individuals to act as their lottery chairperson, and we include the names and addresses for your benefit. If there is no chairperson named in your county, we would be pleased if you would see your way clear to send your losing tickets to New York State Association For Retarded Children, Inc. 175 Fifth Avenue, New York, N.Y. 10010.

CHEMUNG COUNTY, ARC

Richard D. Peet, Treas.
743 Dawn Drive
Elmira, N.Y. 14904

CHENANGO COUNTY, ARC

Thomas M. Whittaker
11 Howard Street
Norwich, N.Y. 13815

CLINTON COUNTY, ARC

Kathy Ryan
14 Lakeside Ct.
Plattsburgh, N.Y. 12901

COMMUNITY LEAGUE — WASSAIC CHAPTER

Michael LaSala
47-21 41 St.
Sunnyside, N.Y. 11104

CORTLAND COUNTY, ARC

Karin Burgess
P.O. Box 764
Cortland, N.Y. 13045

DUTCHESS COUNTY, ARC

Mrs. Muriel Anderson
Valley View Road
Pleasant Valley, N.Y. 12569

ERIE COUNTY, ARC

470 Franklin St.
Buffalo, N.Y. 14212

GENESEE COUNTY, ARC

Jan Dentino
c-o 64 Walnut St.
Batavia, N.Y. 14020

LEWIS COUNTY, ARC

Mrs. Louise Cooke
36 Trinity Ave.
Lowville, N.Y. 13367

MONTGOMERY COUNTY, ARC

9 Pershing Rd.
Amsterdam, N.Y. 12010

NIAGARA COUNTY, ARC

Judy Goldberg
1555 Third Avenue
Niagara Falls, N.Y.

ORANGE COUNTY, ARC

Susan Garrett
84 Sandburg Ct.
Middletown, N.Y. 10940

ROME DEVELOPMENTAL CENTER

Ed McCaffrey
Box 550
Rome, N.Y. 13440

SUFFOLK COUNTY, ARC

Eileen Fleischer
2900 Vets. Hwy.
Bohemia, N.Y. 11716

WELFARE LEAGUE — LETCHWORTH VILLAGE

Sherri Hecht
P.O. Box 812
Thiells, N.Y. 10984

YATES COUNTY, ARC

Linda Travis Skinner
Williams Hill Rd.
Bluff Point, N.Y. 14417

Chapter	Chairperson	'80-'81 Membership	'81-'82 Goal	'81-'82 Membership
Chemung	John Bryant	220	300	387
Cortland	Sara Discenza	137	175	194
Delaware	—	250	300	315
Franklin	Sadie Reandeau	83	110	117
Genesee	—	404	450	459
Onondaga	Mary Carol Fisher	181	225	562
Oswego	Kathy Boutell	74	100	139
Rome D.C.	Ethel Lombard	158	175	318
Schoharie	Dorothy Keyser	135	175	209
Schuyler	Mrs. Thomas Brown	224	260	391

YES, I want to help, Enclosed are _____ losing "Instant Winnings" Lottery Tickets.

Please credit them to _____ Chapter.

Your Name: _____

Address: _____

Critical issues reviewed at YAI Conference



The three ladies on the left are members of the Canadian ARC's "People First" movement; the gentleman in the middle of this picture is Dr. Hugh LaFane, Director of the Canadian ARC and former Director of the O.D. Heck Developmental Center. Beside

Dr. LaFane, on the right are: State President, Eleanor Pattison, Community Residence Chairperson, Henrietta Messier and Education Committee Chairperson, Betty Pendler along with the Executive Director of the Young Adult Institute, Joel Levy.

By John J. Scaturro

During the week of April 6th, 2,500 people, including professionals, educators, students, consumers and advocates in the field of Developmental Disabilities, gathered in New York for the Young Adult Institute and Workshop's International Conference. "The turnout was fantastic," said Executive Director Joel Levy of the Young Adult Institute. He continued, "Twenty years ago maybe 250 people would have come. It says a lot about the interest in disabled people, their rights, their plight, and the services they receive, generated over the last two decades.

The conference, entitled "From the 60's into the 80's: An International Assessment of Attitudes and Services for the Developmentally Disabled," also drew many people from allied disciplines as well as government representatives from all levels, because of its broad spectrum of panels, symposiums and workshops. Speakers and participants came from as far away as Canada, Luxembourg and Uruguay, making this conference a truly International Assessment.

Over the three main days of the YAI International Conference, April 8th, 9th, and 10th, over 35 different symposiums addressed such varied topics as:

1. Implementation of Normalization and the Least Restrictive Environment Alternatives
2. Various Medical Issues in Mental Retardation
3. Consumer Advocacy
4. A Political Forecast - Political Issues Impacting on Delivery of Services to the Mentally Retarded.

SOL GORDON ON SEX

A truly dynamic session was presented by Dr. Sol Gordon on *The Missing Link in Rehabilitation - Sex: Promotion of Self-Esteem and Responsible Sexuality*. Dr. Gordon seems to have a humorous anecdote to illustrate each topic that helps drive home the concept. As Phil Levy,

Associate Executive Director of YAI, said: "He was great. He had so many good things to say and such a way of getting them across. After the humor wears off, I'm sure everyone's going to remember a lot of points he made."

Other highlight sessions included, but were not limited to:

Instrumental Enrichment: Teaching the Mentally Retarded How to Think, during which Dr. Leonard Blackman and Dr. Reuben Feuerstein addressed the particular problems faced by the borderline mentally retarded clients in various programs.

Development of Attitudes and Problems in Changing Attitudes, which discussed various techniques of measuring attitudes and strategies of implementing change in attitudes in the community.

Penhurst - Willowbrook: What Does it all Mean? This panel, consisting of professionals who worked on both cases, discussed each movement from a historical perspective, noting the different approaches taken to implement judicial social action strategies in order to shape state governmental policy toward mentally retarded and developmentally disabled citizens. This symposium proved to be extremely timely in that the very next week the U.S. Supreme Court handed down a ruling which will have a devastating impact on the movement.

U.N. HEADQUARTERS MEETING SITE

On Wednesday evening, April 8th at United Nations Headquarters, 750 people gathered for the Plenary Session of the conference. There, consumers, providers, and others interested in Developmental Disabilities, heard some of the most important people in the field address various topics on the theme of the International Year of Disabled Persons.

Bengt Nirje and Niels Erik Bank-Mikkelsen, early proponents of the deinstitutionalization movement in Scandinavia, spoke about the International

Perspectives of Planning and Implementation of Services and Programs for the Mentally Retarded.

Harold O'Flaherty and Leila Doss of the UN spoke on the International Year of Disabled Persons and the ramifications here in the United States and the developing nations of the world, respectively. Dr. Herbert Cohen, from the President's Committee on Mental Retardation, addressed the future of services and a programming in this country.

For a political perspective, the diverse audience heard from Commissioner James Introne, State Office of Mental Retardation and Developmental Disabilities, and Commissioner Sara Kellermann, New York City Office of Mental Health, Mental Retardation and Alcoholism Services. Both addressed the important and timely issue of funding, now and in the future. They also stressed the importance of maintaining community-based services and remaining committed to the concepts of "deinstitutionalization" and "the least restrictive environment".

COMMITMENT FROM ALL

As a provider, Joel Levy also stressed that commitment was necessary from all factions, both public and private, in order to maintain the high quality of services famous in New York. Mr. Levy summed up the sober mood of the evening when he said, "Today we look at our achievements with great pride. However, we realize that there is much work ahead. Communities must be informed of the needs of the mentally disabled, Creative programmatic concepts must be implemented. Appropriate funding sources must be available to all of our clients. Consumers, parents, volunteers, agencies and interested government officials must work together. We have gathered here tonight to lend our support of this monumental task. But we must make it clear throughout the world that we are determined. . . Mr. Levy went on to say, to the unanimous

approval of all in attendance that, "... We must remember that before the legislators, before the media and before the public was made aware of the problems we face, it was the parents and developmentally disabled themselves that waged the war against neglect. It is the parents and their handicapped children that are the real heroes. . ."

Some additional aspects of interest and delight included an ongoing Information Fair where various agencies disseminated informational literature and the YAI Drama Club performed improvisational theatre projects. Also, several films dealing with various aspects of developmental disabilities were shown, including the Academy Award winning documentary *Best Boy*; A U.N. film done in honor of the International Year of Disabled Persons, *It's the Same World*; an African film presentation, *To Be a Man*; and an Australian film about a theatre project called *Stepping Out* (entitled *Breaking Free* in the U.S.). Also various bio-medical gadgets designed for the physically and multiply handicapped were demonstrated.

SELF ADVOCACY SEMINAR

On Wednesday afternoon, a self-advocacy seminar was held by members of the "People First" movement in Canada. Twenty Canadian consumers were the guests of the Young Adult Institute during the conference week and stayed at YAI community residences. These consumers spoke about the similarities and differences in programming and encourage New York consumers to get involved in a self-advocacy movement. On Friday evening, April 9th, YAI hosted a party for staff, consumers and conference speakers and attendees at the Young Adult Institute's Manhattan Day Treatment Program. Over 150 people attended including Dr. Hugh LaFane and Bengt Nirje. Tentative plans were also made for 20 YAI consumers to visit their new Canadian friends this summer in a sort of exchange program.

One of the impromptu highlights of the conference occurred at Friday afternoon's cocktail party where conference personnel and attendees got to chat informally with many of the conference speakers including Bank-Mikkelsen and Nirje.

The night before, both men were honored at the YAI International Ball held at the Waldorf-Astoria. Gloria Vanderbilt, mistress of ceremonies, presented Bank-Mikkelsen and Nirje with the 1981 YAI Humanitarian Award for service embodied in a beautiful piece of engraved Steuben Glass.

All in all, the conference was a tremendous success and an important event in the history of service to the Developmentally Disabled people of the world. As conference coordinator, Nina Lieberman put it, "This was a once-in-a-lifetime event and we are pleased to see so many people in the field taking advantage of this unique assemblage of professionals. We here at the Young Adult Institute are extremely proud to have been the hosts of such an important event."

**Wait. Don't throw away
that 'instant loser'. Make it
a winner for the retarded**

N.Y.C. Conference held at Fordham Lincoln

The New York City Conference on Prevention of Mental Retardation and Developmental Disabilities was held on June 4, 1981 at Lincoln Center Campus of Fordham University.

The Conference was jointly sponsored by the Association for The Help of Retarded Children, New York City Chapter; the New York State Association for Retarded Children, and the New York State Institute for Basic Research in Mental Retardation. Dr. Jack Gorelick, Associate Director of the City Chapter, was the Conference Chairperson. He was ably assisted by Gerry Sherwood, Assistant Executive Director of the State Association.

The keynote speakers were: Dr. Margaret Giannini, former Director of the Mental Retardation Institute, Valhalla; Dr. Herbert Cohen, Professor, Albert Einstein College of Medicine and Vice-Chairperson of the President's Committee on Mental Retardation; and Dr. Linda Randolph, Associate Commissioner, N.Y.S. Department of Health.

More than 200 persons attended, participated in discussions, and helped formulate the recommendations. Afternoon workshops were held on: Genetic Disorders; Environmental Factors; Program Design and Evaluation; and Community and Professional Education.

Chautauqua meets on prevention

On April 2, 1981, the Chautauqua County Resource Center co-sponsored a one-day workshop on Preventing Mental Retardation and Developmental Disabilities.

The workshop content was based upon the information found in a two-volume curriculum handbook designed for use with teenagers on the topic of prevention. The curriculum, **Toward the Prevention of Mental Retardation in the Next Generation**, was developed by Ms. Sarah Litch and has been adopted by the schools in Indiana and in Iowa. Ms. Litch has presented the curriculum throughout the U.S. and in four foreign countries. It has generated enthusiasm and interest wherever it has been presented.

The workshop was presented by Ms. Litch, Director of the Project, Prevention: To Be Born and Grow Well, and by two of her associates, Dr. Samuel Rhime, a staff geneticist for the Marion County Association for Retarded Citizens, and Dr. Curtis Leggett, professor of special education at Indiana University.

The workshop was coordinated by the Western New York Task Force on the Prevention of Mental Retardation and Developmental Disabilities, which was formed in September, 1980. Our Agency is represented on this Task Force by Pamela Murphy-Cleary, Director of Children's Services.

The Task Force had arranged to have Ms. Litch and her training team present the same workshop in the Buffalo area on April 1st before traveling to Jamestown for a second session.

The training itself was offered free to area teachers, public health personnel, parents, etc. Our Agency staff was also present.

The cost for the training was co-sponsored by the Chautauqua County Resource Center, the New York State Division for Youth - Chautauqua County Youth Board, and the Jamestown Public Schools.

An important outcome of the conference will be the formation of a permanent New York City Committee on Prevention which will work closely with the Governor's Conference for the Prevention of Developmental Disabilities and Infant Mortality to promote and implement the State's Prevention Action Plan.

The Conference recommended that barriers to providing quality prenatal and delivery care due to economic or cultural factors be eliminated; and that all children be screened for developmental problems at birth, between 15-24 months, at school entry; and at 10-15 years of age. Early intervention and mandated education beginning at age 3 was endorsed.

Strong support was given for the development of prevention education programs within the schools, and for incorporating prevention issues in the training of physicians, nurses, teachers, social workers and other professionals.

Burgess appointed

Karin Burgess, a member of the Board of Visitors of the Syracuse Developmental Center, has been appointed chairman of the state Council for Mental Hygiene Planning by Gov. Carey.

The State Senate has confirmed Burgess' appointment.

The council sets and reviews goals, plans and implementation of mental hygiene programs and reports to the governor.

Burgess is an executive committee member of the state Association of Boards of Visitors; chairman of the Institutions Committee and executive director of the Cortland County branch of the State Association for Retarded Children; and past president of the Board of Visitors of the Syracuse Developmental Center.

Herkimer holds Prevention Symposium

The second annual **Symposium on Developmental Disabilities**, sponsored by the Herkimer Chapter was held on May 28 and 29, 1981 at the Herkimer County Community College in Herkimer, New York. Parents and professionals were invited to participate.

Harold Russell, Chairman of the President's Committee on the Employment of the Handicapped since 1963, was the keynote speaker. Mr. Russell lost both of his hands during World War II in a demolition accident. During rehabilitation he became so adept at the use of his prosthesis that he was asked to act in a film to encourage other veterans in their rehabilitation. The quality of his acting caught the eye of a Hollywood producer resulting in a supporting role in the now classic 1946 film, **The Best Years of Our Lives**. This role earned Mr. Russell two Academy Awards. Following this film success, President Truman invited the young veteran to be a member of the new council being formed for employment of the handicapped. Mr. Russell has served on the President's Committee ever since.

Mr. Russell currently heads his own firm which does research and studies for government and private industry to encourage training and hiring of the handicapped. He has made seven trips around the world on behalf of the handicapped. Mr. Russell is currently co-starring in a new film, **Inside Moves**. Mr. Russell has described this film as "a simple story", revolving around a handicapped bartender with a bad leg who yearns to become a



The greenhouse being used in Chautauqua County's new horticultural program.

A growing experience

Approximately 25-50 handicapped individuals will be "green - thumbing it" at the Chautauqua County Resource Center as they participate in a horticulture training program for handicapped clients. The program has begun with the leasing of 20,000 square feet of greenhouse at the former Johnson's Florists in Jamestown. The clients of the Resource Center will be taught, under the supervision of a horticulturist, how to raise vegetables, plants and flowers. Within this 20,000 square feet of space are seven houses that are operational and two that will be refurbished.

Currently, several of our clients are sorting through the numerous plants that were left in the greenhouse. Many of these have already begun to revive. In preparation for Memorial Day, 8,000 geranium plants arrived the last week of February. Clients have already begun planting Christmas Poinsettia bulbs, of which cuttings will be taken sometime in July or August. In addition, we are

planning such plants and flowers as fuchsia, begonias and ivy geraniums. Plants will be raised to sell both for retail and wholesale. The Center will initiate a new service of plant rentals to various professionals for use in offices in the Jamestown area. A florist shop will be open five days a week for the sale of flowers for all occasions. Floral catering will also be provided for weddings.

In addition, the vegetables grown at the greenhouse will provide a steady flow of fresh produce to the Resource Center's community residences.

At present the CCRC Maintenance Department is doing repair work at the facility in preparation for the opening. The transportation logistics for the clients are also being worked out.

This is the first full scale venture into a program of horticulture by any ARC in Western New York. The ultimate goal of the program is to train clients to a point where they can participate in outside conjunctive job situations.

baseball player. The lure of Hollywood is not apt to divert Mr. Russell from his lifelong dedication to serving the handicapped. As he has noted "about 15,000 young people between the ages of 18 and 29 become confined to wheelchairs each year as the result of spinal cord injuries. Unfortunately, there's no lack of handicapped people."

Mr. Russell addressed the plenary session of the Herkimer Symposium for one hour each morning. He conducted two workshops each day following the plenary sessions. The Friday workshops were geared towards employment. On Thursday evening, May 28 at 7 p.m., also at the college, clips of Mr. Russell's movies and recent television appearances were shown. These were followed by a short presentation by Mr. Russell after which questions from the audience were accepted.

The balance of each day was filled by ten concurrently running workshops. Some of the topics covered were: Your Rights to Medical Records, by Burton Pollack, D.D.S., J.D., M.P.H.; Fetal Alcohol and Other Rx Drug Induced Syndroms, by Ann Willey, Ph.D., from Birth Defects Institute; Minimal Brain Damage and the School Age Child, by John Doris, Ph.D., from Cornell University where he is Chairman of Doctoral Dissertations; Overcoming and Living With a Handicap, by Evelyn Pugh, a mother of three and

full-time employee although she was born without arms.

The Symposium was open to all who wished to attend.



HAROLD RUSSELL, author (with Dan Ferullo) of his new autobiography, **THE BEST YEARS OF MY LIFE**.

(Paul S. Eriksson, Publisher, \$11.95)

CHAPTER NEWS

.... What our Cha

First, in the number of Instant Winner Lottery Tickets for the month of May is the first in the Chapter News this edition. **CATTARAUGUS County Chapter** led the way in May by collecting 4,105 valid tickets. That's the way to go Cattaraugus.

ORLEANS County Chapter will lease space in the newly renovated basement of the New York State Armory Building. This space will allow for the expansion of Orleans Chapter's workshop.

HERKIMER County Chapter sponsored a two-day Developmental Disabilities Symposium on May 28th and 29th at the Herkimer Community College. The keynote speaker was Harold Russell, Chairman of the President's Committee on Employment of the Handicapped. A number of top professionals presented 30 individual workshops for each of the two days.

Our **OTSEGO County Chapter**, in a joint venture with the city, and the Town of Oneonta, has begun a contract to staff the John G. New Glass Recycling Center. The Center was named after a local environmentalist. The clients who staff the Center will be paid minimum wage for this work.

were pleased to see their accomplishments. Everyone who attended had a good time.

Three cheers for **ERIE County Chapter** for the excellent display and presentation they put on at the Annual Home and Garden Show in the Buffalo Coliseum. Rave reviews were received for their work.

We also have to rave over Erie Chapter's **Deposit Here — Losing Cashback Lottery Tickets** posters that were put in with their March - April newsletter. You're a tough act to follow, Erie.

While, for our people at **ONTARIO County Chapter**, the music played and all developmentally disabled residents over the age of ten were invited to learn to dance the "jig" (Irish, that is!) and for those so inclined, square dance lessons were also made available later in the season.

The Saratoga County, Hotel, Restaurant and Liquor Dealers Association sponsored Saratoga County Chapter's Annual Charity Ball this year and donated the \$10,000 proceeds to the workshop.

The only problem at **SCHENECTADY County Chapter** is that they can't grow



The **ULSTER Association for Retarded Children's** new Intermediate Care Facility is nearing completion as the photo taken in January will attest. Located on Murray Street in Kingston, the new facility will serve to meet the medical and therapeutic needs of the residents. It is scheduled to open this year.



There are lots of work activities in addition to direct production at the **NASSAU Association For The Help of Retarded Children's** two vocational training centers which accommodate nearly seven hundred mentally retarded men and women. The centers, located in Plainview and Freeport, Long Island, include food service departments where training is given in a variety of occupations such as food preparation, kitchen maintenance and counter service. In the past some of the trainees have been successfully placed in community jobs.

The Center was funded \$15,000 by the city, \$10,000 by the Town and additional funds from the State Department of Environmental Conservation.

Additional funding was also received for the purchase and renovations of a new building. At last count, \$587,000 in grants and state aid were already in.

NIAGARA County Chapter is expanding its remedial Education Services to the areas of nutrition and Food Purchasing. Initially, this program is to be incorporated into its present remedial Education classes with an eye towards creating a separate class in the future.

Congratulations to our **YATES County Chapter** who recently moved into a new building. The Open House was quite a success. The workers came in to demonstrate the programs and the visitors

enough at their Pine Ridge Greenhouse to supply all the demand for their flower and vegetable plants. This is the third straight growing season that they've been "cleaned out".

GREENE County Chapter has had a change of leadership as Kitty Hagan retired as President of the Board after 14-years of dedicated service to the Chapter. She turned the reins over to Arnold Hyland. Greene Chapter also ran a very successful Bike-Hike that saw 150 riders turn out despite extremely adverse weather conditions. Good work, Greene!

Our **MADISON County Chapter** is doing a fine job with their First Annual Ski-A-Thon that netted them \$400 and 3-weeks of press coverage. Unfortunately, the fire that destroyed five of the Chapter's six

buses in May also made the papers. The five buses valued at \$125,000, were stored for the weekend in a warehouse and were lost when the building burned down. The Chapter has received much support from the community. The local Gannett Foundation awarded a \$1,000 grant for temporary transportation, and the Oneidas tribe donated \$250.00.

On the lighter side, Madison Chapter is promoting a Country - Western Festival / Picnic — co-sponsored by the New York State County Music Association on June 20th and expects to raise \$10,000 for their effort plus a lot more press coverage.

A new barrier-free residence is planned by **ALBANY County Chapter**. It will house 12-multiply disabled persons, Albany Chapter is also expanding its day-treatment and workshop areas.

WELFARE LEAGUE - LETCHWORTH VILLAGE has just completed its Fourth - Annual Meeting to report on the progress of the Advocacy Program. The League considers this one of the most important annual events it sponsors, due to the information and comfort it can bring to those who avail themselves of it.

Welfare League / Letchworth Village Chapter tells us that on a recent visit, Mrs. Fanfani, the wife of the Leader of the Italian Senate, after visiting hospitals for the handicapped throughout the world, said that she was impressed with the quality of services at Letchworth Village Developmental Center.

The new residence, opened in Hermon, is one more example of the fine work we're doing in **ST. LAWRENCE County Chapter**.

The house, incidentally, is historical, having been built in 1870 with bricks made locally from the village's own soil.

J.N. ADAM DEVELOPMENTAL Center Chapter is conducting another terrific membership drive this year. They plan to continue the excellent work they've accomplished.

RENSSELAER County Chapter reports that plans are moving along nicely on the development of a new Day-Treatment Program. Everyone's particularly excited about the fact that this represents the first programming in the northeast section of Rensselaer County.

Rensselaer's Vocational Training Program will also be expanded and a recently negotiated agreement will supply more space for the workshop program in the factory directly opposite the present Rensselaer Center.

CLINTON County Chapter hosted their 27th Annual Banquet on May 16th. It included an enjoyable video tape presentation and the awarding of two continuing education scholarships to Clinton Chapter staff members.

BROOME-TIOGA County Chapter employees are continuing to have great bands to play at their monthly dances thanks to the efforts and contributions of the Musicians Local No. 380 and their national office in Washington, D.C.

It was moving day for **ULSTER County Chapter** employees earlier this year, when they combined the Pilot Industries Programs from Kingston and Saugerties with the administrative offices into one consolidated location in a new facility.

Ulster Chapter has advised us that its new Intermediate Care Facility is nearing completion. The new facility, scheduled to open this year, has been designed to meet the medical and therapeutic needs of the residents.

PUTNAM County Chapter made a great impression on a visiting group of employees from New York State Gas and Electric Company. So great that they went back to the office and obtained pledges totalling \$7,400 for the local fund drive.

The article by Harold Sipes in the "Purchasing Professional" presented the programs and functions of **MONROE County Chapter** in a most exemplary manner. Good work!

NASSAU County Chapter now accommodates nearly seven-hundred workers in two vocational training centers. The Food - Service Programs continue to offer excellent training in the areas of Food Preparation, Kitchen Maintenance and Counter Service that led to successful community employment for many. (PIC)

Congratulations are in order for **LEWIS County Chapter's** 25th Anniversary. This milestone occasion was celebrated on April 23rd with a dinner-dance that was attended by 100-people. ARC President, Ellie Pattison and Rome Developmental Center's Director, Keith Hoffman, were among the honored guests.

A day of festivities preceded the dinner with a ribbon-cutting at the new Child Development Building and an Open House at both the Workshop and Community Residence.

Ribbon cutting in Lewis



At the opening of the Child Development Center, a new program for Lewis County Chapter, were the following scissors wielders in front row — left to right Keith Hoffman, Director of Rome Developmental Center, Kathy Dawson, Director of the Child Development Program, Tom Yousey, Mayor of Lowville, and Ellie Pattison, President of the N.Y.S. A.R.C. Looking on in the back row, left to right, John Bertrand, Executive Director of the N.Y.S. A.R.C., Anne O'Hara, President, Lewis Co. Chapter, Gary Wolcott, Executive Director of Lewis Co. ARC and Robert McCue, landlord peeking out from ??????????

St. Lawrence strikes gold

"After coming within \$200 of its \$30,000 goal, the St. Lawrence County Association for Retarded Children (ARC) will likely make its first fund-raising effort "an annual affair", Executive Director Richard Laurin said recently.

ARC came away with some \$29,800 in profits by selling 2,172 "\$25-shares" that entitled the purchasers to participate in a drawing held on Friday at the Flanders Inn in Massena. A total of \$54,300 was collected in the effort, with some \$24,500 going for prizes and other expenses.

An Oswegatchie man, Richard Seifert, beat the odds and was the winner of the three top prizes in the ARC give-away. His name was drawn for the \$9,000 in gold, an \$8,000 Volkswagen Rabbit, and a \$995 Zenith Beta Max video tape recorder.

Reportedly, Seifert purchased 30 chances to win in the drawing when instead of collecting a \$740 bill from ARC, for pallet lumber he supplies, he gave the association \$10 more and thus had 30 of the

\$25-shares to win.

The ARC attempted the fund raising effort since it lost some \$30,00 last year when the St. Lawrence County United Way withdrew its support of the association."

Executive Director Richard Laurin made the following comment about the fund-raiser. "The key to success in any campaign doesn't necessarily fall to the cause or how well it is administrated or publicized, but moreover, the ability of each individual volunteer being; staff, board member, and friend who spent many hours making contacts in soliciting the donations. Without the more than one hundred volunteers who sold the majority of the certificates, the campaign wouldn't have been successful.

To the 1699 individuals and groups who responded with their contributions, a final word of THANKS! Without you and your generosity, the campaign of course, could not have been a success."

Elmore composes original song for handicapped

In October, 1980, James Elmore (Director of Community Residence for the Niagara County ARC, Niagara Falls, N.Y., and first Vice - President and Board Member of the New York State Association of Community Residence Administrators) recorded a song specifically dedicated to the handicapped.

As you know, January, 1981, marked the beginning of the "International Year of the Handicapped". Mr. Elmore, as a tribute to this major event, wrote the song to present to the U.S. Counsel for the International Year of the Handicapped and other organizations dealing with handicapped. He hoped to have it accepted as the theme song for that year.

The song is entitled "A Special Child" because most people have at least one individual who will be brought to mind from hearing the words. The composition is done in universal terms to cover children and adults with all hadicapping conditions.

The lyrics are:

A SPECIAL CHILD

Special Children
With special needs,
Raised in the world
For all to see.
Trying to become
What they can,
To live in this world
With their fellow man.

Being taught
What they need
To cope with life
and reality.
Potentials and goals
They'll try to seek.
Their highest heights
They hope to reach.

Now is the time
To take the chance
To give them their rights
The best we can.

We've all learned
What must be done,
To help them to live
In this world as one.
So if you listen
To my plea,
You'll cherish the thought,
Their normalcy.

Lyrics and Music by James Elmore
Copyright 1980 James Elmore

For further information regarding this endeavor, contact:

James Elmore
16 Riverdale Drive
Grand Island, N.Y. 14072

As mentioned previously, it is hoped that this endeavor will further enhance all the events proposed for the "International Year of the Handicapped" and perhaps touch a few hearts to donate to efforts for the handicapped.

Chapters are doing for our children and adults

Again, this spring, Lewis County Schools sponsored a Swim-A-Thon, and one district raised almost \$3,000. It is hoped that the total will exceed last year's \$4,000 figure. .

WESTCHESTER County Chapter's 11th Annual Ball was a huge success with a good time had by all. . .

COLUMBIA County Chapter continues to grow as it adds a Day-Treatment Program to its list of service programs.

Our **WAYNE County Chapter** reports that "Operation Horseshoe", the first event to celebrate the United Nations Year for Disabled Persons, was a big success. . .

FULTON County Chapter is in the process of acquiring and renovating the former Bishop Burke High School as the permanent home for their Day - Treatment Program. . .

Everyone was "on the run" in a 4.1 mile race sprint in a fund - raiser sponsored by the Smithtown Junior Auxiliary of the **SUFFOLK County chapter**. . .

The Carnival was in town for the fourth consecutive year, sponsored by the Owasco - Fleming Kiwanis to raise money for **CAYUGA County Chapter's** Camp Columbus and naturally it was a big success. . .

Everyone at **CORTLAND County Chapter** is happy with their new quarters in the McNeil Building on Main Street. The building is barrier - free and the decor is as nice as any you'll find anywhere. . .

CHENANGO County Chapter has come a long way in the past ten years. There were only five or six clients in the workshop then — compared to a current population of 160. . .

SCHUYLER County Chapter's Annual Dinner at the Montour Falls Moose Club was a gala occasion. The support of the community to this Chapter is overwhelming to say the least. With a county population of 16,000, we have built a membership of over 340. Incidentally, the dinner was a sell out! . . .

ROCKLAND County Chapter's new sophisticated packaging machinery is opening the doors for new and more lucrative contracts that are enabling their workers to earn higher pay checks; that's what we all like to hear. . .

Approximately 25-50 workers will be "green-thumbing it" at the **CHAUTAUQUA County Chapter's** horticulture training program.

The program has begun with the leasing of 20,000 sq. ft. of greenhouse space. Plans are to accommodate both the wholesale and retail trade. . .

In **ONONDAGA County Chapter**, there is anticipation for the upcoming National Football League exhibition game. Anyone planning to go better get their tickets early, according to Don Boudov, who is anticipating a sell out! . . .

The **SARATOGA County Chapter** won a National Award for their workshop's marketing brochure.

This brochure, titled "Your Profits Can Keep Pace with Rising Costs", won the first place award.

The criteria judged included content, style, creativity and overall appearance at the Second Annual Publications Competition sponsored by the Center for Management Systems in the Program Brochure Category. We congratulate **SARATOGA Chapter** for a job well done.



A well attended annual banquet was held on Saturday, May 16th at the Pinecone Restaurant in Cadyville, N.Y. in Clinton County. Newly elected officers of the Clinton Co. A.R.C. Board of Directors are: Carol Harrell, President; Dr. Barbara Flood, 1st Vice President; William Martina, 2nd Vice President; David Di Renzo, Corresponding Sec.,; Janet Calkins, Recording Sec.,; William Drew, Treasurer.

In addition to the installation of officers and an enjoyable video tape presentation, the Board awarded two scholarships to A.R.C. staff members for the purpose of continuing education. Pictured above right is Susan Carr, recipient of the Dorothy Merritt Memorial Scholarship. Above left is Jill Hewson who was awarded the Carol Hebert Memorial Scholarship. Mike Conine, Assistant Executive Director, congratulates the lucky winners.

Parents critical of proposed law change

The NYS ARC, through its President and through many individual parents, spoke out strongly against a draft recodification of the Mental Hygiene law proposed by the Officer of Mental Retardation and Developmental Disabilities. In one hearing at OD Heck Developmental Center on January 9, State President Eleanor Pattison, testifying on behalf of the Association, pointed out that the short notice given those invited to testify, the unpopular format of the draft and the lack of copies for agencies to use in preparing their comments led to a situation in which she was forced to say "If the Department is asking for meaningful comment, I'm afraid this is a charade".

TESTIMONY OF PARENT

Testifying at the same hearing, Kate Klein, Chairman of the Association's Public Information Committee, gave the following testimony:

My name is Mrs. Kate Klein. I live in upstate New York in Colton. My husband is retired. We are the parents of a 23-year old mentally retarded daughter who has never been institutionalized.

My concerns today relate to both the codes as they now exist and they are to be changed and are a summary of opinion after having read the recodification recommendations about 30 times.

In the community where I live, I can point out to you two people who are holding jobs in the community who are mentally retarded, one a CP complication, but these people now in their 30s have never been in any program, not even special education. But their parents, like us, know that within the next ten years one parent will probably be dead, perhaps both. We look at these codes to see what is available for us. My opinions today represent the opinions of this kind of parent and I hope you will listen to me as though you were listening to many many parents like us. I am a member of the Association for Retarded Children but many of the parents I know and talk to are not members of any advocacy organization and would not have access to the information ARC provides to its members.

The State Office of Mental Health recently released its 1981 five-year plan and explained that (From the New York Times Article) "the popular perception of the Office of Mental Health as the primary provider of mental health services is a holdover from former times. Our emerging role is one of leadership and control of the larger public health system."

Changes in this recodification draft seem to me to be a blend of the above statement in relation to what OMR-DD sees as its role. But the changes planned, according to how I see them and try to make sense of them, bring about ways to exclude the consumer and, through the device of finance, control the lives of people who have always lived in a community with as near an institutional pattern as existed on the wards of the developmental centers as it is possible to structure and still be legal.

CODES CONFUSE

The codes confuse me as to what a community is — and who the consumer is. Is the consumer the mentally retarded person — or the parents, (foster parent or guardian) or both.

The policy states, you plan "services to serve the full range of needs of the mentally retarded and developmentally disabled by expanding the number of types of community-based services and developing new methods of service delivery. . . and what the code changes bring in to not follow each other logically. In fact, what the policy plans for the MR person who has always lived in the community (and will on the death of parents need a community residence) the codes as much as it is possible — and this is a

strange phrase — "institutionalize freedom".

In the kinds of community residences planned and operating, the life style will not embellish the MR never - institutionalized person so much as contribute the dependency by establishing a life under control of the service provider.

Attached is a study on the results in language development comparisons which highlight the difference between the language accomplishment of an institutionalized child and a non - institutionalized child. It was published at the urging of the School of Human Communication Disorders, McGill University, Canada.

To me, a parent who is trying to understand what the codes mean, there is a blurring of what community is that allows this kind of detrimental absorption. The deinstitutionalized person coming from the developmental center to the community residence seems to me to be bringing the institution with him. And that is the ersatz "community life" you expect the never - institutionalized person to accept as a benefit.

NEVER-INSTITUTIONALIZED HAVE RULE MODELS

The never - institutionalized person has had as a role models the real community - parents, foster parents, relatives and friends (and an attachment to these people) but in joining his new family in the community residence the changing personnel because of "burn out", and the combination of therapists, whether medical, recreational or nutritional — some even from the probation department — are a far cry from home life.

Has the department ever met with a representative group of parents of the never - institutionalized mentally retarded

person to find out what kind of community residence they would consider suitable for their adults who are mentally retarded? If being in the community is a goal of the department why isn't the opinion of community parents valuable? Valuable enough to collect? Valuable enough through your codes to accompany this mentally retarded person in the new life in the residence and community?

It seems to me that what we must do as parents is technically disinherit our mentally retarded relatives and give them to you — the practitioners and experts on — institutions.

Where in the codes is the "empowered" parents or guardian? Where is the mandate for a surrogate parent as in school committees on the handicapped? Where is the mandate to parents to meet officially and understand what due process means to their relatives in the community residence?

By actual count there are many more mentally retarded people already in the communities around the state who will need community residence than in institutions. Haven't you felt a lack of support from these parents for your deinstitutionalized community residence concept?

NEED FOR SUPPORT IS MUTUAL

The truth is we need you and you need our support. Others in communities who know us and know our children and have watched them become adults watch us, too, (because they have been visible in our communities all of their lifetime) they look to see how we react to the community residence idea. When they observe there is no rush to place our people in your residences or your pattern of care they very reasonably wonder why.

State ARC, OMR/DD recognize Center employees

Twenty-two employees of the Office of Mental Retardation and Developmental Disabilities were recognized for their outstanding work during the year of 1980. A reception and luncheon was held on June 7 and 8 at the Americana Inn, Albany, New York.

The 22 represented one individual in every developmental center in the State plus an employee from the Institute of Basic Research and the Central Office of OMR-DD.

Selected by their peers for their outstanding effort on behalf of the Mentally Retarded, the employees were greeted at a cocktail hour sponsored by the Association on Sunday evening, June 7, by Commissioner James Introne.

The Outstanding Employees and their facilities are:

Gerrie LaRosa Cowan
Vincent Testa
Jean Carson
Mary Briscoe
Marian Bickle
Margaret Stratton
Rev. Thomas Gallagher
Edmond Gagnon
Creaola Shelton
Marian Catteau
Anne DeMartino-Rejack
Roy Mattoon
Ruth Jones
Ann Vikingstad
Daniel Mecklenburg
Joan Seubert
Sophie Menchetti
Rev. John Anderson
Mary Reynolds
Leonard Breen
Doris Warren
Edward A. Bischoff

The following morning, a special tour of the Capital and the State Museums was arranged and a luncheon was held at the Americana in their honor. Each employee was presented a certificate by OMR-DD in recognition of the occasion. The Association also made presentations of individual Bronze Name Plates to each employee, which will go on the plaque at their respective facilities, as well as a check in the amount of \$100.

Chairman of our Scholarship and Awards Committee, Ed Licence, Member of the Board of Governors of Nassau County, State President Elinor Pattison, and Executive Director, John Bertrand, represented the Association at the proceedings. Assistant Commissioner Zygmund Slezak represented the Commissioner at the luncheon.

Bernard M. Fineson Developmental Center
Bronx Developmental Center
Brooklyn Developmental Center
Broome Developmental Center
Craig Developmental Center
J.N. Adam Developmental Center
Letchworth Village Developmental Center
Manhattan Developmental Center
Monroe Developmental Center
Newark Developmental Center
O.D. Heck Developmental Center
Rome Developmental Center
Staten Island Developmental Center
Suffolk Developmental Center
Sunmount Developmental Center
Syracuse Developmental Center
Wassaic Developmental Center
Westchester Developmental Center
West Seneca Developmental Center
Wilton Developmental Center
Central Office
Institute for Basic Research

The parents I talk for today, like me, are eager for residences for our retarded relatives, especially as recognition of the limitations of aging taper off the energy we have to cope with the demands of a handicapped person at home. We are not the parents who "cannot let go of our handicapped." But the models of homes you have designed to not yet live up to the original hope we had of a family-style substitute.

Put this design in your codes and you will be astonished at the success of a community residence program. I know your department has spent millions of dollars to promote acceptance of community residences. These hopes have not been realized. But people already in the home community should be part of your design-put them and that kind of home residence before the communities and one residence will sell the other. Thank you.

According to the Saratoga Springs Saratogian, the local newspaper, the hearing closed as follows: "After facing about an hour of scorching comments Friday from representatives of private agencies at a public hearing held at OD Heck Developmental Center hearing Officer Paul Litwak, council for the State Office of Mental Health admitted, "It's confusing for me and I wrote it."

Ellie in the Solomons?



No, she hasn't run off with the Association's riches, but was just passing the United Nations during the Y.A.I. Prevention Symposium. With all the woes of being State President, maybe it was wishful thinking that our Ellie Pattison sat down in the chair for the Solomon Islanders.

Greco relaxes



Former New York State Assemblyman and now Director of the Speaker's Buffalo Regional Office, Stephen R. Greco, sits in his hand carved, dragon decorated ornate chair which was refinished by Allentown Industries, the sheltered workshop of the Erie Co. Chapter ARC, within the last year. The chair was featured on the AM Buffalo Television Program during the Buffalo Home Show at the Convention Center in March. The chair was used by Allentown Industries as an example of their fine refinishing service during the Home Show.

Eulogy for a man

Anne Kraus of New York City Chapter recently shared with us this moving eulogy. We hope it might hold some inspiration for others who would read it, and we take the liberty of reproducing it in its entirety.

Recently, my brother Bennett died at the age of 61. All his life he had been severely retarded.

The Rabbi who presided at the services did not know Bennett.

But he was able to muster a eulogy, which I have enclosed, which says most succinctly what I never thought was sayable.

I am hopeful that you will find the same when you read it. And that you will do him the honor, Rabbi Greenberg that is, of publishing this profound eulogy.

It may serve others who find themselves in the same position, — what to say?

It is a thought I have never heard before. That a retarded person, not withstanding, lives the best he can. And that is enough!

BENNETT KAUFMAN

We who have mastered so much, and we who understand so much about life — at times we must acknowledge our own uncertainty and powerlessness as we confront human existence, and a supposedly inherent order to our world — that at times seems so hard to comprehend.

I did not know Bennett Kaufman — and while you, his family, share much with him, and gave much to him — I suspect that you too, will acknowledge that there is much about his life that was known and understood only between Bennett and his Creator.

I learned yesterday that there was a time in his life when this very sacred soul was able to derive pleasure and rootedness in his being Jewish.

Ours is a tradition that affirms the sanctity of each and every human life — a tradition that also acknowledges our inability to apprehend all of God's ways —

a tradition that implores us to make of our lives — to make of each day — the most that we possibly can.

I think of a man who I never knew and who I never met.

What can I say that will accord to you, Bennett, the honor and the dignity of which you are so deserving.

Perhaps the following passage applies well to you. It is a strange and hard to understand passage that appears in the Book of Ecclesiastes: "And the day of death is better than the day of one's birth."

No, the verse does not mean or seek to convey what would appear to be the obvious meaning. Rather, our sages explain that the statement becomes intelligible when we compare it to two ships, both laden with merchandise, both resting at the seashore.

One ship is about to set out on its journey; the other has just arrived. Many people mill about the ship that has arrived, cheering and praising it.

Very few approach the other vessel.

For a vessel that has weathered the storm, and has come through it — that is the one that merits the praise. Not the one that has not yet begun its voyage.

And in a very real way, life can be compared to a voyage.

The ocean is deep and filled with high waves, storms, and many obstacles.

We are given that which we are given to aid us in the voyage — some more and some less — today we give honor to the memory of a man who faced life with the most he had — he has completed his voyage.

Bennett, you made the journey in the best way and in the only way you could.

Your mother — your brothers — all of us who are here today, to you we say — *lech-b'shalom* — Go thou in peace — go thou to meet thy Creator — and may He watch over you and grant you eternal rest and peace. Amen.

Task Force Active

As many areas of our state are beginning to realize with budget cuts coming down left and right, Prevention of Mental Retardation and Developmental Disabilities, is the only cost effective means of lessening the incidence of Mental Retardation and Developmental Disabilities.

Erie County ARC was in full support of a conference on Prevention of Mental Retardation and Developmental Disabilities held in Buffalo, New York in May of 1980, and has continued to support the Western New York Task Force on Prevention of Mental Retardation and Developmental Disabilities formed as a result of the May 1980 Conference. This Task Force is an effort to bring together public and private agencies toward the goal of Prevention of Mental Retardation and Developmental Disabilities.

Issues:

1. lead screening children 0 - 5.
2. auto restraints children 0 - 5.
3. fetal alcohol effect.
4. health curriculum for junior and senior high school students.

These are issues addressed by the Western New York Task Force. They are non-controversial issues dealing with prevention. The criteria for these issues was developed over the last 15-years by people prominent in the field of prevention.

One of those people, Erie's own, is Dr. Robert Guthrie, developer of the PKU Test and 6 other Newborn Screening tests. These newborn screening tests are used in every industrialized country in the world. Dr. Guthrie is Project Director for the Western New York Task Force.

Mrs. Joan Edwards, mother of a mentally handicapped son, Bobby age 14, and an Erie ARC Board Member, is the coordinator for the Western New York Task Force.

At the November 1980 N.Y.S. ARC Convention, Ad Hoc Committee on Prevention, it was Mrs. Edwards who chaired this state-level committee with a chairperson for each region.

As evidenced by other prevention conferences held by ARC chapters across the state (Herkimer, Chautauqua, Mrs. Sarah Litch team trainers for health curriculum, New York City Chapter) it is clear that the New York State ARC has set its sights high on Prevention.

We of the State Ad Hoc Committee for Prevention encourage all chapters to select a prevention representative and make contact with the appropriate regional person.

Together, as a powerful State ARC organization, we can accomplish much From this generation For the next generation.

Northeast Region

Mrs. Jean Emerson
21 Grandview Drive
Cobleskill, N.Y. 12043
(518) 234-3784

Western Region

Dr. Robert Guthrie
SUNAB 3435 Main Street,
Room No. 352
Acheson Hall,
Buffalo, N.Y. 14214
(716) 831-2351

Southeast Region

Mrs. Gail Fishkind
1 Ramapo Trail
Harrison, N.Y. 10528
(914) 835-2069

Central Region

Dr. Herbert Schniederman
736 Irving Avenue
Room No. 107
Syracuse, N.Y. 13210
(315) 424-6655



At Buffalo Conference on Prevention of Mental Retardation and Developmental Disabilities, from left: Ellie Pattison, State ARC President, Dr. Robert Guthrie and Joan Edwards.

Lewandowski objects to handicapped cuts

We share with you the following letter from Raymond A. Lewandowski, Executive Director of our Madison County Chapter, which was printed in the Utica Daily press in Utica, New York, in April of this year. We think it speaks for itself with regard to the Federal Budget cuts and are delighted to reprint it here in its entirety.

"I am writing to voice my concern over the enormity of newspaper coverage of President Reagan's proposed budget and particularly how it would affect hundreds of thousands of handicapped individuals. I am displeased and outraged at how blind we can be to support the elimination and reduction of programs for the disabled.

It is incomprehensible that our elected officials would adopt blindly a federal budget which, in a sense, commits a mild form of genocide. The budget preserves nothing more than an insensitivity to the minorities in America.

It is most crucial that the budget cutting process slow down so that careful consideration of the real impact of cuts can be assessed by those committees that are most knowledgeable of particular areas.

Everyone favors the reduction of costly administration, the overkill of paper work and the concept of decentralization, but the "cut and slash" approach can destroy the very nature of our country's social strength.

Many people are unaware that rehabilitation services enable disabled people to become more productive and independent. Last year, about 5,600 tax consumers became tax producers in New York State alone.

For thousands of other severely disabled individuals availability of such services

prevented the need for their institutionalization — resulting in savings of \$15,000 to \$25,000 per year per individual.

The administration proposes to combine numerous existing programs into two block grants — one to local education agencies and one to state education agencies. Although the grants are supposed to be used for the purposes similar to those in existing law, the new block grants are expected to replace existing law and programs.

These block grants include funds provided for disadvantaged children under Title I of the Elementary and Secondary Education Act and funding for education of handicapped children under Public Law 94-142.

The block grants will likely strip away all effective targeting, procedural safeguards, parent involvement, maintenance of state and local effort and civil rights provisions. Sixteen years of federal legislation would be nullified as well as equal education opportunities for all children.

There are several other areas which will be directly affected and, despite claims that the proposed cuts are "even-handed," in reality they fall disproportionately on the most vulnerable and defenseless people — such as the mentally disabled — because these are the people who can't fight back.

Furthermore, the media needs to become increasingly conscious of the administration's strategy to move quickly and its desire to focus on the apparent broad public support for the proposed budget. Polls show strong public support for continuation of virtually every individual program."

Day treatment directors organize

A meeting was held in Albany on June 4th and 5th, 1981, with representatives from the 90 Day Treatment Programs around New York State. This was the Annual Meeting of the State Association of Day Treatments Programs.

There are almost 6,000 clients in these programs across the State and this meeting was an opportunity for those who are active to meet and discuss some of their most serious concerns. Robert Norris Associate Commissioner of OMR-DD gave a presentation to the group on the background of Day Treatment Programs and they then spent time discussing such topics as the need to develop a continuum of care, Legislation for Day Treatment programs, problems with fee systems, a Medicaid management and information system and others.

Issues brought up by the various centers in their priority order were:

- 1) Funding
- 2) Standards and Regulations
- 3) Membership
- 4) Staff Training

- 5) Committee functions and membership
- 6) Liasons with other State Organizations
- 7) An information pipeline
- 8) Publicity and Public Relations

Reports were heard from their regional committees and from committees which had been established on Legislation and Standards and Regulation. The organization hopes to meet on a quarterly basis with the next meeting being September 11, 1981 at the Onondaga ARC.

Look back; move forward

in Albany, October 15 - 18

Intl. Year of Disabled in North Country

Three North Country advocates for the handicapped gathered in Canton recently to launch a campaign to fight the myths and misconceptions surrounding people who are disabled. The county drive is part of an international effort to recognize 1981 as the Year of the Disabled.

"Whatever the various agencies around the county do to support International Year of the Disabled (IYDP) recognition of rights and needs depends on our work to change attitudes towards people who are disabled," William Serafin, county health services director, commented.

"The important visible effort we are asking all agencies to continue and stress is the 'destroying of myths' about physical and mental disabilities," he went on.

His two colleagues, Sigrid Ouderkirk, St. Lawrence County Easter Seals regional director, and Kate Klein, chairperson of the Public Information Committee of New York State Association for Retarded Children, attended a conference in Albany Feb. 17 to obtain background information on IYDP objectives.

The practice of referring to "the person with a disability" rather than "the disabled person" is a simple, effective way to attack the myth that a disability brings about excessive frustration for a person with a handicap.

"Emphasizing the person rather than the disability is preferred," Mrs. Ouderkirk said. "The fact is that an effective environment reduces frustration," she maintained. The goal of Easter Seals is to develop considerations in the home and community for the special needs of each person, she explained.

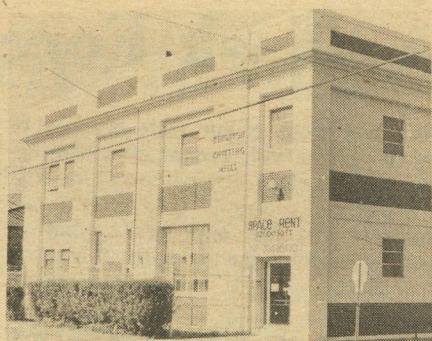
"Eliminating architectural barriers which limit how the physically handicapped operate in our society is the goal. We continue to encourage architects to design attractive exits and entrances to public and private buildings so that no one is kept out because of such difficulties," Mrs. Ouderkirk stated.

Mrs. Klein, state ARC committee member, expressed enthusiasm for the concept of "See Me As a Person" — the IYDP goal for children and adults who are mentally retarded. "This has long been an objective of our association. Highlighting it during IYDP will be a focus of ARC chapters across the state," she said.

Social attitudes toward the mentally retarded and developmentally disabled population have been altered in the past decade, but the practice of referring to people who are mentally retarded as "patients" still prevails, when in fact they are more accurately described as "developmentally slow," she went on.

The year 1981 was proclaimed by resolution of the U.N. General Assembly in 1976 as a year to encourage rehabilitation of the estimated 450 million people on earth who suffer from some form of physical or mental handicap.

"Our attitude towards people who are disabled can be their biggest handicap," Serafin concluded.



ULSTER COUNTY'S NEW FACILITY

Ulster gets act together

The Ulster County Chapter recently consolidated three of its programs in one new facility, but did so in one big move.

Obviously it was quite an undertaking but it went extremely well as pointed out by Public Relations coordinator Bob Taylor in the following article:

The consolidation of the UARC administrative offices, Pilot Industries Kingston and Pilot Industries Saugerties has taken place. The moving vans started with the Saugerties workshop one day, picked up the equipment at the old Trailways bus terminal on Broadway in Kingston the next, and then loaded up everything from 70 Lindsley Avenue on the last day.

It was originally planned as a staggered move with the Pilot Industries section moving in January, and the administration to follow a month later. However, the decision was made to move everybody by January 30th. That's when the fun started.

Planning ahead, trying to anticipate all contingencies, seemed like a staggering job to those responsible. Good planning, plus great cooperation from all staff people saw everything go pretty well like clockwork. Watching the finishing touches at the new building — that is, the erecting of temporary office cubicles — still going on just hours before the move, I didn't see how it could work. But it did, and by the end of the day (January 30th) everything was in the building. On Monday morning, Feb. 2, it was business, not quite as usual, but functioning.

Hats off to all of those who worked so hard on the move. It was a job for super people.

Franklin buys ambulance for Sunmount D.C.

The Franklin County Association for Retarded Children, recognizing the need of ambulance services for Sunmount residents, had purchased an ambulance for Sunmount Developmental Center's use.

The A.R.C. Board of Directors allocated monies from a special "Institution Fund" for the purchase of the ambulance. This fund evolved from contributions made by all ARC Chapters throughout the state who have people from their respective counties residing at Sunmount.

Ann LaVoy, day supervisor of the Tupper Lake Volunteer Ambulance and Emergency Squad, who spearheaded the project, brought this need to the attention of Franklin County A.R.C. According to Mrs. LaVoy, the increasing demand for the Ambulance and Emergency Squad's services has put a strain on the voluntary staff, more than 90 percent of whose ambulance runs are to Saranac Lake.

Ed Chairperson speaks out

In April of this year, Betty Pendler, Chairperson of our State Education Committee was invited to Warren - Washington Chapter to speak to the monthly parents meeting. Upon her return, Mrs. Pendler spoke with us about the warmth of the membership of the chapter and how very much she had enjoyed her visit. It was also interesting to note that the local newspapers had felt her visit important enough to report in some depth and we repeat here the story by Kathlene Kathe, a staff writer of the Glens Falls Post Star which she headed **A Taste of Independence Prepares Retarded Children for Challenges:**

"I am the parent of a daughter who is retarded."

The speaker was Betty Pendler, a New York City woman who has committed her life to educating parents about the difficulties of raising retarded children. Mrs. Pendler is chairwoman of the education committee of the State Association for Retarded Children and a member of the board of directors of the New York City chapter.

She visited Hudson Falls recently to tell members of the Warren - Washington counties Chapter of the State Association for Retarded Children (ARC) that she regards Lisa as her daughter first and a retarded child second.

UNDERSTANDING IS KEY

Mrs. Pendler conducted workshops for the local ARC staff on how to cope with parents of retarded children. She also addressed the parents, sharing insights into the emotional problems they face in raising handicapped children. She stressed the need for parents to understand that their retarded children need some independence to lead lives of their own.

"A child who is retarded grows up to be an adult who is retarded," she said.

Mrs. Pendler emphasized the need for "client - readiness" and "parent - readiness" as parents and children prepare for a child's life in a group home.

Mrs. Pendler warned parents against placing their own comfort ahead of what is best for their children. She told them to get in touch with their feelings.

"We need to be more honest with ourselves," she said.

Some children are not ready to learn independence because the parents are overprotective, Mrs. Pendler said.

She cautioned parents against overprotection, saying that, if the children are going to have to "fend" for themselves in the world, "we have to let them do things for themselves."

Lisa, Mrs. Pendler's 23-year-old daughter, has Down's Syndrome. She has been living in a group home in New York City for the past two years. Mrs. Pendler said, "Lisa was ready long before I was."

She said she had unconsciously begun to prepare her daughter for independent living while she was still very young. Mrs. Pendler said she began by giving the child responsibilities she could handle.

When Lisa was six, she attended special classes at a school in the city. One day she brought home a note, instructing her mother to send a China plate, knife, spoon and fork to school with Lisa the next day. Although Mrs. Pendler said she had misgivings about the knife and China plate, she complied with the request.

LISA LEARNS

Several days later, the parents attended school to take part in a Mother's Day dinner. She said she saw Lisa cutting celery with a knife. That was a task Mrs. Pendler said she would have considered dangerous for Lisa to handle at home. But, she said, it was a lesson in the "dignity of risk," which Mrs. Pendler identified as an experience that helps the child learn to become more independent.

She suggested other experiences geared toward helping the child gain the confidence and the ability to live in a group home. For instance, she mentioned summer camp; visits to a bank where the child can cash a check or traveling alone to a specific destination.

The training sessions for independent life are not easy on the parents. Mrs. Pendler said that, when her daughter was 17, she realized Lisa should be able to travel alone to her class at the occupational training center in New York City. The trip involved three changes on the subway.

After several trial runs with Mrs. Pendler seated in another car on the same train, Lisa was ready to make the trip on her own.

When the day came, Mrs. Pendler said she waved good bye to her daughter.

Then, she remembered, she ran for the closet, donned an old coat and hat that Lisa would not recognize, and followed her to the subway.

She followed her daughter all the way to school, waited for dismissal and then followed her home again without being detected. She let Lisa arrive home first and then came in later. When she opened the door, Lisa ran to her saying: "I made it. I made it."

It was several more years before the mother could face the thought of her daughter leaving home but, she said, it is important to weigh the motives for keeping a handicapped child at home.

She asks parents: "How much is love or how much is it that we have become dependent on the dependency?"

Letchworth Installation



At the Letchworth installation, Mr. Edward Jennings, Director of Letchworth Dev. Center officially installs Bernice Volaski as President of Letchworth Village - Welfare League Chapter of the State Association.

Take a chance;
give ARC a chance.

Your losing lottery ticket
will be a winner for ARC.

News and Views:

We try a little harder — parents of children who are handicapped always have to work harder. . . "the parent of the normal child skips monthly PTA meetings and his behavior is not only considered normal, but enviable; the parent of the exceptional child skips monthly parent meetings and he is said to be uncaring and hard to reach. . .

The working mother of normal children screams at the kids and breaks into tears after a harried supper. She is said to be overworked and is offered an evening out. The working mother of a handicapped child does the same — she is said to be emotionally upset and is offered a psychiatrist.

A couple with normal children divorce — they are said to be incompatible. The couple with an exceptional child divorce, and it is said the child ruined the marriage.

A group of normal children's parents read that the number of teachers and classes has been reduced, and they bemoan the present state of education. A group of exceptional parents read that the number of special classes has been cut, and they are forced to march upon the legislature. (Taken from "The Link" Society for Autistic Children Newsletter.)

But all of that makes us strong — and we do get results. Janet Calkins, Education Committee member, very active in Clinton County, gets to educate the educators, and has succeeded in such accomplishment as getting better transportation for one student; getting a physical education program for about 65 handicapped students, improved special therapy services.

YOUR RIGHT TO MEDICAL RECORDS

By Judy Shalvey
(Member of the Education Committee)

Can you recall the time you were directed to the examining room and told, "Undress your child; the doctor will be with you shortly." Do you remember while "shortly" turned into one hour, you had the curious desire to read your child's medical file placed neatly nearby? If you are a daring individual, you may have succeeded in a sneak preview. If not, you probably convinced yourself that you wouldn't understand the medical jargon anyway, so why risk an embarrassing situation if someone "caught" you.

Access to your own medical files is your right. There is no need for mature adults to be reduced to childlike fears and behavior other than the fact that tradition has dictated denial of parents' access to medical records on the grounds of insufficient knowledge to interpret that information. Not too long ago, this same reasoning was used to deny parents access to their child's educational records.

There are many reasons why you may want your child's medical records. You are the person who must coordinate the health care needs of your child and often make critical decisions. You are also the person who must monitor the provision of services as they are recommended by the professional's evaluation to be provided by your local educational agency.

Ironically, by tradition, not law and unless you assert your right of access to medical records, you may be the one person who cannot receive a written medical report. Until you assert your right of access to medical records, you will also be asked to sign release forms to have records (which belong to you) sent to other professionals, without ever having the opportunity to read and know the information that is to be released.

Our motto is that parents are and should be the prime advocates for their own child, and when parents know their rules and regulations, and their rights, they get results. We urge every chapter to familiarize themselves with the procedure of the Committee on the Handicapped, the Individual Education Program, Related Services, etc., so that they can help their parents get a full and appropriate education.

We have an added tool now — Section 504 to aid us in this area. (See "Know Your Child's Rights under the Federal Law, Section 504).

Education Committee members testified at all public hearings sponsored by the State Education Department and the Board of Regents in regards to revisions in the regulations, and one of our members made the headlines. See article attached. (Problem of including this is that by the time the paper is issued, there may be changes — either the revisions will be rescinded or ??? so do with this what you wish.

Parents, Professional Groups and NYSUT agree — believe it or not! At an unprecedented meeting of the minds, a coalition of concerned organizations for the Education of Children with Handicapping Conditions registered their strong objections to proposed revisions of the Commissioner's regulations. Hearings in Syracuse, Buffalo, Suffolk and New York City gave the message loud and clear — not enough time to properly react to all the revisions, and, as a result, the Board of Regents did not act on them but called for their own hearings. The New York State Association for Retarded Children was conspicuous through all these negotiations.

Consumers in New York State have the right to a copy of their medical records, Under N.Y.S. Regents Regulations, Section 29.2(a)7, effective October 1977, your doctor is required to give you a complete copy of your files if you request them in WRITING. If you do not get results, call the State Department of Health (212-488-3928, 2 World Trade Center, N.Y.S.) and ask to speak to a medical conduct investigator.

NOTE: Hospitals in New York State are not yet required to release medical records. However, since physicians must release records upon WRITTEN request, you can circumvent this problem when requesting records from a Clinic or Emergency Room by addressing your written request to the physician in-charge.

Frances Berko named advocate

Governor Hugh L. Carey has announced the appointment of Frances Giden Berko, J.D., M.A., of Melville, as New York State Advocate for the Disabled.

Dr. Berko, is a graduate of Hunter College and Fordham Law School. She holds master's degrees in vocational rehabilitation, speech pathology and special education.

Since December, 1980, she has been coordinator for the New York State Commission on the International Year of Disabled Persons on loan from the Suffolk Developmental Center where she served as chief of mental retardation treatment services.

Before that, Dr. Berko was executive director of the Special Children's Center in Ithaca, and supervisor of special education at the Institute of Logopedics in Wichita, Kansas.

With all the changes coming so rapidly, it is very important that your Board of Regents hear from you periodically. Below are their names and addresses, write to them and get to know them. Write to your local legislature at the same time on the same subject. Herkimer County Chapter testified at the hearings and wrote to Regent Griffith, with copies to their assemblymen — this is the political action that is necessary. Assemblyman Alan Hevesi is the new chairman of the New York State Assembly Legislative Task Force on the Disabled. Write to him in Albany and let him know the kind of legislation you want drafted. Our committee is very anxious to see legislation enacted to mandate training of hearing officers. We also would like to see a change in the existing law to insure that the child's teacher is invited to attend a committee of the handicapped meeting, because in more cases than not, the required members of the COH have never laid eyes on the child and make decisions based upon pieces of paper found in the child's folder. We would like to see wording such as . . . each school district shall establish a committee on the handicapped composed of . . . (existing law). ADD: The committee shall invite the appropriate professionals most familiar with a child's handicap or handicaps including the child's teacher, to attend and give input to any meeting concerning the educational program for such a child. By inviting the child's teacher to give input would allow him or her to be involved with the committee meeting, but not necessarily allow for voting or evaluation.

Geriatric home in Essex County

The Farmers Administration recently approved a loan of \$327,000 for the reconstruction of the Geriatric Community Residence in Essex County. Construction on a new Association for Retarded Children residence here is scheduled to begin this summer, according to Essex County ARC Director Charles Hayes.

The home will be built on the site of the former St. Fredric's Hotel. The hotel served as an ARC hostel for elderly mentally retarded until it was destroyed by fire last April.

A 327,000 loan from the Farmers Home Administration will finance most of the construction costs. Another \$55,000 will be provided by Essex County Facilities — the ARC title-holder.

Dr. Berko replaces John L. Gerity who has resigned to become special counsel to the State Commission for the Blind and Visually Handicapped. Mr. Gerity is himself blind.

"Providing the disabled citizen access to the job market and full participation as a member of the community has always been my goal. I make this appointment with the belief that Dr. Berko's training, experience and past achievements hold promise that this goal can be achieved in that same able tradition begun by the late Harold Unterberg."

Dr. Berko has co-authored three texts: "Speech Therapy in Cerebral Palsy," "Communication Training in Childhood Brain Damage," and "Management of the Brain Damaged Child."

REGENTS MAILING ADDRESSES

Genrich, Willard, A., Chancellor, LL.B., L.H.D., LL.D., Litt. D, 4287 Main Street, Buffalo, N.Y. 14226.

Myer, J. Edward, Vice Chancellor, B.A., LL.B., 280 Park Avenue, N.Y. 10017.

Clark, Kenneth, A. B., M.S., Ph.D., LL.D., L.H.D., D. Sc., 60 East 86th Street, N.Y. 10028.

Newcomb, Harold E., B.A., 330 Main Street, Oswego, N.Y. 13827.

Griffith, Emyln, I., A.B., J.D., 225 N. Washington Street, Rome, N.Y. 13440.

Kendall, Mary Alice, B.S., 242 Belmeade Road, Rochester, N.Y. 14617.

Batista, Jorge L., B.A., J.D., LL.D., P.O. Box 3114, Church Street Station, N.Y. 10008.

Yavner, Louis E., LL.B., 42 Broadway, N.Y. 10004

Chodos, Laura Bradley, B.A., M.A., Box 32G, R.D. No. 2, Rexford, N.Y. 12148.

Barell, Martin C., B.A., I.A., LL.B., 645 Fifth Avenue, N.Y. 10022.

Matteoni, Louise, B.A., M.A., Ph.D., 214-16 16th Avenue, Bayside, N.Y. 11306.

Reed-Delaney, Arlene B., B.A., M.D., 524 Madison Avenue, Albany 12208.

Carballanda, R. Carlos, B.S., 271 Main Street, Arcade, N.Y. 14009.

Linton, Floyd S., A.B., M.A., M.P.A., Route 25 and Giant Oak Road, Ridge — 11961.

Sclafani, Salvatore, J., 435 Bay Ridge Parkway, Brooklyn, N.Y. 11209.

EDULETTER is yours: USE IT!

TO ALL CHAPTERS: This is YOUR column, we want your news and views of what is happening in your chapter in education — what techniques do you use to get your parents to speak up — how does your school district comply with 94-142 — what are the success stories — what are the problems? Please communicate with us.

NEWSLETTER EDITORS: Won't you have an education column and use our valuable reprints to bring information on testing, IEP, etc. to your readers — keep your parents informed so they can make intelligent decisions about their child's placement. It is a much needed service, help your parents know what to expect at COH meetings, and IEP conferences, etc.

The Eduletter continues to include items of interest to parents, teachers, administrators and other professionals. If you or anyone else you know would like to receive a free copy, please fill out the coupon below. (Chapters: won't you please reproduce this coupon in your own newsletter. Thanks.)

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

NAME _____

ADDRESS _____

TEL. NO. _____

CHAPTER AFFILIATION _____

Return to:

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

Legislative Review Continued from page 1

dollars if enacted. At present, it has not moved out of Committee.

(4) Amends the Family Court Act and the Education Law to extend provisions enlarging the powers of these bodies to include handicapped persons over twenty if such persons, if they were under twenty-one, would be entitled to receive appropriate education opportunities as handicapped children, under Article 89 of the Education Law. In effect, this provides, under the Family Court Act, services for certain handicapped beyond the age of twenty-one on Family Court Orders (S-749, Calandra; A-1126, Lipschitz).

We are in favor of this bill, but at this writing, nothing has happened.

(5) An amendment to Section 4407 of the Education Law to require the Education Department to authorize Boards of Education to provide transportation to and from rehabilitation and other facilities for handicapped who attain the age of twenty-one.

This is part of our Legislative Program and we are in favor of it, but nothing has happened. (A-1302, Lack).

(6) Amendment to the Mental Hygiene Law exempting parents from liability for fees for services for children under twenty-one to include claims for such fees which arose prior to and were pending on August 5, 1977. This is to take care of those claims arising before the liability of parents after August 5, 1977 for minor children's fees was removed. (S-852, Padavan; A-1198, Kremer).

The Association is in favor of this bill which passed the Senate on February 23, and now rests in the Assembly Mental Health Committee, Elizabeth Connelly, Chairwoman.

(7) A voluminous bill amending the Mental Hygiene Law and the Executive Law, requiring an Advisory Council and Mental Retardation and Developmentally Disabilities consisting of at least 12 instead of 14 members with certain provisions for who shall be honored. Establishes within the Executive Department a Developmental Disabilities Planning Council to perform duties and functions required by the Federal Developmental Disabilities Services Act of 1970 and the Developmentally Disabled Assistance and Bill of Rights Act of 1975.

(S-6779, Padavan; A-8535, Connelly). Nothing has happened with this bill and the Association takes no stand on it.

(8) A bill to prohibit life insurance companies and others from rejecting any applications for a life insurance policy or to refuse to issue such a policy solely by reason of retardation of the insured. (S-2570; A-3333, Flynn and Gottfried).

The Association, of course, is in favor of this.

It is possible, however, that this measure has been included in A-6663 (Hevesi), an omnibus Civil Rights Bill for the disabled that amends the Civil Rights Law and others as well as the Insurance Law to prohibit discriminatory practice with regards to civil rights, housing, admission to college, employment, labor organizations and life insurance.

We understand this bill has passed both houses and we are awaiting a copy of the bill to see if it includes the provisions of S-2570; A-3333 Insurance Bill.

(9) A-1555 (Sanders) amends the Labor Law to extend definition of employees for the purposes of minimum wage to include persons engaged in sheltered employment for the mentally retarded, mentally ill and for the physically handicapped.

We oppose this vigorously, and urge all to write to their leadership and their own assemblymen and senators to kill it.

This bill has no conception whatsoever of the relationship between the handicapped and sheltered employment. Sheltered employment pays at the rate of minimum wage translated into the ability of the worker to produce in piece work. An absolute minimum wage would mean the demise of the sheltered workshops as we know them.

It is noteworthy that the Legislative Program for the disabled has introduced a bill (A-7387, Dugan) that would guarantee that blind workers, employed in sheltered workshops, receive the minimum wage.

We must, on principle, oppose this bill as well as the Sanders Bill as this is the open door to change the character of sheltered workshops to the status of employers without regard to disability.

In summary, we find little movement in the bills we have outlined. Without vigorous participation by the Chapters (with their legislators) on a local level as well as vigorous pursuit of the program in Albany, we will have window-dressing without substantive changes.

I urge, therefore, that we all get into this act and write to Mr. Stanley Fink, Speaker of the Assembly and Mr. Warren Anderson, President of the Senate Pro Tem, presenting the views of your Chapters and your constituency on these programs. There may still be time although it is certainly running out.

There is nothing occult or mysterious about legislation. It requires a lot of preparation, devotion to the task, persistence and grass roots pressure on everyone in the Legislature for those bills that the Association, in its policy, has made of prior importance.

Although this Session may go down in our history as one of the worst in terms of legislation for the mentally retarded (and it is still hoped that something will come out of this session), it teaches us one thing, We can never relax our vigilance, our efforts, and our homework if we are to get something through the legislature in competition with all those who want something from the state. Then we will have at least gained something from this very disappointing experience.



It's off to work for these residents of the Nassau Association For The Help of Retarded Children's Baldwin community residence as the men and women leave for their jobs in the community or at the AHRC sheltered workshops. The folks that live in the Baldwin community residence follow a regular schedule of work activities as well as chores in the home but there is still plenty of time to participate in AHRC's planned leisuretime program.

A first is really a second

In our special OCV honoring Executive Director Joseph T. Weingold (which later became the centerfold of our January issue) we ran an article about a billboard indicating that, in 1953, it was the first promotion of our Association.

Shortly after this issue went out to our general membership, we received a letter from Gene Laughery, Executive Director of the Westchester County Chapter with a letter from one of his members which gave us the headline **A First Is Really A Second**.

The letter reads:

Dear Gene:

The Westchester Chapter of AHRC led the way in many things back in the very early days of the struggle for public recognition and support for the mentally retarded. I am thankfully mindful of the part, however small, I played in working for that end.

If nothing else, I, and others at the time, succeeded in prodding the public into the beginnings of an awareness of the problem and the need for effective action.

In 1952, using my experience in publicity, I got the cooperation of the Yonkers and Mt. Vernon billboard people and General Outdoor Advertising to donate billboard space throughout Westchester calling attention to the existence of AHRC and its efforts in behalf of the mentally retarded. The only cost the Chapter had was the cost of the billboard paper.

The Billboards were beneficial and, with other publicity and promotional ideas, were encouraging in our efforts.

The enclosed Children's Voice clipping is in error in reporting the first use of billboards.

It is a small thing in the light of the history of progress by AHRC. However, it is my training in factual reporting that leads me to make this correction.

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