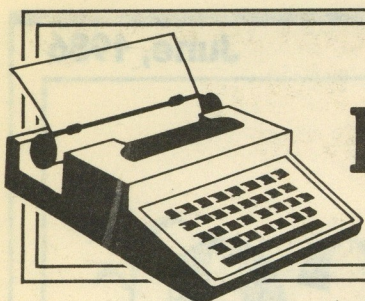


OUR Children's Voice

Retarded Children Can Be Helped



**The Joseph T. Weingold
Building Dedicated**
see pages 8 and 9



EDITORIALS

ORS - One More Time

For the past three years a Governor sponsored initiative to remove the Office of Vocational Rehabilitation (OVR) from the State Education Department has been held up by the Senate. The desire to have a separate Office of Rehabilitation Services (ORS) was first presented a decade ago when the Association was successful in having legislation sponsored. At that time, the State Education Department presented to the Legislature a plan to "re-organize" the Office of Vocational Rehabilitation. The attitude at the time was to give OVR a chance to demonstrate their ability under the new re-organization to deliver affective Vocational Rehabilitation Services in New York State.

After years of poor coordination and lack of appropriate funding, almost all rehabilitation agencies in New York State support the concept of a separate and distinct cabinet level agency to coordinate and integrate rehabilitation services. An independent agency would effectively integrate the rehabilitation programs of other state agencies by establishing common goals, service definitions, eligibility requirements and reporting formats.

The Commissioner of the New York State Education Department, Gordon Ambach, states that, "my argument is this program is an educational and training program and that's why it should be maintained as an integral, combined program." Our Association differs with that view and in fact feels that OVR has not been doing good job either at educating or training.

In recent years, spending on administration and counseling have more than tripled while spending on job training has, taking inflation into account, declined. In 1977, job training services made up about 68 percent of the budget; last year it constituted but 45 percent of the budget.

According to an editorial that appeared in the Albany Times Union on May 20, 1986, "more and more money has been going to provide administrative jobs and support government personnel while less education, precisely what is needed if the disabled are really to be rehabilitated."

The ORS bill for the past two legislative sessions was overwhelmingly passed by the Assembly. In all likelihood when this edition of OCV will be printed, they will again have passed, for the third year, ORS. It is time for the New York State Senate to bring ORS to the Senate floor for debate and vote. To deny responding to, not only NYSARC, but the entire disabled community on this issue, will not speak well, now and for years to come, for the New York State Senate leadership.■

On-Site Client Advocacy Urged For Develop- mental Centers

The New York State Legislature has before them this session a bill which would establish an ombudsman in each of the states twenty developmental centers. The Association is most appreciative of Senator Frank Padavan who is sponsoring the bill in the Senate (S.8857) and to Assemblywoman Elizabeth Connelly who is sponsoring the bill in the Assembly (Assembly bill in progress).

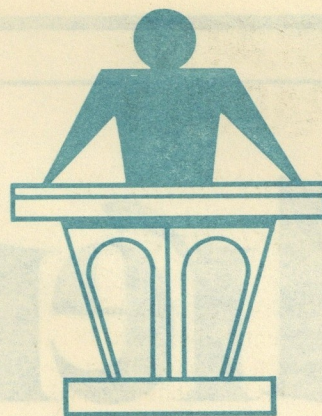
The bill is long overdue and should have been in place years ago. The bill calls for an existing item in each of the states twenty developmental centers to be used as an ombudsman. These twenty individuals would be directly responsible to an outside agency rather than OMRDD. The ombudsman would provide to parents and residents of developmental centers on-site advocacy.

The need for such on-site advocacy is becoming more and more critical as developmental centers are phasing down. The bill states that "developmental centers are large, often isolated from outside scrutiny, and so complex that non-client care administrative concerns do not always receive the attention that they deserve. Furthermore, existing oversight agencies and organizations outside, are severely limited in the resources and expertise necessary to monitor institutional conditions. Therefore, the Legislature declares the need for an on-site client advocacy function that is independent of the Office of Mental Retardation and Developmental Disabilities."

It is the intention of our Association that the ombudsman position, while being independent of OMRDD, would work with the administration of the developmental centers in resolving any problems and issues brought to their attention. As more and more individuals move into the community, those that remain in developmental centers must have their rights and quality of life protected.

While the Association well recognizes that no one individual can resolve all of the day-to-day problems that occur in developmental centers, it is felt that an independent ombudsman would serve as an on-site advocate. As the systems become more complex and as the day-to-day needs become, oftentimes, secondary to bureaucratic requirements, the ombudsman is seen as a simple safeguard for those who have questions and needs to be met.

We urge the Senate and Assembly to follow the lead of Senator Padavan and Assemblywoman Connelly. Our Association calls upon the New York State Legislature to act favorably on this measure during this legislative session. To do otherwise would be a step backwards.■



The President Speaks

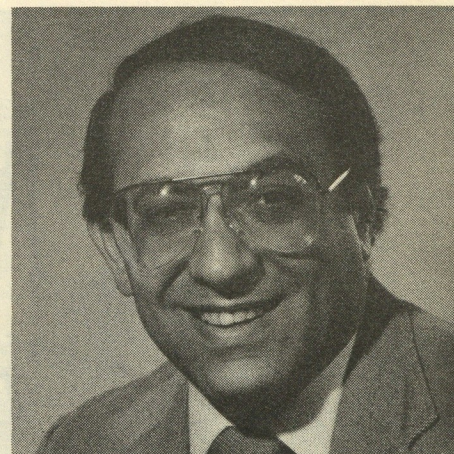
As this edition of OCV is being printed, many of our chapters are either holding their annual elections or are in the midst of installing their new officers and Board of Directors. As President of the New York State Association for Retarded Children, Inc., I want to personally thank the one thousand individuals who serve our sixty-four chapters on the local Board of Directors.

Serving as a volunteer is often frustrating and time consuming. The collective hours put in by our many volunteers and most certainly our Board of Directors would be too numerous to keep count. Hopefully, our continued collective successes provide the reward and satisfactions that each of us seek for persons who are mentally retarded.

As with any organization that reaches its thirty-seventh year, as ours has, changes are often necessary to keep pace with existing and ongoing needs. At the October Board of Governor's meeting, I appointed an Ad Hoc Committee to Review and Make Recommendations on the Structure of the NYSARC, Inc. Ms. Shirley Valachovic, Senior Vice President of the Association, Chairs the Committee.

The Ad Hoc Committee consisting of representatives from every region of our Association met several times. During the second week in May, their report was distributed in the mail to our Board of Governors, Chapter Presidents, Committee Chairpersons and Executive Directors. While each of us views change differently the report gives concrete suggestions and recommendations. I urge each Board of Director to review the recommendations and to discuss the report at your next Chapter Board meeting.

In addition to the Ad Hoc Committee Report, I have requested our State Associa-



tion Executive Director, Marc N. Brandt, to also prepare a report concerning the ongoing needs of our chapters in the area of technical assistance.

I have asked Marc that in his report he list the areas of need that the chapters have and to propose a working paper for the Board of Governors to discuss on how to implement this need. I am also seeking him to explore the various funding mechanisms available to fund these services and to give this report to the Board at the Fall Board of Governor's meeting.

Hopefully, between the recommendations of the Ad Hoc Committee on the Structure of NYSARC, Inc. and our Executive Directors Report, we will be able to move ahead, keeping pace with current needs.

Once again, as President, I thank you all for your continued efforts and enthusiasm.■

David B. Lettman

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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ASSOCIATION'S LEGISLATIVE PLATFORM MOVING RAPIDLY

Over Twenty Bills are Sponsored and Many are Reaching the Floor of the Legislature

At the thirty-sixth Annual Convention held in October, 1985, the Delegate Assembly, representing the membership of the NYSARC, Inc., approved the Association's 1986 Legislative Platform. At the time of this writing, over twenty bills have been sponsored for the Association by the Legislature. Much of the Association's 1986 Legislative Platform is the direct result of chapter requests for needed reform.

Commenting on the variety of bills being sponsored during this legislative session, Mr. John Bryant, Chairperson of the Association's Legislative Committee, stated that, "new legislation was being aimed at issues including educational space for handicapped children, rate setting, reimbursement of land and personal property, interest costs and Developmental Center Advocacy."

As of the date of the printing of OCV, the following is an overview of the Association's bill currently before the Legislature:

— S8851 by Padavan (Assembly bill pending) requires that fees established for ICF/MRs and Community Residences include the cost of land for newly established facilities.

— S8386 by Padavan (Assembly bill in progress) eliminates the State's ability to automatically stay a court order for the care and treatment of a person who is mentally disabled. This bill reaffirms the right of a responsible person to act in the best interest of a mentally disabled person as determined by a court of law.

— S4558 by Donovan (Assembly bill in progress) makes it possible for clinical professionals to receive scholarship benefits in exchange for working in voluntary not-for-profit agencies licensed by OMRDD.

— S8715 by Padavan (Assembly bill in progress) enables providers of mental retardation services to receive reimbursement for interest expenses on loans attributable to the purchase of personal property items.

— S8714 by Padavan (Assembly bill in progress) requires the Commissioner of OMRDD to submit a plan to the Legislature with respect to the regulation of facilities licensed by the office. Such plan shall distinguish critical regulatory areas such as health and safety from other areas and establish separate visitation schedules for each area based on relative importance.

— S8857 by Padavan (Assembly bill in progress) provides for an Ombudsman to advocate for the appropriate care and treatment of individuals residing in Developmental Centers.

— S8712 by Padavan (Assembly bill in progress) requires the Commissioner of OMRDD to formulate procedures to establish a final reimbursement rate for residential programs prior to the opening of such programs. Such procedures would enable program operators to receive a full rate of reimbursement upon the opening of a facility.

— S8716 by Padavan (Assembly bill in progress) establishes a procedure to require OMRDD to promulgate amended fees within 90 days of the receipt of a completed rate appeal application to amend a fee for an existing program.

— S8725 by Donovan (Assembly bill pending) increases rental which BOCES can pay for space from \$5.00 to \$10.00 per square foot. This legislation is aimed at enabling special education classes to locate within normal public school settings.

— S8812 by Donovan (Assembly bill pending) increases building aid for special education classroom space from \$2,000.00 to \$3,000.00 per pupil. This legislation is aimed at enabling special education classes to locate within normal public school settings.

— (Senate bill in progress, Assembly bill pending) A bill to prohibit the placement of handicapped students in facilities located outside of normal public schools based on the availability of space alone.

— (Senate bill in progress, Assembly bill pending) A bill to require that school districts contracting with BOCES host BOCES classrooms for handicapped children in such school districts when appropriate.

Additional bills which the Association has initiated in the past or is currently supporting before this year's Legislature are as follows:

— S3736 by Flynn and A5900 by Hevesi removes the Office of Vocational Rehabilitation from the State Education Department and creates a separate office in the Executive Department called the Office of Rehabilitation Services.

— S2204 by Padavan and A5932 by McPhillips requires the posting of warning labels on alcoholic beverages regarding the danger of ingestion of such products to pregnant women.

— S7283 by Padavan and A8012 by Connelly clarify the right of a legal guardian of a mentally retarded person to sign for medical or dental consent.

— S4305 by Lack and A5793 by Harenberg award high school diplomas to handicapped children having successfully completed an Individualized Education Plan (IEP).

— S1246 by Donovan and A6973 by Serrano address preschool education and the need for 180 days of school programming for certain handicapped children.

— S2084 by Mega and A1260 by Schminger establish a temporary state commission on the prevention of developmental disabilities.

— S807 by Padavan defines penalties to be applied towards persons convicted of abusing clients in institutions operated by OMH and OMRDD.

— S1540 by Volker and A2190 by Eve establish programs for screening for and preventing lead poisoning in children.

— S957 by Padavan and A4217 by Prescott establish a procedure to evaluate the planned colocation of non-mentally retarded persons in developmental centers.

The next edition of OCV will report the outcome of many of the above bills.■

FINAL 1986-87 N.Y.S. BUDGET ADOPTED - Budget Contains Many NYSARC Initiatives

The Budget of the State of New York for fiscal year April 1, 1986 - March 31, 1987 was agreed to by the Legislature and Governor during the first week of April. The Legislature sent to the Governor a budget which contained a number of increases to programs and services serving persons who are mentally retarded and developmentally disabled. Most of the Governors original requests were included or in some cases were even enhanced.

The Budget overall was quite positive and contained some major increases to existing programs and some new initiatives. We must, however, be watchful as to how some of the new initiatives are used and where the overall direction of services for persons

who are mentally retarded are going.

The following is a summary of the New York State Budget for fiscal year 1986-87.

Overall Local Assistance funding was increased by almost 17% in the final budget over the total FY85-86 Legislative appropriations. Included in this amount were increases for such programs as Family Support Services and Supportive Workshop Demonstration programs up 39% and 200% respectively over FY85-86 funding levels. Furthermore, Day Treatment Advance Funding was up 70% from FY85-86 levels to reflect the approval of startup funding for non-medical day programs.

(continued on page 4)

HIGHLIGHTS OF SPRING BOARD OF GOVERNOR'S MEETING



The two "Dare Devils" at work. Florence Siegel and Beverly Epstein reviewing NYSARC Client Abuse Position Paper.

On May 2 and 3, 1986 the governing body of the NYSARC, Inc., the Board of Governors, met in Albany, New York. The 113 member governing board reviewed many issues, all of which affect the lives and well-being of persons who are mentally retarded.

A summary highlighting the major actions of the Board of Governors' meeting are as follows:

— Reviewed an overview of the proposed OMRDD Medicaid Waiver proposal.

— Reviewed and adopted the Association's 1986-87 Budget.

— Reviewed and adopted a position which will serve as guidelines to the chapters of NYSARC relating to Hepatitis B.

— Reviewed and adopted a position statement on client abuse as it relates to developmental centers.

— Approved a number of chapter by-law requests.

— Adopted a policy on confidentiality of chapter membership lists.

— Reviewed the request of the Fulton County Chapter to amend the NYSARC,

Inc. Articles of Incorporation to allow chapters to operate skilled nursing facilities.

— Approved the concept of the NYSARC, Inc. development proposal which would assist chapters with their development needs.

— Reviewed and discussed the issue relating to salary enhancement and parity.

— Received an oral report from the AD Hoc Committee to Review and Make Recommendations on the Structure of NYSARC, Inc.

— Received a report from the trustees of the New York State Retardate Trust.

— Added a number of scholarship and awards to the Association's Scholarship and Awards program.

— Adopted changes in the procedures of resolutions at the Association's Annual Convention.

— Approved the formation of an Ad Hoc Committee to Study Parent Outreach Programs to Parents of Newborn and Newly Diagnosed Children.■

Letters To The Editor

Dear Editor:

In your January 1986 issue of Our Children's Voice, there appeared an editorial accompanied by a cartoon depicting a group of individuals purportedly seeking admission to a community residence. The copy indicated that they were rejected because of lack of space.

It was very upsetting to the Willowbrook Chapter (now known as the Staten Island Developmental Center Chapter) officers, directors and members alike. Once again, after a hiatus of several years, the New York State Association for Retarded Children seems to be reverting to the stone-age concept of pitting the community chapters against the institution chapters.

Let us refresh your collective memories by stating that the gains of the community-based residence program in this state as well as in other areas have been stimulated by the legal involvement of the parent groups of the institutionalized residents over a long period of time and could not have been achieved without the struggles that led to the Willowbrook Consent Judgement.

We feel that your editorial and ill-placed cartoon was a cheap shot! Would it not have been better to support the more logical policy of sharing and expanding community placement instead of once again making villains of the institution population? Who was responsible for this divisive editorial and who unearthed this antiquated relic of the past? Where did the input originate and at who's prodding?

In the future let us pull together...not apart. Nobody gains if we are divided in our efforts to help the retarded. Today we are still faced with the dilemma of solving the problems of the deinstitutionalized as well as providing services to the community people who have similar needs. A community-based system to help all the mentally retarded should be our goal.

Sincerely,

Anthony Pinto, Al Turk, Mannie Barsky
Benevolent Society

Editors Response

It is most unfortunate that our Benevolent Society Chapter has interpreted both the editorial and the cartoon in the January 1986 OCV as being against deinstitutionalization. The fact is that the current policy of placement into a community residence is harmful both to the community and developmental centers. Placement into a community residence should be made based upon clinical decisions after considering such things as age, sex, medical condition and functioning level to name but a few. Placement should not be made based upon where someone resides.

Establishing a Quota System as Assembly Bill A.2511-A calls for might find no admissions into a community residence from a developmental center in some parts of New York State. Our Association, by the very fact that it is concerned for all persons who are mentally retarded - no matter where they may reside - cannot support a Quota System.

The Association's position calls for individuals to be placed from both the develop-

mental centers and from community-based upon clinical need not a quota system. We have asked the Legislature to amend their bills so that "admissions criteria for community residential placements shall not discriminate on the basis of prior residency in developmental centers or in family homes."

Our position, unlike what is being proposed, advocates for all persons who are mentally retarded whether they reside in a developmental center or at home. Isn't that our purpose?■

OCV Welcomes letters from readers. Letters for publication must include the writer's name, address and telephone number. Because of the large volume of mail received, OCV reserves the right to limit the amount of letters printed.

1986-87 Budget

(continued from previous page)

NYSARC, Inc.'s budget platform was significantly taken into account in the final FY86-87 budget. Initiatives advocated for by NYSARC and enacted into law included:

- 250,000 for a Hepatitis B inoculation program for employees and staff in Community Residential programs.
- 500,000 to fund rehabilitation to comply with Chapter 21 life safety code standards recently promulgated by the Federal government.
- Addition of Budget Language requiring the Commissioner of OMRDD to regionalize cost guidelines for real property options in recognition of varying local real property market conditions.
- An enrichment of the building aid formula for special education classroom from 1,500 to 2,000 per student in order to increase the amount of classroom space for handicapped children in normal public school settings.
- Restoration of 1,000,000 to fund crisis intervention teams for community based programs.
- Restoration of budget language mandating minimum staffing standards at non-Willowbrook class developmental centers.

Other major areas which were contained in the Budget are as follows:

A) Small Residential Units

One of the most important budget issues during the FY85-86 session related to SRUs (Small Residential Units). This initiative was approved by the Legislature. However, important changes were made in the final SRU appropriation. Most importantly, the Legislature required that SRU funding be transferred from OMRDD's Community Services program to OMRDD's Institutional service program and that SRU placements be counted as institutional rather than Community placements. In taking this action, the Legislature agreed with NYSARC, Inc. that lumping together SRU and Community programs was ill advised. Such action could lead to a situation whereby Community funding might be used for SRUs. Further, it created

the potential to substitute SRU placements for Community placements. Final Legislature action eliminated this possibility.

Additionally, the Legislature through budget language mandated additional requirements with respect to SRUs.

These include:

- Requiring the Commissioner of OMRDD to hold hearings by June 1, 1986 for the purpose of promulgating regulations with respect to SRUs. (We have written to the Commissioner concerning the dates of these hearings.)
- Requiring OMRDD to submit quarterly reports to the Legislature concerning the number of persons placed and discharged from SRUs, criteria for selecting clients for placement into SRUs and information relating to programming and alternative placements for clients in SRUs.
- Requiring that the Commissioner "to the extent practicable: limit the size of each unit to no more than twelve beds; ensure they are physically separate from existing developmental center buildings and services; ensure that they are sited in a manner which encourages integration with surrounding non-institutional (residential) communities; ensure that units are not in close proximity to other units; and ensure that clients residing in SRUs attend community based day program and recreational services."

Finally, the Legislature appropriated \$14,905,000 in capital funds and \$5,031,000 in operating funds for SRUs.

B) State Operated Programs and Facilities

1. Developmental Center Staffing

The Legislature has again required minimum staff to client ratios according to client care and administrative/support categories for non-Willowbrook class Developmental Centers. The legislative language requires that: "a) the weighted average client care staffing ratio shall range between 1.235 and 1.250 filled client care staff for each client and b) the weighted average administrative/support staffing level shall range between 4700 and 5100 filled administrative/support personnel exclusive of..... laundry service positions." Additionally, OMRDD must report to the Legislature on this matter after every payroll period as well as quarterly.

2. Community Services

The State Budget again emphasizes the provision of services to families by community services staff from the B/DDSO's. The Commissioner is required to assure the effective coordination of respite services; report to the Legislature on State resources devoted to serving clients living at home and with their families; utilize funding appropriated by the Legislature for crisis intervention services as a partial alternative to the case management system and assesses the impact of providing family support services.

3. Total State Operations Appropriations

a) Institutional Services Program	
1985-86	\$521,360,000
1986-87	\$572,642,000
b) Community Services Program	
1985-86	\$152,900,000
1986-87	\$185,065,000

C) Voluntarily Operated Programs/Local Assistance

1. Day Programs

In addition to enacting initiatives contained in NYSARC's budget platform the Legislature added other new items to the Local Assistance budget. Included was an addition of \$375,000 to increase the clinic fee from \$32.00 to \$42.00 per visit. Also, added to the budget was \$500,000 to fund day program maintenance expenses.

2. Residential Programs

The legislature made slight reductions in both the requested ICF/MR appropriation (decreased by \$556,000 or by 1%) and the requested Community Residence appropriation (decreased by \$500,000 or by 2%). These decreases did not reflect reductions in actual program levels but rather a reestimate of expenditures which would be needed to support program levels requested by the Governor.

D) Capital Funding

As depicted by the following list, the Legislature approved of the Governor's Capital requests for Institutional programs, State Community programs and State Aid for voluntarily operated community programs. All of these categories are increased over 1985-86 appropriations levels.

Institutional	
FY85-86	\$41,460,000
FY86-87	\$53,587,000*
State Community	
FY85-86	\$16,941,000
FY86-87	\$22,340,000
State Aid	
FY85-86	\$7,247,000
FY86-87	\$9,300,000

Also, the Legislature added budget language to reappropriated capital funds "to provide funding in advance of project approval and on a demonstration basis, for a total of up to 10 percent of the purchase price of real property related to a community project." This funding is intended to make it possible for providers to hold onto perspective capital development sites during lengthy state approval procedures by offering the Seller a down payment.

* Includes \$1,905,000 transferred into the Institutional Services program capital appropriations by the Legislature.

E) Office of Vocational Rehabilitation

The Legislature continued that \$2,500 funding level for individuals enrolled in the Sheltered Employment Program (SEP) which includes \$1,000 in exempt income. The FY86-87 appropriation level approved was \$38,411,700, which was the amount requested by the Governor.■

SUMMER SCHOOL FUNDING VETOED

At the end of April, Governor Cuomo vetoed the section of the Local Assistance Budget and eliminated the 7.5 million dollars included that would have finally mandated summer school for certain children with handicapping conditions, removing summer school from the Family Court and placing it where it has always belonged, under the Committee on the Handicapped.

While the Governor stated in his veto message that "the provision of services for handicapped pupils of schoolage attending summer school and for those attending pre-school programs is an objective which I fully share" he indicated that expecting the state to fund the program at 95% of the costs is "neither warranted on the merits nor appropriate because of the precedent it would create for other shared responsibilities of the state and local governments."

He went on to say, that while the bill was silent as to who would pick up the other 5% of the funding, the indication was that the counties would continue to have the responsibility. He feels that it is not appropriate to have county government financially responsible for a program when the local districts would assume programmatic responsibility. It is his strong feeling that "local school districts should be responsible for the education of all school-age children and that these services should be provided under a cost-sharing formula comparable to the present excess cost arrangement for children with handicapping conditions." The Governor has in fact, submitted his own proposal which would assign both programmatic and fiscal responsibility to the local school districts. His bill also includes giving to the counties, program and fiscal control for pre-school.

The removal of summer school for school-aged children from Family Court as well as the placing of this responsibility under the Committees on the Handicapped has been a long standing goal of this Association.

A meeting was held on May 12th at the NYSARC office with representatives of various concerned organizations to attempt to seek a solution to the funding of summer school and to discuss each others views on the preschool issue. NYSARC recommended, and it was generally agreed by most of the groups attending, that summer school and pre-school be separated in total and that legislation be pushed this year for just summer school. While at the writing of this article, it looks doubtful that this will occur; our Association will continue to work for summer school funding and pre-school reform.■

Get Well Mr. "T"

The Association's Mr. "T", Anthony J. Terranova, Executive Director of our Cayuga County Chapter, was stricken with a heart attack during the first week of May.

The entire New York State Association for Retarded Children, Inc. sends our warmest get well wishes to you. We want you to rest up - we miss you.■

NYSARC Library Re-Established



NYSARC Library Consultant, Mary Meachem.

The ARC Library previously housed in New York City is currently in the process of being re-established in its new location in Delmar, New York. The library will serve many purposes.

First this small specialized library will serve as a resource center. As such, it will contain current reference materials relating to all phases of mental retardation and the related fields of particular interest to its users (including an extensive pamphlet file, reprints, videos, etc.); a complete and current collection of law books (both state and federal); specialized periodicals and newsletters (with as complete a file of back issues as is possible); and materials of valuable historical significance for research purposes.

Secondly, the library will serve as archive for committee reports, seminars, convention proceedings, chapter bulletins, publications, surveys, press releases and all pertinent information on New York State Association for Retarded Children, such as budgets, publications, surveys and studies, annual reports and histories. The collection contains much information both on and from state and federal agencies whose policies and decisions affect the field of mental retardation. All minutes of Board of Governors meetings are on file in the library as well as a wealth of invaluable documents for historical research.

Finally, the library will serve as a referral agency for all the chapters. While the library at its present stage of development, cannot answer all the needs of its users, resources will be added as new topics are to be undertaken and money is allocated. Meanwhile, the library can provide a beginning to a central collection - a sort of one-stop shopping center for those searching for information of current topics or interests. If we can't help you, at least we can lead you to those other agencies and groups who can. With this in mind, we will have bibliographies; listing of organizations and their publications; indexes, directories; publisher's catalogs and a listing of federal and state publications.

Over the past several months, Mary Meachem, NYSARC's new Library Consultant has been working very hard to restore and organize existing library materials.

If anyone has collected their own professional library over the years and would like to donate books or other publications to help expand the library resources, please let Mary know. A book plate will be placed on the inside cover of all donated materials indicating who's personal library the publication came from.■

Quote of the Quarter

"As your President, I am seeing time and time again the importance of our State Office to be in a position to assist our chapters through this ever changing environment. I believe that we are at a time in our development where we need not only to grow but to protect that which we have accomplished."

David B. Lettman, President
NYSARC, Inc.
Reporting to the Board of Governors
May 2, 1986

Past Copies of OCV Needed

Back copies of "Our Children's Voice" are being prepared for binding to help preserve these valuable newsletters.

We are in need of several issues to complete this task. If you have any of the following editions, we would appreciate it if you would send them to us.

1984 Volume 36	No. 1
1982 Volume 34	No. 1
1981 Volume 33	No. 1
1980 Volume 32	No. 1 & No. 3
1976 Volume 28	No. 2
1970 Volume 22	No. 1

Any OCV's prior to 1960

Copies may be sent to Susan A. Lyons, Public Information Coordinator, at the NYSARC office.■

Upcoming Conference

"An Ounce of Prevention"

June 13 - 14, 1986
Brock University
St. Catharines, Ontario

A New York State/Province of Ontario action oriented conference on Prevention of Mental Retardation and Developmental Disabilities.

Areas of concentration will include: opportunities for the prevention of developmental handicaps; innovative community prevention programs; and implementing effective programs and strategies.

For more information contact:
Joan Edwards (716) 835-3674 or
Dr. Robert Guthrie (716) 831-2351

Open House Held For Chemung Chapter Children's ICF

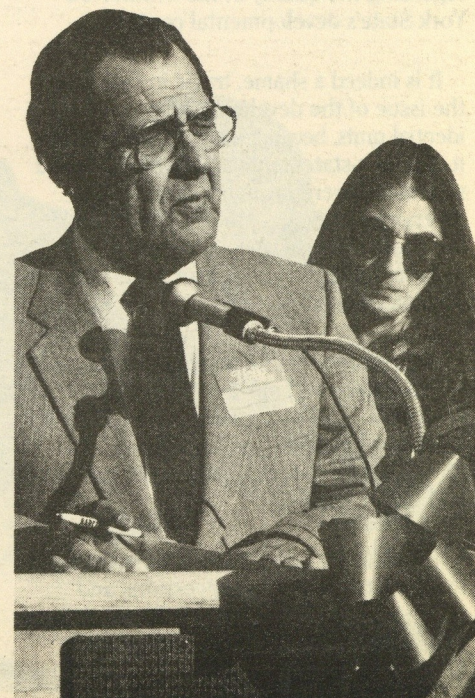
The Chemung County Association for Retarded Citizens held an Open House on November 24, 1985 from 2:00 p.m. - 4:00 p.m. for the area's first Children's Intermediate Care Facility. This residence will serve children ages 5 through 18 who are mentally retarded/developmentally disabled.

Representing the Association for Retarded Citizens at the Open House were Maryann Bryant, President of the Chemung County Association for Retarded Citizens' Board of Directors; Michael A. Doherty, Ph.D., Executive Director; Randy S. Denierio, Residential Services Program Director and William Losinger, Program Manager.

Speakers for the Open House were: New York State Senator, William T. Smith; Village of Elmira Heights Mayor, Gordon Brink; former Village of Elmira Heights Mayor, Chester Lunner; Trustee of Village of Elmira Heights, Elona Manges; Vice President Central Region, New York State Association for Retarded Children, Inc., John Bryant.

Richard D. Peet, President of Chemung County Association for Retarded Children from September 1983 - June 1985, cut the ribbon marking the opening of the home. Mr. Peet was instrumental in making this home a reality for disabled young people.■

William T. Smith addresses audience at Open House for Chemung County ARC's first Children's Intermediate Care Facility. Maryann Bryant, President of the Board of Directors listens in background.



NYSARC's Response to Public Hearings Concerning Regulations Governing SRUs

On Monday, May 19, 1986 the Office of Mental Retardation and Developmental Disabilities held three hearings concerning regulations governing the development of small residential units. The hearings were held in New York City, Schenectady and Syracuse. The Executive Director of the NYSARC, Inc., Marc N. Brandt, represented the Association at the Schenectady hearings. The following was the testimony given by Mr. Brandt.

"I am Marc Brandt, Executive Director of the New York State Association for Retarded Children, Inc. The history of our Association is filled with documentation that we have always been involved in the fundamental mission of advocacy. One of the primary objectives of our Association from the beginning was, and continues to be, protecting the rights of persons who are mentally retarded in the State of New York no matter where they reside.

We as an Association, continue to be concerned about those who live in developmental centers. We recognize an obligation and a need to voice concern about the age-old problem of the living conditions in developmental centers and the problems relating to the managing of these facilities. At a point in time when the focus has been in the direction of community programming, we continue to closely scrutinize the management policies and practices that directly impact on the lives of institutionalized children and adults who are mentally retarded.

We are here today to give testimony on regulations governing the development of SRUs. The Legislature, by adding language to this year's New York State Budget, requiring the Commissioner of OMRDD to hold hearings, has demonstrated, once again, their collective and ongoing concerns regarding the quality of life within New York State's developmental centers.

It is indeed a shame, tragic in fact, that the issue of the development of small residential units, became the controversy that it did. Mis-statements and misunderstood statements were brought about to such an enormous degree, that the real residential needs of those who will be remaining in developmental centers for years to come was oftentimes lost sight of.

Let us hope that we can learn from our past mistakes and move on with what we all collectively seek for New York State's persons who are mentally retarded. To err is human—but to repeat one's mistakes is sheer stupidity.

The hearing notices listed six main areas in which to focus our suggestions and comments concerning proposed regulations which will govern the development of SRUs. Our Association has three main comments regarding the regulating to SRUs.

Comments one and two relate to the six areas which are listed in the hearing notice and the third relates to additional areas.

Our first comment relating to our feelings concerning the six areas is to promulgate regulations in accordance with the language included in the 1986-87 New York State Budget. That is to say that 'to the extent practicable; limit the size of each unit to no more than 12 beds; ensure they are physically separate from existing developmental center buildings and services; ensure that they are sited in a manner which encourages integration with surrounding non-institutional (residential) communities; ensure that units are not in close proximity to other units; and ensure that clients residing in SRUs attend community-based day program and recreational services.'

Our second comment relating to the proposed regulations is that SRUs should be governed as any intermediate care facility is in New York State. That is to say, SRUs should fall under Part 681, which are the state regulations pertaining to ICFs. All regulations applicable under 681 should be adhered to within SRUs.

Thirdly, our Association has a number of comments and concerns regarding SRUs, falling outside of the regulatory process yet relating to SRU development. While some of our comments relate more to philosophical concerns, they all nevertheless, relate to the quality of life that will be afforded to individuals in need of and who will be residing in SRUs.

First and foremost is the strong concern that our Association has regarding the future use or misuse of buildings that may be vacated due to the development of SRUs. It would be foolish for us to think for one minute that the concept of SRUs would benefit persons who are mentally retarded while being co-located next to programs and services relating to persons who are in custody of the criminal justice system.

Besides the normalization and advocacy concerns that the co-location issue raises, it is just plain common sense not to put side by side our most fragile and vulnerable individuals who need to be integrated within society from those who need to be kept from society. Our Association, while understanding that the regulations may not be able to address this concern, urges—implores the Office of Mental Retardation and Developmental Disabilities to begin to address this concern by being in the forefront of advocating against co-location. While it may not be a politically expedient position to take, I can assure you that OMRDD would be remembered for generations to come, by New York State's disabled and their families, should such policy against co-location become reality.

We also feel that SRUs could become, if properly staffed and managed, a training ground for future professionals to work with the severely and profoundly retarded. While SRUs will become a reality there are no reasons to believe nor support for the concept, that everybody who currently resides in a developmental center needs an SRU. If the SRUs are used, however, as a model, not just an alternative, perhaps many other individuals currently residing in older rundown buildings would be afforded the opportunity for community—real community placement.

I personally, believe, that from all I have seen, the Office of Mental Retardation and Developmental Disabilities has the talent, resources and knowledge necessary to make SRUs not just an alternative living arrangement, but a program where new concepts could be developed in working with individuals who are severely and profoundly retarded.

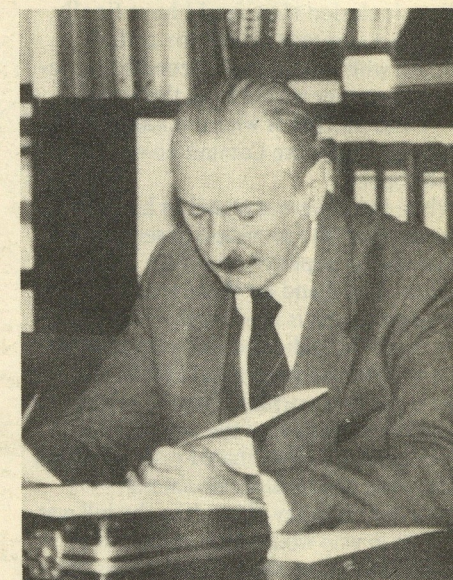
Obviously, it goes without saying that if SRUs would be used as a program concept, with training and educational implications, that the very reasons why SRUs are being developed must be critically and immediately dealt with. I am of course, speaking about the issues surrounding the development of community-based residential programs.

Individuals currently residing in developmental centers who could be placed within the community should not be relegated to SRUs no matter how well run they may be, because the systems needed to develop in the community are not able to keep pace with the need. If we can find ways of 'fast tracking' the system to build SRUs than surely we can set as a priority the restructuring of a system which does anything but what it was intended to do—develop community residences.

Again, I state that we should learn from these past few months. The issues that divided many of us concerning SRUs should now unite our efforts to bring about positive change. We all desire quality programs and services for those persons who are mentally retarded. It now becomes and actually always has been, a matter of the distribution of money, manpower, the management systems, federal and state social policy and funding mechanisms which promote our current system.

We have always recognized our obligation in the past to see that changes occurred to promote the well-being of all persons who are mentally retarded no matter where they reside. The development and regulating of the SRUs is current policy. If SRUs are to become a permanent part of the continuum of residential services for persons who are mentally retarded only time and how we manage the first SRUs will tell."■

NYS



George Hirsch, NYSARC Treasurer, carefully examines documents provided at the Executive Committee meeting held at the NYSARC State Office.

Mission Statements Approved for Three New NYSARC Committees

Three new NYSARC, Inc. Committees were formed when the Association revised their by-laws last year. At the Spring Board of Governors' meeting the Board of Governors approved the mission statements of the Adult Services, Incident Review, Supplementary Recreation and Special Olympics Committees. The adopted statement of purposes are for each committee as follows:

Adult Services Committee

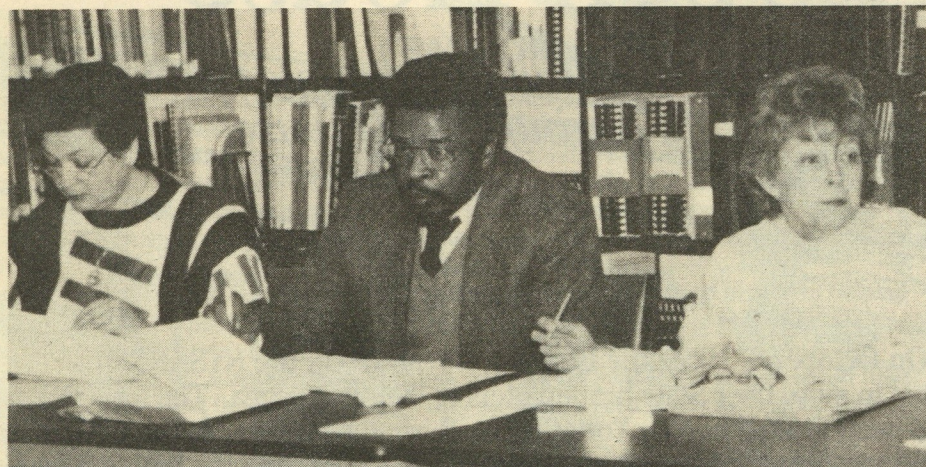
"The Adult Services Committee shall advise, educate and provide leadership to the NYSARC, Inc. Board of Governors on matters which impact upon adult service in the areas of Day Treatment, Day Training, Vocational Rehabilitation and Sheltered Workshops and other day services initiatives. The committee will recommend policy, position statements and direction on matters affecting the adult mentally retarded/developmentally disabled population which NYSARC, Inc. chapters serve."

Incident Review Committee

"The Special Incident Review Committee shall gather information regarding the reporting and review of untoward incidents by Chapters so as to recommend to the Board of Governors, guidelines for the reporting of serious incidents by chapters to NYSARC; they shall establish guidelines for the dissemination of information to all chapters regarding the prevention of untoward incidents; they shall both initiate and react to policies or recommendations of regulatory and review bodies regarding the review and reporting of untoward incidents."

Supplementary Recreation and Special Olympics

"To promote greater involvement in Special Olympics and to create an awareness of innovative recreational programs."■



Bernice Volaski, John Bryant and Ellie Pattison listen intently to issues raised at the Executive Committee meeting held at the State Office.

Recipients of Scholarship Awards Give Thanks to NYSARC

Each year, the New York State Association for Retarded Children, Inc. awards scholarship money to individuals who are either working in one of the local chapters, developmental centers or enrolled in a college program in Special Education. The scholarships, which are granted to individuals for the purpose of furthering their education, are given in honor of persons such as Joseph T. Weingold who have made tremendous contributions to the New York State Association for Retarded Children, Inc. and to the field of mental retardation.

The recipient of these scholarships are chosen by the Scholarship & Awards Committee of NYSARC and their selection is based upon recommendations from the chapters and/or their academic achievements and work experience in the field of mental retardation.

Recently, two letters of appreciation were addressed to Kay R. Nogaj and Francis Reville thanking them for selecting them as the recipients of the Joseph T. Weingold and James F. Reville Scholarships. We have included a portion of these letters below to illustrate the positive impact that our scholarships have on the lives of our young people who are interested in working with children and adults who are mentally retarded.

Dear Mrs. Nogaj:

"I trust that earlier this semester, you received my transcript to notify you of my previous courses.

Due to the confidence you have put in my academic potentials and endeavors, I feel you have aided and prompted me to meet and surpass my academic expectations. I also thank you for supporting me financially. Your support has removed the burden of financial worry.

I realize that this last payment will be my final and that contact between you and I will most likely cease. But the reason and purpose that I have received your scholarship will be put into practice.

For four years, I have studied and learned about methods and techniques of teaching. Mostly, I have learned about children—the need for love and caring within the classroom. God has blessed me with a gift of love and patience for all children—handicapped and non-handicapped combined with a belief that all deserve a rightful chance for an education.

I have been chosen as one of two class marshalls representing the School of Education for the 1986 Commencement ceremonies.

Again, I thank you for your confidence and support during my final two years at Syracuse University."

Sincerely,
Arlene S. Muth

Dear Mrs. Reville:

"I am writing to thank you for the generosity expressed through the James F. Reville Scholarship. I was chosen as recipient of this award in 1984. It was gratifying for me to know that I would receive financial aid through this scholarship.

It doesn't seem possible that two years have past since this time. I am pleased to say my academic efforts have been rewarded by having my name placed on the Dean's List. This is a direct result of having some of the financial burden alleviated by receiving the scholarship checks each semester.

My commitment grows stronger as I work to increase my knowledge and understanding of individuals who are mentally retarded."

Tracy E. Edwards ■



Eager to begin work, Linda Hogan, member of the YOUTH ARC Committee and Chairperson, Maythorne Winterkorn "race" to their meeting to begin working.

Special Olympics A Parent's Perspective

Over the past several months, the NYSARC Supplementary Recreation and Special Olympics Committee has been meeting to work on their goals and objectives for 1986. Below is a letter which was written by a parent who's child is involved in a Special Olympics program through one of our chapters:

"Twenty-two years ago when my son was born, it was called mongolism. Marc's arrival into this world brought us joy mixed with sorrow, confusion and fear. What could we have done twenty years ago? We could have placed Marc in an institution where he would be with his "own kind". We could have adopted him out to a family who was willing to take him, or we could keep him and raise him ourselves. We already had three children, but Marc was special and we loved him and wanted him.

We were told raising a child like Marc would be a very difficult responsibility filled with hardships and sacrifices. We were warned about the special supervision he would need and the special education and

medical complications that would be required in Marc's life. No one told us there could ever be swim meets, softball games, dances, dinners and social activities. Words like competition, bronze, silver and gold medals could never be applied to someone special like our son Marc. Not in the view of society in the early 60's.

Marc, however, was to become the pride of our family because of an organization that believed in the potential of all the wonderful children and young adults like our son. It is the Special Olympics Organization. Unique individuals from all walks of life who are mentally retarded have become the heroes and the models of inspiration for all of us. These individuals are strong, courageous people who are extremely proud of their own endeavors and achievements and are determined not to allow their personal handicaps to become a liability to them. They have an eagerness and a willingness to show off their capabilities and not their limitation.

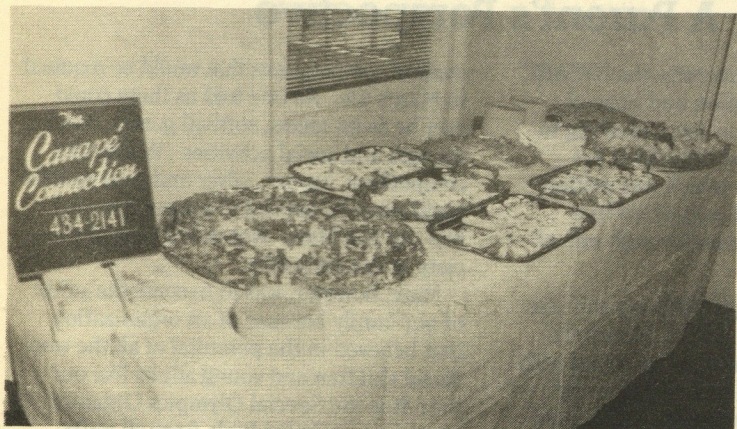
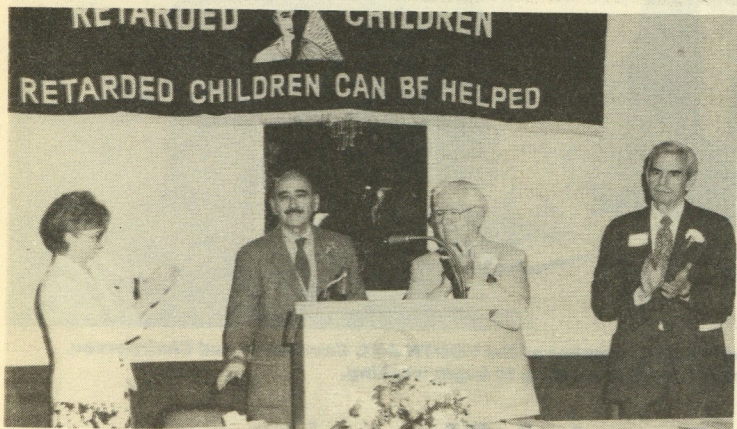
The Special Olympics Organization opened the door for myself, my family and for all of society to see the hidden potential that each of these special people have to offer. Whether it is "going for the gold" or just being part of the team effort, all of these children and adults excel.

No longer do families like my own have to shelter and shut out our children. We have become a strong, supportive group for them as well as ourselves. We have learned from their determination, their exuberance, their need to participate just like other children. The Special Olympics Organization enables us to share with the world the joy, beauty and laughter we always knew existed inside these indeed very special people."

Virginia Glamm ■



Producer Norbort Nathanson (center) joins to the NYSARC Prevention Committee to talk about the development of their slide presentation on the prevention of mental retardation and developmental disabilities.



May 2, 1986 Open House

Over four hundred individuals toured building during Open House.

On October 8, 1982, the Board of Governors of the NYSARC, Inc. voted to move their State headquarters to the Albany area. The Association had been located in New York City for thirty-three years. At the Spring 1983 meeting, the Board of Governors voted to purchase the former Adams House/Bethlehem Town Hall in Delmar, New York. In June of 1983, the Association officially moved into its new headquarters. At the October 1983 Convention, the Delegate Assembly voted to name the building after its first President and Executive Director for thirty years, Mr. Joseph T. Weingold.

Over four hundred individuals toured the building on May 2 and 3, 1986 during an Open House. The Association has attempted to carefully restore the building so as to keep its historical significance while providing the Association with a warm functional work setting.

The new headquarters of NYSARC served in its early years as a stage-coach station and inn, known as the Adams House. One can still see two of the original rooms intact in the attic, dating back to 1838. The Delmar Volunteer Fire Company took ownership of the building in the first quarter of the 20th century. In 1950, the Town of Bethlehem bought the building for use as the Town Hall. The Association's library is housed in the new building as is all the administrative staff of the organization.



May 3, 1986 Dedication

The Joseph T. Weingold Building Dedicated

On Saturday, May 3, 1986 following the Spring Board of Governor's Meeting, the Formal Dedication took place at the Sheraton Airport Inn in Albany, New York. Former Deputy Majority Leader of the Senate, William T. Conklin, served as the Honorary Chairperson. The Senior Vice President of the Association, Shirley Valachovic, was the Chairperson and introduced the various speakers.

The Reverend Randall Patterson from the Town of Bethlehem began the ceremony with the invocation. Speakers that followed were: Ms. Ruth O. Bickel, Deputy Supervisor, Town of Bethlehem; Dr. Alan D. Miller, Former Commissioner of the New York State Department of Mental Hygiene; Mr. David B. Lettman, President, NYSARC, Inc.; Mr. Marc N. Brandt, Executive Director, NYSARC, Inc.; and William T. Conklin. The Reverend Richard H. Mueller, who is the President of the Franklin County Chapter, delivered the Benediction.

Mr. Weingold in his remarks, remembered the many, many individuals who, with him, were the pioneers in the planning and implementing the many programs and services for persons who are mentally retarded. All who were in attendance will long remember this eventful day in our Association. ■



The official plaque that will be affixed to the building was presented by Senator Conklin to Mr. Weingold. The plaque reads:

*This Building
is Dedicated in
Honor of
Joseph T. Weingold
Executive Director
1950 - 1980*

*"While there may be some doubt as to
how much we may be able to change our
children for the world's sake, there can
be no doubt about how much we must
change the world for our children's sake"*

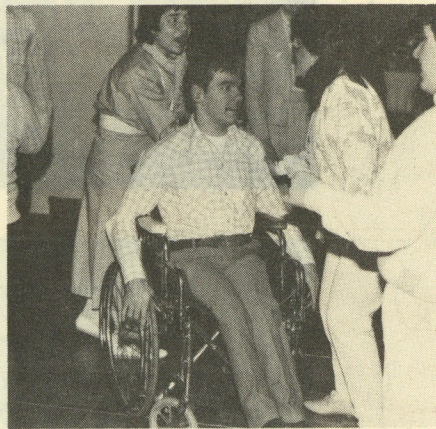


CHAPTER NEWS

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Individuals from Cayuga ARC take part in "Hands Across America" in an effort to help the starving people in America.

HERKIMER

Whiffletree Inn Recognized As Supporter of Valley Handicapped

The Whiffletree Inn, Ilion, has distinguished itself as a true supporter of occupational training of the handicapped through involvement in the Herkimer County ARC's Herkimer Industries HI-STEP Occupational Training program. Currently, the Whiffletree employs one handicapped worker and provides training sites in the areas of food preparation and kitchen aides.

In recognition of their cooperation, Herkimer County ARC nominated the Whiffletree Inn as Employer of the Year. At the annual conference of the New York State Association for Retarded Children, June McCarrell, President of the Herkimer County ARC Board of Directors, accepted an attractive plaque denoting a Certificate of Appreciation. This plaque was recently presented to John Brown, Owner/Operator of the Whiffletree Inn, in honor of their efforts on behalf of the developmentally disabled citizens served by the Herkimer County ARC. ■



"Exceptional courtesy and concern for customers" won David Busch a coveted Silver Dollar Citation from the Friendly's Restaurant chain. David shares his pride with Lois Neuwirth, Supervisor of Rehabilitation Services for the Nassau AHRC. Lois was David's counselor at the time of his placement as an employee with Friendly's after having been in the AHRC Vocational Training program for nearly two years. Through his special recognition by Friendly's, David helps to prove that persons who are mentally retarded make good workers.

NASSAU

ROME DEVELOPMENTAL CENTER

The Rome Developmental Center Chapter recently received a grant for \$5,000 from the IBM Fund for Community Service.

The money will enable the chapter to purchase computer equipment and software. The grant was approved in recognition of the chapter's hard work and dedication to children and adults who are mentally retarded in their community. ■

DELAWARE

State Senator, Charles D. Cook has been chosen as Delaware County ARC's Honorary Membership Chairman for 1986.

As honorary Membership Chairman, Mr. Cook urged all friends of persons who are retarded to join him in becoming members of the chapter. While lauding the chapter's accomplishments, he indicated that there were many services that needed to be developed and expanded. He stated that the support of the membership was needed to assure that the chapter continues to meet the needs of Delaware County's mentally retarded citizens.



State Senator Charles D. Cook, Honorary Membership Chairman for the Delaware County ARC Chapter gives his dues payment to Chapter Treasurer, Anne Ryan (Walton) while Melba, Chairman Luella Rogers (Walton) and President Carmel Banks (Delhi) look on following tour of the new Walton Community Living Skills Center which recently opened at the former Bros. Building.

From left to right: Luella Rogers, Anne Ryan, Senator Charles D. Cook, Carmel Banks

STEUBEN

Steuben ARC Residents Sponsor "Foster Child"

The residents of the Bath Oaklawn Community Residence know what it's like to be a foster child and they are reaching out to help a small child less fortunate than they are.

Thanks to the persistent encouragement of Wanda Beyor, the residents of the Bath Community Residence took on the sponsorship of a needy Latin American child this year. The child is now living with the Bath ARC residents and is being cared for by them.

UQUA

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DUTCHESS

Aerobicize for D.C.A.R.C.

Allsport Fitness and Raquetball Clubs sponsored an AEROBICIZE-A-THON for the benefit of the Dutchess County Association for Retarded Children during the week of March 3rd.

From Monday to Friday of that week, member participants had their attendance in Fit 1, Fit 2, Fit 3, Fit 4, Floor Works, Aqua-Aerobics classes documented, working towards certificates of high achievement. On Saturday, March 8th, the AEROBICIZE-A-THON opened to the public in Fishkill.

Fund raising activities such as AEROBICIZE-A-THON are common happenings at Dutchess ARC and essential to ensure continuation of services and programs. ■

SENECA

Seneca ARC Wins Family Support Grant

The Seneca County Chapter has received notification from OMRDD of the awarding of a FAMILY SUPPORT SERVICES CATEGORY II GRANT, to continue and expand the development of supplementary services to families of the developmentally disabled in Seneca County.

Staffed by two full-time professionals, the program has developed service compo-

ESSEX

New Homes - New Beginnings

Essex County was the answer for 28 clients from Staten Island Developmental Center, six from Letchworth Village and two from the Sunmount DDSO.

The Essex County Association for Retarded Children (ARC) offered to build three intermediate care facilities for the developmentally disabled, in order to provide a much needed alternative to institutional living.

A private charter DC-9 jetliner left Newark, New Jersey bound for Plattsburgh. On board were 36 former residents of Staten Island and Letchworth Village developmental centers heading for new homes in the North Country. Also on board was an assemblage of support staff to assist in the move.

After many months of planning by the Sunmount DDSO, Essex County ARC and

Staten Island B/DDSO, all requirements for community placement were met.

Staff of the Essex County ARC kidded about the "cast of thousands" that would be waiting at the airport when the jet touched down. Actually, at least 100 staff from Sunmount and Essex ARC were standing by when the plane landed, ready to welcome the new North Country residents and help them get settled as quickly as possible into their new homes.

The resident's new homes are located in Keeseville, Willsboro and Schroon Lake and are designed for up to 12 each.

The move of 36 persons from institutional care to the community is not an end of a project, rather it symbolizes a new beginning. ■

YATES

Something New at the Yates ARC

The equipment of the former JKM Printing Company of Branchport, New York is now located at the Yates ARC facility in Penn Yan where it has been integrated as part of Keuka Lake Enterprises, the sheltered workshop. The equipment has been donated to the ARC by Jackie and Barry Milliman and Mr. Milliman will continue as printer. The expense of moving the equipment was partially underwritten by a local builder who donated the use of his equipment.

Tasks in the printing process will be analyzed and evaluated, and clients will be trained to perform those which are deemed appropriate. The acquisition of the Print Shop will give the Yates ARC the capability of bidding on printing jobs posted by National Indus-

CLINTON

Ground Breaking Ceremony Held.

On November 4, 1985, agency officials, board members and local dignitaries turned the first spade for Clinton County Chapter's new Sheltered Workshop facility in Plattsburgh. The planned 18,000 square foot addition will be adjacent to the newly renovated Day Treatment facility and is slated for occupancy in June 1986.

Philip Hoffer, Executive Director, conceptualized the 1.3 million dollar agency expansion project. John McKenna of McKenna Associates in Plattsburgh is in charge of design.

The construction of the Sheltered Workshop and administrative offices will be partially funded by proceeds from a very successful capital campaign, which raised more than \$200,000. A consultant, Brian Wettlaufer, of Developmental Resources, Inc. was hired to lead the campaign.

An Open House commemorating the recent opening of the new Day Treatment facility was held following the ground breaking ceremony. The complex, upon completion, will be known as the Merritt, founder of the chapter and her husband Evalon. ■



Agency officials, board members and local dignitaries turned the first spade for Clinton County Chapter's new sheltered workshop facility.

LEWIS

Lewis County ARC celebrates 30th Anniversary - Reflections 1956-1986.

How do dreams come true?

On April 19, 1956 a small group held a meeting about seeking special education services for their children. Six parents were at this meeting. A second meeting was held on April 24 to elect officers.

The first project was to start a class for a few children who never attended school. The class met in the old Loucks district school for two hours a day for six weeks. The Board of Cooperative Educational Service (BOCES) took over the trainable classes in 1957. Officially we were admitted into the New York State Association for Retarded Children in 1958.

The 1960's saw more growth as the state was now paying for local programs for the handicapped. The ARC was instrumental in getting the Community Mental Health Board formed. The State Department of Mental Hygiene (now the Office of Mental Retardation and Developmental Disabilities) was suffering from growing pains and so were we.

In 1967, a small workshop was started with a budget of only \$2,000 and only six clients. One of our projects was furniture refinishing. In 1977 the agency purchased the old Turin school.

Today we serve 70 clients in the various workshop programs. In 1984 a building was built for the workshop and in 1985 we added a small cafeteria.

A giant step was taken in 1977 when the community residence was opened in Lowville. Today there are 14 clients in the residence and another 14 in the supportive living apartments around Lewis County.

A program for children under 5 years of age started in 1976. There are now 15 children in this program known as the Child Development Program located in Lowville.

A day treatment program became operational in 1985. There are currently 37 clients enrolled in the program.

From the staff of two in 1967, we have grown to over 70 employees. The budget, as you can imagine, is well over a million dollars. We are now serving over 120 clients compared with about six in 1967. Membership in the Chapter has grown steadily from the ten Chapter members to the current membership of over 215. Without our membership to help, I am sure our programs would not be what they are today.

Our dreams have gone far beyond our expectations of thirty years. ■

PUTNAM

Prader-Willi Facility to Open

The Putnam Association for Retarded Citizens, will open a facility designed specifically for Prader-Willi patients.

Prader-Willi Syndrome, a condition which renders its victims compulsive eaters, is so unusual that few doctors recognize its symptoms.

There have been scattered reports of deaths across the country each year by and large there are no suitable private, state or federal programs to provide for Prader-Willi patients.

The facility in New York State will be opening sometime this year under the auspices of the Putnam Association of Retarded Citizens with funds being provided by the Office of Mental Retarded and Developmental Disabilities.

According to Stuart Greif, Executive Director of the Association, "We realized that this particular problem existed many years ago and have fought long and hard to address the problem properly and relieve some of the suffering of both the victims and their families."

Greif added, "I will be happy to share news of the site location and readiness for occupancy. Anyone interested in finding out more information, may do so by calling our Association office at (914) 225-1115. ■

NASSAU

Nassau AHRC Will Honor Government Leader

The Supervisor of Oyster Bay Township, Joseph Colby, will be honored by the Nassau AHRC when that chapter presents its annual Humanitarian Award.

The presentation takes place on June 21st at AHRC's annual Rose Ball to be held at the New York Hilton. That affair, which this year is chaired by Helen Kaplan with Dorthy Ganin serving a journal chairman, raises together with its journal about \$300,000 annually and is the keystone of the Nassau AHRC's community fund-raising. ■

FULTON

They were "Off To See the Wizard" in Fulton County's Day Treatment Department and all the clients and staff followed the yellow brick road to Lexington Center's Gymnasium in Gloversville when the play was presented recently.

The program was unique not only because staff and clients worked together on sets and production, but because the parts were played by duplicate actors and actresses; Dorothy played by both a client and a staff member, the Tin Man played by both, and the Scarecrow and great Oz himself all played by clients and staff in duplicate.

"We all worked hard to make it exciting", said Brenda Toomey, Instructor of Adaptive Learning at the Day Treatment Center, "and it's been especially rewarding to see the client and staff relationships blossom during the planning and practice period."

The script, closely following the original work by Frank Baum, was prepared and choreographed by staff members and clients decided to do not only the performance for other staff and clients of Lexington, but a public performance to benefit the Fulton County Children's Christmas Fund. ■



Dorothy, the Tin Man and Good Witch Glinda were among the doubles at the recent production of the Wizard of Oz at the Lexington Day Treatment Unit in Fulton County.

FRANKLIN

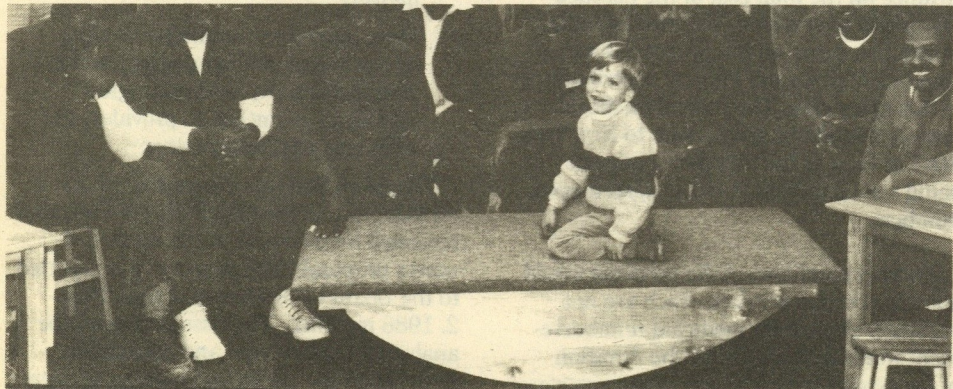
Inmates at the Adirondack Correctional Facility (ACF) at Ray Brook, New York have constructed many hundreds of dollars worth of specialized equipment and adapted toys to meet the needs of handicapped children at Franklin County ARC. After reviewing the design specifications with therapists and special education staff, the ACF inmates order the appropriate materials and construct items as part of their woodworking-shop activities. Over 100 items were made in 1985 with the only cost to the ARC being the actual cost of materials used.

Besides the financial benefits, there is also the community-education benefit of helping others learn more about the handicapped children and finding ways to encourage their involvement with them.

Before making the adaptive equipment toys, inmates involved in the project spend time with the children and their parents so that they are able to get a better sense about how the equipment will be used.

Watching these children maneuver themselves on the balance board, complete the peg puzzle and undo the latches on the latch board gave these men a better sense of the significance of their contribution than any technical description ever could have.

The experience for both the inmates and the family and staff from Franklin ARC has been not only educational but heartwarming to have these two groups working together to make a better world for children with handicapping conditions. ■



Justin Desmarasis, a student in Franklin ARC's pre-school program, Children's Corner, enjoys maneuvering himself on the balance board as inmates from ACF and ARC staff persons look on.

ONEIDA

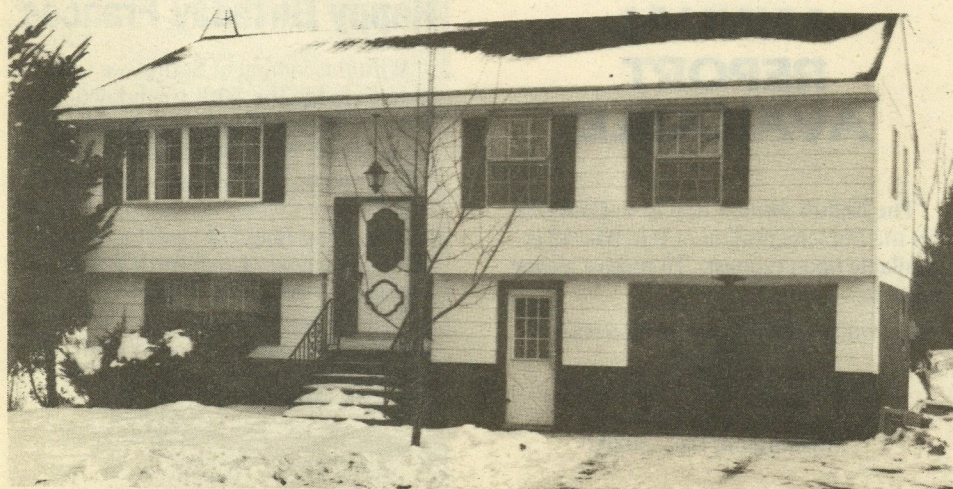
Oneida Chapter Opens Supervised Apartments

The Oneida County Association for Retarded Citizens is the first Voluntary-Sector-Provider of Residential Services in New York State to open three bed supervised apartments at scattered sites. Six supervised apartments have been opened in Rome, Vernon and Utica.

The apartments reflect the attention to detail in creating a home-like atmosphere that is readily seen in Oneida's other residences. Each apartment expresses an individuality and warmth unique unto itself.

Following the Rome DDSO Model being used state-wide, the apartment settings are very different. The locations run the gamut from central city to country and suburban living, offering the residents a choice of life-styles historically not available in supervised apartment programs.

The ARC is a major provider of Residential Services in Oneida County. When the Willowbrook Consent Decree focused attention on reducing the population in the state-run institutions the ARC became the first Voluntary-Sector-Provider of Residential Services in Oneida County. Currently, the agency operates six community residences, 12 supportive apartments and now six supervised apartments, bringing the total number of individuals being served to over 100. ■



Operated by Oneida County ARC, this house is one of the first three-bed supervised apartments of scattered sites to open up in New York State.

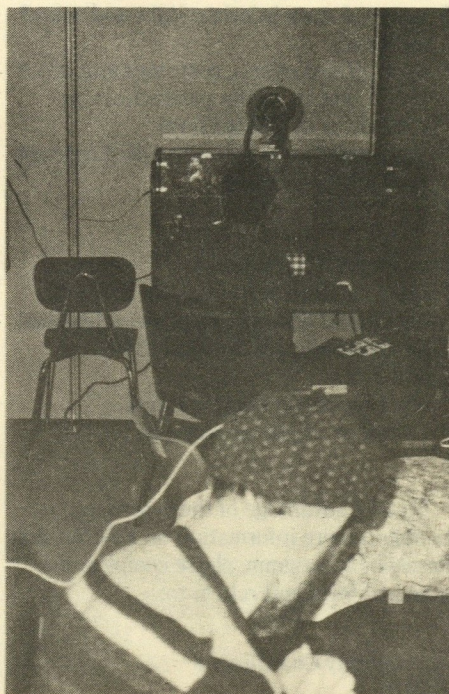
SCHENECTADY

Active Stimulation at Schenectady ARC

The Schenectady ARC Day Treatment Program has initiated a new, innovative program called *Active Stimulation*. Implemented by the Skills Development module at Maple Ridge (a module which serves severely to profoundly mentally retarded adults), Active Stimulation is a new method of learning which is used in conjunction with other intensive training techniques. Based on past and present research and application, the Active Stimulation program has proven to be very successful.

Active Stimulation is defined as a process by which the multiply handicapped person is afforded control of his or her environment through the use of adaptive switches, timers, computer control units and a variety of auditory, visual and tactile sensory reinforcers. Basically, it is a program that can allow an individual maximum opportunity to utilize whatever motor ability he/she possesses in his/her experience with environmental events; thus, aiding in his/her development with the concept of cause and effect.

Although the Skills Development module at Maple Ridge is beginning the new pilot Active Stimulation program with a small, specially selected group of clients, future plans include a greater expansion of the program as more equipment is purchased and designed and as staff develop their expertise in the area of Active Stimulation. Meanwhile, clients who originally were assumed to have little to no potential of learning are finally being given an opportunity to demonstrate their true skills and abilities... an opportunity that will allow them a greater chance to "Be all that they are capable of being." ■



Individuals at Schenectady County ARC Day Treatment program participate in their new Active Stimulation program.

NIAGARA

Niagara ARC Opens Satellite

More than 100 jobs will be created for persons who are mentally retarded and developmentally disabled and unemployed non-disabled adults as the Niagara County ARC expands and opens a satellite site for its Opportunities Unlimited Center.

The new facility, to be housed in Lockport, New York will immediately enable 70 mentally and physically handicapped employees living in eastern Niagara County to work closer to home. Currently, these individuals are traveling a minimum of 40 miles daily to the workshop in Niagara Falls.

The new satellite site will offer the only opportunity for training and sheltered workshop programs in the eastern end of Niagara County; in fact, the only opportunity in the county outside of the city of Niagara Falls.

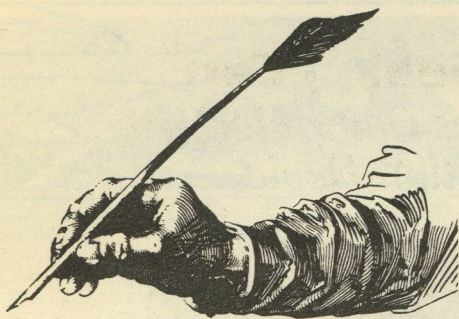
In addition to providing these opportunities in their own community, the transfer to the Lockport Center will provide space for additional individuals needing service in that area and open up more slots in the Niagara Falls Center.

Two major grants have been awarded from private foundations to assist in the startup and support of Opportunities Unlimited Centre II. The Gannett Foundation awarded a \$100,000 community Priorities Program (CPP) Grant to assist in funding added staff, training supplies, new equipment and retooling. Under the Gannett Foundation Grant, a number of non-disabled, unemployed or underemployed workers will also be hired. The uniqueness of the program is that it allows for a division of work by skill level. The integration of the non-disabled employee into the program will enable the development of more sophisticated work contracts and a higher level of skills training and development. In addition, it can fund skilled craftsmen for assistance in the development of a product to be produced and manufactured by ARC workers.

The CPP grant was the largest competitive grant program of the Gannett Foundation and centered on "People and Their Work" focusing on unemployment and other work related programs. Janet Krause, President and Publisher of the Niagara Gazette, a Gannett Company, Inc. newspaper, recommended the proposal locally.

The Eastern Niagara United Way has awarded a \$7,000 Venture Grant to the Niagara County ARC for the Lockport Opportunities Unlimited Centre. The Venture Grant program is a special fund set aside by the Eastern Niagara United way for the development of new programming to meet special needs in the Lockport area. The monies awarded to the Niagara ARC will assist in the startup costs necessary for the development of the Lockport satellite such as renovation and equipment purchase.

The New Opportunities Unlimited Centre is another step in the growth and development of quality services for Niagara County residents who are mentally retarded and developmentally disabled. The support of private foundations and individuals will assist in the development of new skills and opportunities for many more in need. ■



NEW PUBLICATIONS

Several new publications are now available through the NYSARC, Inc. State Office. Listed below is a brief description of each along with ordering information:

New York State Association for Retarded Children, Inc.

A multi-paged booklet which provides information about programs and services available to children and adults who are mentally retarded and their families through the local chapters as well as the State Office. Limited quantities are available at no charge.

Guardianship: A Planning Alternative For Persons With Mental Retardation

A major concern expressed by most parents is for the future well-being of their children when they are no longer able to look after and provide for their welfare.

Parents of children who are mentally retarded find themselves asking questions such as "what will happen to my child after I am gone", what are my choices?; does my child need a guardian?; how do I go about obtaining guardianship?; how best can I provide for my child?"

These are only a few of the questions which are explored in this new 14 page booklet. Booklets are available at a cost of \$1.50 each. Orders exceeding 25 booklets are discounted at \$1.00 per copy.

1986 NYSARC Professional Development And Training: Train-The-Trainer Program

We announce the Train-The-Trainer Program by a ten page booklet which describes this year's training initiative to support chapter on-site, direct care staff development and training.

The Train-The-Trainer Program is a new effort to assist or help initiate chapter training activities by providing a forum for the intensive instruction of 160 potential in-service trainers statewide.

This booklet describes a program which has broad applicability to all program service areas. Information regarding instruction, objectives, format, agenda, materials, registration information, schedules and locations is also provided.

Copies of this important booklet are available at no charge.

TO ORDER THESE OR OTHER NYSARC, INC. PUBLICATIONS, PLEASE WRITE TO OR CALL:

Susan A. Lyons
Public Information Coordinator
NYSARC, Inc.
393 Delaware Avenue
Delmar, New York 12054
(518) 439-8311

The Empire State Institute for the Performing Arts

ACCESS FOR ALL

Designed to make the performing arts at the Egg accessible to everyone, ESIPA's Arts Accessibility program represents an exceptional and forward-looking model for similar endeavors throughout the United States. This comprehensive program includes services to theatre-goers, as well as disabled employees, artists and students involved in productions at ESIPA. Services offered include pre-attendance assistance, special seating, interpreted events, consumer information services and educational services, enabling disabled persons to include performing arts in their regular schedule of activities.

ARTS ACCESSIBILITY SERVICES

The following services are presently provided by ESIPA on a regular basis. Other special-needs services are available as individual needs dictate.

Consumer Information Services

Through brochures as well as through personal contact, the consumer is provided with information concerning the following areas:

- physical access
- program access
- interpreted performances
- ticket purchasing
- transportation

Interpreters

Interpreters are provided for one performance of each production. Teacher inservices are also interpreted, an other theatre programs can be interpreted upon request.

Ticket Information and Reservations

- season brochures in regular print, large print, braille and on cassette, sent through the mail
- ticket ordering by phone and TTY
- reserved seats in prime sight and sound locations
- descriptions of sets, costumes and other visual aspects of the production on cassette or in printed form
- large-print programs or braille programs available on request

Transportation Services

- information/reservations for S.T.A.R., the Capital District bus services designed for those who are disabled (518) 482-2022
- wheelchairs for theatre access
- escorts available on request

To take advantage of these services, or to obtain more information on ESIPA's Arts Accessibility program, please complete the attached form and return to:

Accessibility Coordinator
ESIPA
Empire State Plaza
Albany, New York 12223

For further information:
Voice: (518) 474-1199
TTY: (518) 474-6143

RESTRUCTURING OF SERVICES PROPOSED BY OMRDD THROUGH MEDICAID WAIVER

In November of 1985, the Office of Mental Retardation and Developmental Disabilities submitted to the Federal Health Care Financing Administration (HCFA) of the Department of Health and Human Services a formal, comprehensive Medicaid research and demonstration waiver proposal.

OMRDD believes that its proposal addresses Federal concerns about the growing cost of Medicaid, while at the same time, enabling New York to accomplish its goals or reducing developmental center placements for persons who are mentally retarded in favor of community-based placements and of expanding day service opportunities.

In summary, the proposal requires that the State and Federal Governments, through NYS OMRDD and HCFA, would agree in advance on the total cost of the planned expansion of services. The two agencies would also agree on the proportionate amounts of State and Federal contributions to this expansion. The federal Medicaid revenues would be guaranteed to New York State as long as the number of persons being served increased to the agreed upon numbers.

Another condition of the proposal would allow for certain services which are not currently eligible for Medicaid reimbursement would be covered for the duration of the demonstration project. Such programs as vocational services, case management, in-home care, transition-to-work programs, personal care, supportive work, clinical services, minor adaptations to the home, transportation, family support and respite care, would now be eligible for Medicaid reimbursement.

The Office of Mental Retardation and Developmental Disabilities states that the above and other changes would ultimately result in a new system of care for citizens in New York State who are mentally retarded and developmentally disabled. The waiver proposal calls for the following major elements:

- 1) Limit New York's receipt of Federal Medicaid revenues continue to flow to the state so as to provide a stable and predictable source of funds.
- 2) Enable New York State to pay Medicaid for the full continuum of services needed to care for eligible individuals, both in home and out of home, in order to promote a less costly system of care than is currently allowed under the existing Medicaid program.
- 3) Unify and simplify the Local Assistance funding.
- 4) A single comprehensive client services continuum would replace existing fragmented array of services.
- 5) Simplify the existing Quality Assurance system by using key indicators for purposes of certification. Furthermore, focus on an appropriate match between client needs and actual service delivery.
- 6) Move away from funding according to cost based methodologies towards reimbursement methodologies providing incentives to providers to offer cost effective services.

The Adult Services Committee of the NYSARC, Inc. at their April 18, 1986 meeting reviewed an overview of the Medicaid waiver proposal. The proposal was reported to the Board of Governors at their May 2, 1986 meeting. The Association will be analyzing the proposal and conception in depth in the weeks and months to come.

Commenting on the initial proposal, NYSARC, Inc.'s Executive Director, Marc N. Brandt said "the proposal has many positive aspects and calls for needed reform in many areas which the Association has been concerned with for years. However, the Association must spend considerable time digesting and analyzing the proposal before it can fully support the proposal or concept. While reform is needed, the total restructuring of our program models as we know them today should be carefully and cautiously undertaken."

The Association will be monitoring the proposal and will be keeping our membership up-to-date on this major issue. ■

P.L. 94-142 ANNUAL REPORT AVAILABLE

The Eighth Annual Report to Congress on the Implementation of P.L. 94-142 is available upon request. To receive a copy, write to:

Office of the Assistant Secretary
OSERS
Switzer Building, Room 3130
330 C. Street, S.W.
Washington, D.C. 20202

Happy Birthday Frances

With the coming of Spring, we wish to acknowledge the 80th Birthday of Frances Reville. Frances currently serves on the State Association Board of Governors and on the Association's Budget and Finance Committee. She is an active member and Board of Director of the Welfare League - Letchworth Village Developmental Center Chapter.

Frances has served well her Chapter and our Association for many years and all of us wish her the very best on this, her 80th. HAPPY BIRTHDAY!

I.E.P. Diplomas Regents Considering Regulations

After several years of attempting to get legislation through both houses that would allow for the awarding of IEP diplomas to certain students, the New York State Board of Regents have agreed to consider amending their regulations to allow for these diplomas. The proposed regulations are to be discussed at the May 22-23 meeting of the Regents. There is the expectation that if they are accepted, that they will be implemented by this June. Those students who because of the seriousness of their disability are unable to achieve the required competencies, will at long last, receive the recognition that they so justly deserve.

It is unfortunate that so much effort has had to be used in order to obtain the IEP diploma through legislation as it has always been within the power of the Board of Regents to grant such a diploma through regulations. We are heavily burdened with the knowledge that so many of our students have been denied the recognition due them during the last several years as they have graduated being given a mere Certificate of Attendance. We are grateful that finally the necessary action is being taken that students now and in the future will be given appropriate recognition.

We must express our deep gratitude to members of the Assembly, who for three years under the guidance and sponsorship of Assemblyman Paul Harenburg, passed the IEP diploma bill unanimously. We are also appreciative to Senator James Lack for his continued support and leadership as sponsor of the Senate bill and also to the almost unanimous support of the Senate had they had the opportunity to vote for the bill. We must also express our thanks to Governor Cuomo who for two years has stated in his State of the State message that the awarding of an IEP diploma is a "fair and just entitlement."

The following are the proposed regulations:

The regulations of the Commissioner of Education are amended, effective May 28, 1986, by the addition of a new section 100.9 to read as follows:

100.9 High school individualized education program diplomas. Notwithstanding the provisions of Section 3.45 of this title, the board of education or trustees of a school district shall, and the principal of the nonpublic school may, issue a high school individualized education program diploma to a pupil with a handicapping condition, as defined in section 200.1(cc) of this Title, in accordance with the following provisions:

- a) Prior to awarding any high school individualized education program diploma, the governing body of the school district or nonpublic school shall adopt written policies and procedures ensuring that students with handicapping conditions are provided appropriate opportunities to earn a high school diploma in accordance with the provisions of section 100.5 of this part.
- b) A board of education or trustees of a school district shall, and the principal of a nonpublic school may, award a high school individualized education program diploma to a student with a handicapping condition at the end of the school year in which the student attains the age of twenty-one upon a finding that such student has achieved the educational goals specified in the student's current individualized education program.

- c) A board of education or trustees of a school district or the principal of a nonpublic school may, upon application of a student with a handicapping condition, or such student's parent, as defined in section 200.1(y) of this Title, award a high school individualized education program diploma at any time after such student has attended school or has received a substantially equivalent education elsewhere for at least twelve years, excluding kindergarten, upon a finding that such student has achieved the educational goals specified in the student's current individualized education program.

- d) Each high school individualized education program diploma shall be identical in form to the local high school diploma issued by the school district or nonpublic school, except that there shall appear on the front of such high school individualized education program diploma an annotation to indicate that the diploma is awarded on the basis of the student's successful achievement of the educational goals specified in the student's current individualized education program as recommended by the committee on the handicapped.

- e) If the student receiving a high school individualized education program diploma is less than twenty-one years of age, such diploma shall be accompanied by a written statement of assurance that the student named as its recipient shall continue to be eligible to attend the public schools of the school district in which the student resides until the student has earned a high school diploma or until the end of the school year of such student's twenty-first birthday, whichever is earlier.

- f) Each superintendent of a school district or a principal of a nonpublic school shall submit to the department, within fifteen days after the June graduation, a report concerning students awarded individualized education program diplomas in that school year. Such report shall be in a form prescribed by the Commissioner and shall contain such information as the Commissioner may require. A copy of the school district's or nonpublic school's policies and procedures adopted pursuant to subdivision (a) of this section shall be on file in the district office and available for review by the Commissioner.

Three New Chapter Executive Directors Are Named

Within the last few months, three new Chapter Executive Directors have been named. Our Nassau Chapter has named Dr. Sam Lamagna to head their Chapter. Dr. Lamagna has been with Nassau AHRC for many years serving as their Director of Educational Services. Our Sullivan Chapter has named Stephen Helfgott as their new Director. Steve served for eight years as the Executive Director of Delaware ARC. And, our Delaware Chapter has named their Assistant Executive Director, George Suess as their new Executive Director. We wish Sam, Steve and George the very best in their new positions.

"Can You Speak, I Can" Cayuga ARC Uses Computerized Communication Device

Did you ever hear the saying "a picture is worth a thousand words"? Well in Glenn's case, it's true. It's hard for most of us to imagine never being able to speak. But what do you think it would be like having a head full of ideas and thoughts just waiting to burst out and when the words came, it was a single monotone sound, unintelligible to others around you.

For Glenn, the thoughts are there and are very much alive in him. If you see him, he approaches you with much excitement wanting to tell you what he's thinking. He usually communicates through hand movements and sounds, and always a hug, but you're never sure if you truly understand what he is describing. It can be a little frustrating for you; it must be very disappointing for him as you both fumble your way through the conversation. A smile and a hug or a friendly touch always seem to ease the moment, but for someone who is as outgoing as Glenn, needs more.

Such were the thoughts of Sue Sealy, the Speech Therapist at Intensive Services Program, a day treatment program operated by the Cayuga Chapter ARC. Three and a half years ago, Sue was given the opportunity from the Schaefer Communication Center, at the Cerebral Palsy Center in Syracuse, to use a "Handi-Vois".

Glenn was the perfect candidate. With the foundation he had received from family and his day program, he had developed sight reading skills and the ability to spell, along with word and object recognition. With Sue's help, Glenn learned to touch the grid squares on the machine that would communicate the thoughts in his head. Through the computerized pre-programmed "Handi-Vois" a synthesized voice would speak for him saying "My name is Glenn" or something even more useful like "I would like a cheeseburger and french fries. And a soda."

The flip side of this great opportunity was the time frame they allowed to try out the "Handi-Vois". After 30 days it had to be returned, but not before Sue and Glenn's father, Will Schwarting, had the opportunity to present it to Mr. Schwarting's Kiwanis Organization, the Kiwanis Member's of the Olde Tyme Fair.

Glenn and Sue demonstrated how the machine is used hoping the members would agree that it was a worthwhile idea as a target fund raiser. They accepted and with the help of another agency, OVR, were able to cover the cost in approximately three years. But it was not a three year period in limbo. With the knowledge that the machine would eventually come, Ms. Sealy concentrated on all aspects of development that would give Glenn it's immediate use. Learning sessions revolved around the game "Scrabble", other tools such as the calendar, the T.V. Guide, the family picture album, just to name a few. Sue pushed her imagination to the limit knowing what end result was needed for Glenn's success.

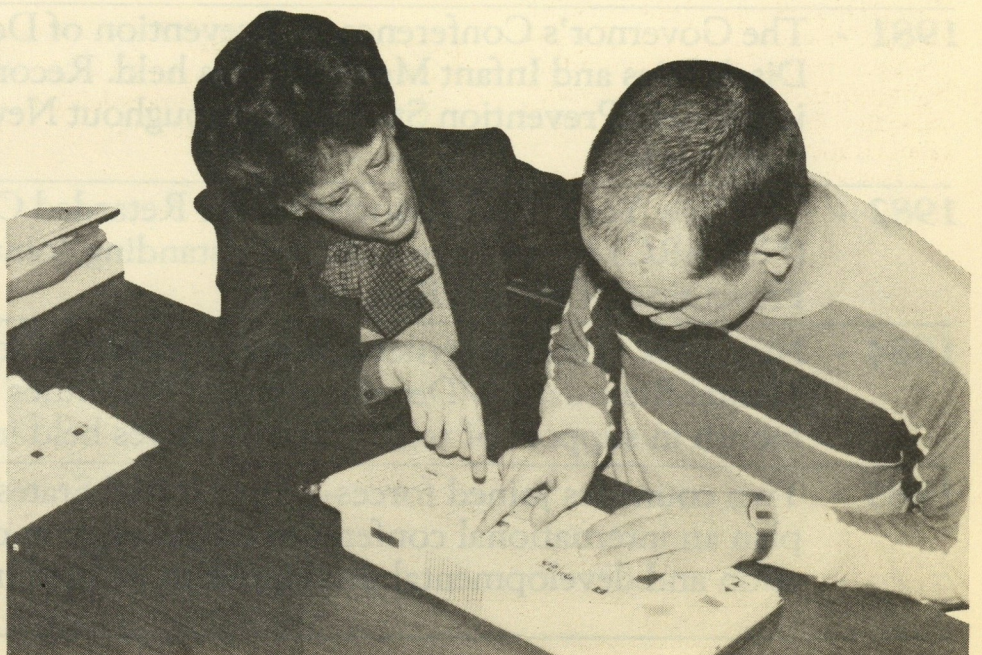
And the three year wait was not in vain. Glenn now has the "VOIS 135". It is a better tool than the "Handi-Vois" because it is programmable. And even though it is very time consuming to phonically break each word apart by vowel and consonant sound, the end result is unique. What is entered into the machine is "exclusively Glenn".

The "VOIS 135" will program up to 3,000 words and can spell anything in the English Language. The machine has five levels in which facts about Glenn's family, his personal information, his feelings, a menu of foods, places to go, the months, the days and other words too numerous to mention have been programmed.

Eventually, Glenn will carry the VOIS 135 around all the time and communicate with everyone. He knows how to care for the machine and is aware that it must be plugged in for daily recharge.

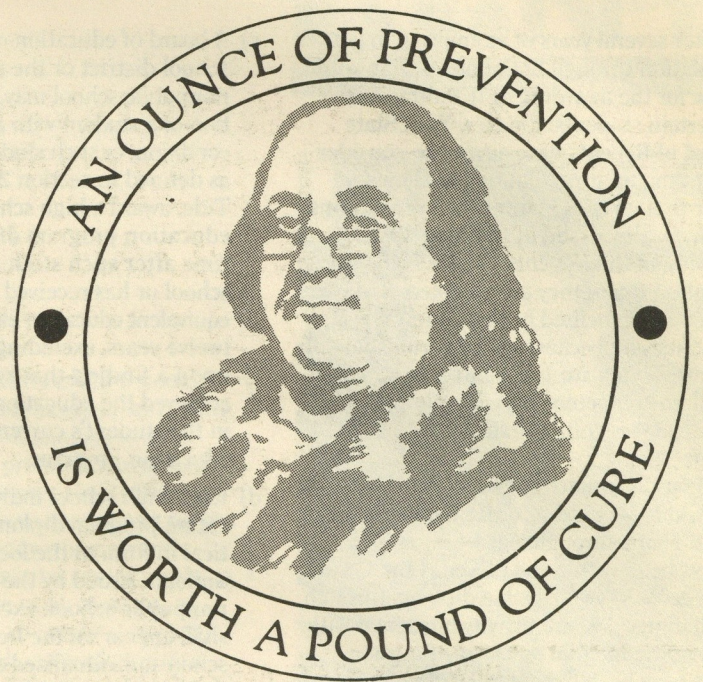
Conversation, which used to be a void in Glenn's life, is now a reality. Just talking to a friend to share the day's experiences is not impossible anymore. And you can be sure if you see Glenn and ask how "things are", he'll be glad to tell you all about it. ■

"Glenn" and speech therapist, Sue Sealy from Cayuga, study their new Handi-Vois communication board.



"A useful truth may be known and exist a long time before it is generally received and practiced."

A quote by Benjamin Franklin in a letter to his friend Benjamin Vaughan warning him of dangers of lead poisoning among tradesmen such as plumbers, glaziers, painters, stonecutters and soldiers.



Milestones of Prevention in the United States and New York State

- 1961** - President's Committee on Mental Retardation (PCMR) was established.
- 1964** - "ARC state chapters throughout the United States succeeded in obtaining laws mandating screening of all newborn infants to detect and prevent mental retardation and developmental disabilities due to PKU and other rare conditions in 37 states. New York State was one of the first states to pass such a law." Quote by: Dr. Robert Guthrie, Developer of the PKU Test.
- 1967**
- 1971** - PCMR set a goal to reduce the incidence of mental retardation and developmental disabilities 50% by the year 2000 through the application of knowledge already in existence.
- 1979** - A conference, partially sponsored by the New York State Association for Retarded Children, Inc., on prevention of mental retardation and developmental disabilities was held to generate interest in prevention efforts on a local level.
- 1980** - The first community action Primary Prevention Education Program was established in Buffalo, New York.
- 1981** - The Governor's Conference on Prevention of Developmental Disabilities and Infant Mortality was held. Recommendations to implement Prevention Strategies throughout New York State were made.
- 1982** - The New York State Association for Retarded Children, Inc. (NYSARC) formally established a standing committee on Prevention of Mental Retardation.
- 1984** - New York State Governor Cuomo proclaims October 1984 as Mental Retardation/Developmental Disabilities Prevention month in support of regional conferences held in the State.
- 1985** - Two countries joined forces—The United States and Canada plan an international conference on prevention of mental retardation and developmental disabilities to be held in 1986.

What is Prevention?

To prevent is to prohibit something from occurring by advanced planning or action. Therefore prevention of mental retardation refers to the actions taken by individuals such as parents and physicians to help reduce the risk of this disability occurring.

There are three major categories of Prevention:

- **Primary Prevention**—refers to an attempt to eliminate the occurrence of mental retardation before it happens.
HOW?—Good prenatal care and prevention of catastrophic illnesses, accidents, poisonings, abuse and neglect.
- **Secondary Prevention**—represents an attempt to identify the problem early so that the severity of the condition may be minimized.
HOW?—Through the early identification of high risk conditions and the application of medical, social, educational or therapeutic interventions.
- **Tertiary Prevention**—is aimed at controlling and minimizing the long term effects of mental retardation.
HOW?—Through comprehensive programs and services designed to meet the specific needs of each individual.

Why is Prevention Important?

- FACT:** It is estimated that 50% of the incidence of mental retardation could be prevented if we applied the knowledge that exists today.
- FACT:** There are over 200 known causes of mental retardation.
- FACT:** Over six million Americans are mentally retarded.
- FACT:** Each year 60,000 babies born in the United States will be diagnosed as mentally retarded before their first birthday.
Source—President's Committee on Mental Retardation (PCMR)

MANY KNOWN CAUSES OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES CAN BE PREVENTED!



NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

NYSARC Prevention Brochure Read Throughout State

Since its publication in 1985, the NYSARC Prevention Brochure "An Ounce of Prevention" has become one of most requested informational brochures available through the State ARC office.

Because of its popularity, OCV has been requested to reprint the brochure so that the information may be shared with our readers. Copies may be obtained by writing to or calling the NYSARC office.

Prevention Areas

Prenatal Care

FACT: Studies have shown that the risk of still birth and infant death during the first week of life among babies born to smoking mothers increases by 28%.

It is well known that the maternal care and lifestyle of an expectant woman can affect the intellectual development of her unborn child.

Malnutrition during pregnancy increases the chances of prematurity, stillbirths, low birth weight babies, and babies that are functionally immature.

Excessive alcohol consumption, improper use of drugs and smoking during this time have also been proven to be risk factors which can lead to health problems, including mental retardation, in the newborn.

Good prenatal care is extremely important to the development and health of the unborn child.

If you are considering having a baby, visit your family physician as soon as possible to ensure proper care of both you and your baby.

Information was taken from
Prevention of Intellectual Handicaps

By: Dr. John B. Fotheringham

Fetal Alcohol Syndrome (FAS) Alcoholic Related Birth Defects (ARBD)

FACT: One out of 700 children in the United States suffers from FAS and ARBD.

"Do not drink excessive amounts of wine and spirits on your wedding night, or you may birth a foolish child." (A quote to Sampson's mother from an angel on the eve of his wedding to Delila. Judges 13: 3, 4, 5, 6)

Women who drink heavily during pregnancy may give birth to a child with fetal alcohol syndrome. When a pregnant woman takes a drink of beer, wine or liquor, that same amount of alcohol enters the bloodstream of the unborn child. This can endanger the growing brain.

FAS is the nation's third greatest cause of birth defects and is totally preventable.

The risk of alcoholic related birth defects (ARBD) is three times greater than the risk of FAS. Since no safe level of alcohol consumption is known, it is recommended that pregnant women should not drink!

Lead Poisoning

FACT: In 1983 an estimated 675,000 American children between 6 months and 5 years of age were affected by lead poisoning.

Developmental damage by lead exposure is the result of the ingestion of lead containing substances such as old paint or putty or of dust which is contaminated with lead from a variety of sources such as gasoline containing lead.

Lead exposure can cause permanent brain damage, with children between the ages of one and six being the main victims.

Lead poisoning can be prevented.

The presence of lead exposure can be detected by the use of a simple, inexpensive blood test. Contact your local Health Department.

NOTE: Federal agencies strongly recommend periodic screening of all children under the age of six for lead exposure.

NOTE: The Environmental Protection Agency strongly recommends a complete ban on the sale of leaded gasoline in the United States.

Automobile Safety

FACT: Automobile accidents are the number one killer of children with thousands of other youngsters being seriously injured every year.

The two most common injuries received by passengers in automobile accidents are head trauma and spinal cord damage. Both these can lead to a lifetime of disability. It is estimated that 65-75% of these injuries could be prevented through the use of seat restraints and other car safety devices.

NOTE: New York State was the first state to pass a compulsory adult seat belt law. The first six months after the law was passed a 27% reduction in auto accident fatalities was noted.

Health Curriculum for Teens

FACT: Early education about prevention of mental retardation in unborn children can greatly reduce the incidence of mental retardation in our children's children.

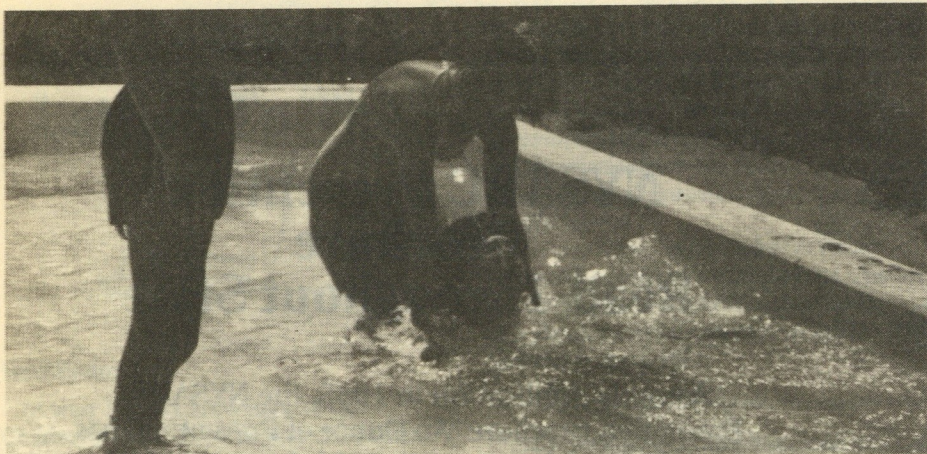
A health curriculum provides a systematic and comprehensive approach, educating students through grades 7-12, as to what responsibilities they must take as expectant or potential parents to lessen the probability of giving birth to a child who may be or may become mentally retarded.

This curriculum allows teachers of biology, advanced science, health, home economics and special education to easily incorporate areas of prevention into their own curriculum to provide their students with a broader base of information, and to reinforce the importance of prevention of mental retardation in future generations.

Begin to Reduce the Incidence of Mental Retardation and Developmental Disabilities by:

- Practicing good prenatal care.
- Contacting your local school districts stressing the importance of implementing a prevention curriculum at the high school level. (Curricula have already been developed and are available.)
- Contacting your local governmental officials and encourage them to fund prevention activities in your community.
- Challenging the perceptions of the general public and service providers by contacting private citizens, agency personnel, members of civic or volunteer organizations, medical personnel, educators and others to initiate prevention activities.
- Continue to correctly use auto safety devices (car seats for children and the use of safety belts.)
- Start working together **today** to decrease the incidence of mental retardation in our children **tomorrow**.

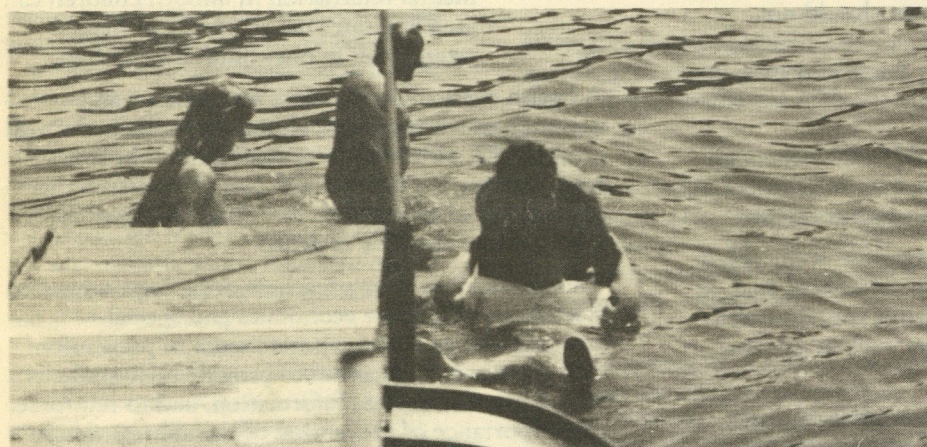
For more information, please contact the NYSARC Office at (518) 439-8311 or the local chapter nearest you.



Individual Swim Class for Young Men with C.P.



Boy's and Girl's Swim Class.



Adult men swim class.



Women's Physical Education "Hockey".



Individualized Exercise Session.



First Day Campers Arriving.

Good Times, Happy Faces at Camp Columbus

"Hello Mudder, Hello Fadder, Things are fine in Camp Granada..."

Camp Granada it isn't, but Camp Columbus it is! Located on the eastern shore of Owasco Lake, Camp Columbus serves 125 children and adults for a six-week period of summer, with the last week reserved as resident camp.

What was once an idea of a few parents many years ago was nurtured and sponsored by the Cayuga County Association for Retarded Children. Campers have been able to enjoy the fresh air surroundings for 23 summers and Cayuga County's Chapter is proud to have one of the few remaining summer camps available for the benefit of the developmentally disabled children and adults.

With summer off to a fantastic start weatherwise, all sorts of activities at camp can be enjoyed. Dance and music generates high spirits and enthusiasm as the children do the latest rendition of the "Hokey Pokey". The adults are more creative. They've put together a "dancercize" routine.

Everyone enjoys arts and crafts and the kitchen crew has discovered some great "cooks". Some campers are busily making chocolate chip cookies, Honey Bee's and corn bread for the Parent's Night Special.

Story and drama is bringing out the actor and actress in each camper. Pretty soon the camp will have it's first musical revue bringing to the stage acting unseen in many years.

Physical education started off with a bang. The adult women are doing so well in soccer they are thinking of going professional — watch out Pele. The boy's hockey teams are becoming superstars and the girls and boys kickball games have become rather competitive.

All campers brave the lake for the morning or afternoon plunge. Swimming lessons are given to improve stroke skills and aerobic swimming seems to really build endurance and tone the "tummy". Each day brings excitement and laughter from everyone in class.

Pearl Simmons, the camp's director, has a fine "knack" of keeping the camp running smoothly. After seventeen years of being with Camp Columbus herself, she knows that a solid staff and good core of volunteers gives rise to a happy bunch of campers. In this atmosphere, all those happy faces seem to grow and blossom.



Counselor Giving "A Little Help" Getting Out of the Lake!

Summer Camp Programs Directory

NEW YORK STATE SUMMER RESIDENTIAL/DAY CAMP PROGRAMS FOR CHILDREN AND ADULTS WHO ARE MENTALLY RETARDED

Now that spring is here, plans for summer camp programs are beginning to get underway throughout the state.

Over the past several months, the NYSARC office has received numerous phone calls and letters requesting information about summer camp programs.

In an attempt to assist parents in locating a camp which will be appropriate for their child or adult who is mentally retarded, a list of day/residential camp programs is provided below.

Please note that this listing is intended to serve only as a reference for parents or other interested persons looking for summer camp programs. NYSARC DOES NOT ENDORSE ANY OF THE FOLLOWING CAMP PROGRAMS!

Before registering your child at any day/residential camp program that you are not familiar with it may be a good idea to call your local ARC chapter to see if they know of the camp program. If so, they might be able to provide you with some additional information that will be helpful in deciding whether or not the camp program is appropriate for your child.

CAMP	LOCATION	TYPE	AGES SERVED	CONTACT
Adult Camp	West Copake, NY	Residential	Adults	Edward Cross (518) 672-4047
AHRC Day Camp	Brookville, NY	Day	Children and Adults	Ellen Siber (516) 626-1000
Boy Scouting for the Handicapped	Staten Island, NY	Residential	Young Adults (teens)	Anthony Cardiello (212) 242-1100
Buffalo Developmental Day Camp	Buffalo, NY	Day	Children and Young Adults (6-21 Years)	Robert Toone (716) 856-4201
Catholic Guardian Society Summer Educational Day Camp	Astoria, NY	Day	Children and Young Adults (6-21 Years)	Suzanne Taffet (718) 596-5500
Catskill for Community Clients	Liberty, NY	Residential	Children and Adults (8 Years and Up)	Irene Wagner
Cayuga ARC Camp	Auburn, NY	Day/Residential	Children and Adults (3 Years and Up)	Philip Gauthier (315) 255-2285
The Children's Aid Society City & Country Day Program	New York City	Day	Children and Young Adults	Barry Morowitz (212) 949-4800
Clover Patch Camp	Scotia, NY	Residential	Children and Young Adults	(518) 374-4555 (Winter) (518) 399-4759 (Summer)
Community Participation Education Program, Inc.	New York City	Day	Children (8-18 Years)	Shirley Middough (212) 234-4700
Camp Cummings	New York City	Residential	Adults	Jan Morrison (212) 234-4700
Camp Echo/WARC	Cold Spring, NY	Residential	Young Teens and Adults (14 Years & Up)	David Gasparri (914) 949-9300
Empire State Speech and Hearing Clinic	Spencer, NY	Residential	Children and Adults (6-21 Years)	Anthony Jay Renzi (607) 732-7069
Camp Epworth	High Falls, NY	Residential	Children and Adults	Kathleen Cotber (914) 997-1570
Samuel Field YM-YWHA Special Services	Little Neck, NY	Day	Children (3-18 Years)	George Singfield (718) 225-6750
Frost Valley Y.M.C.A.	Olivera, NY	Residential	Children (7-15 Years)	Mr. Terry Murray (914) 985-2291
Camp Goodwill	Chittenango, NY	Residential	Children and Adults (6-50 Years)	Eileen Healy (212) 532-8830
Camp Hidden Valley	Fishkill, NY	Residential	Children (8-12 Years)	Owen Engler (212) 221-0900
Camp Hope, Camp Joy	Carmel, NY	Residential	Children (6-16 Years)	Marie L. Olson (914) 225-2005
Camp Huntington	High Falls, NY	Residential	Children and Adults (7 Years & Up)	Bruria Falik (914) 985-2291
Kamp Kiwanis	Dunkirk, NY	Residential (boys only)	Children and Young Adults (8-19 Years)	Robert Toone (716) 856-4201
Kips Bay Boys Club	Bronx, NY	Day	Children (6-13 Years)	Sal Drakeford (212) 893-8600
Harriman Lodge	East Jewett, NY	Residential	Adults (18 Years & Up)	Francis Fitzgerald (212) 254-8048
Loyaltown, AHRC	Hunter, NY	Residential	Children and Adults	Paul Cullen (516) 626-1000
Camp Mahican	West Copake, NY	Day	Children	Edward Cross (518) 672-4047
YWCA Mini-Camp	White Plains, NY	Day	Children and Young Adults (4-21 Years)	Donna Eastman (914) 949-6227
Operation F.U.N.	Brooklyn and Queens, NY	Day	Children (3-6 Years)	Dick Costa (212) 596-5500
Orleans ARC Day Camp	Albion, NY	Day	Children and Adults (3-21 Years)	Paul Monachino (716) 589-5384
Camp Portaferry	Fine, NY	Residential	Children and Adults	Richard Laurin (315) 347-3271
Project Hands for the Handicapped	Bronx, NY	Day	Children (5-18 Years)	Rev. Patrick McCahill (212) 988-8563
Camp Rainbow	Croton-On-Hudson, NY	Residential	Children (6-11 Years)	Marc Weiler, Ph.D. (914) 949-6761
R.E.A.C.H.	New York City	Day	Children and Young Adults (6-21 Years)	Linda Takourian (212) 360-8134
Rotary Camp Onseyawa	Ovid, NY	Residential	Children (9-16 Years)	Robert Goodman (315) 331-4536
Rotary Sunshine Camp	Rush, NY	Residential	Adults	Joan Van DeWall (716) 454-3367
The South East Consortium	Larchmont, NY	Residential	Children and Young Adults	Keelin O'Sullivan (914) 835-1121
Camp Sunshine	Bronx, NY	Day	Children (6-14 Years)	Jay Brito (212) 882-4000
YWCA Camp Tall Timbers	Bear Mountain, NY	Residential	Children (5-18 Years)	June H. Rabel (201) 545-6622
Camp Tikvah	Staten Island, NY	Day	Children (6-11 Years)	Eugene Spatz (718) 891-1500
U.C.P. Jened	Rock Hill, NY	Residential	Adults (17-80 Years)	Cheryl Brust (212) 947-5770
Vanderkamp	Oneida Lake, NY	Residential	Adults	Joan Van DeWall (716) 454-3367
David S. Van Santen Day Camp	Sacandaga, NY	Day	Children (5-14 Years)	Sandy Cloud (518) 773-7931
Wagon Road Camp	Chappaqua, NY	Residential	Children (8-15 Years)	Richard Steinberg (914) 238-4761
Wayne County Chapter NYSARC Children's Day Camp	Newark, NY	Day	Children (6-21 Years)	Chris Karsten (315) 331-7741
Camp Whitman	Dresden, NY	Residential	Children and Adults	Maria Pero (315) 789-7416
Camp Wilton	Wilton, NY	Residential	Children and Adults	(518) 584-3110 1-800-962-6620
Charles B. Wollen Memorial Day Camp	Frankfort, NY	Day	Adults (18 Years & Up)	Leeanne Wereszynski (315) 735-6477



NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

1986 Convention
"Family & Friends — Volunteers Crucial
To The Future"

Thursday, October 23, 1986 -
Sunday, October 26, 1986
Concord Hotel
Kiamesha Lake, New York

FEATURING OVER 50 WORKSHOPS AND
PRESENTATIONS

WATCH FOR MORE INFORMATION, INCLUDING
REGISTRATION IN THE NEXT ISSUE OF OCV

1986 ASSOCIATION CALENDAR OF EVENTS

JUNE

- 4 Executive Committee Meeting
Delmar
- 6 Prevention Committee Meeting
Delmar
- 7 Central Region Meeting
Oneida County
- 10-11 Train-The-Trainer Seminar
Rochester Sheraton Inn
- 19-20 Train-The-Trainer
Holiday Inn & Holidome - Suffern
- 21 Northeast Region Meeting
Albany
- 28 Southeast Region Meeting
Orange County

JULY

- 18 Youth Committee Meeting
Supplementary Recreation and
Special Olympics Committee
Meeting
Delmar
- 18 Community Residential Services
Delmar
- 19 Guardianship Committee Meeting
Delmar
- 19 Supplementary Recreation and
Special Olympics Committee
Delmar
- 24 Public Information Committee
Meeting
Delmar
- 25 Developmental Center Committee
Meeting
Delmar

AUGUST

- 8 Education Committee Meeting
Delmar
- 15 Legislative Committee Meeting
Delmar

SEPTEMBER

- 6 Southeast Region Meeting
- 18-19 Train-the-Trainer Seminar
Sheraton Airport Inn - Albany

OCTOBER

- 16-17 Train-The-Trainer Seminar
Hotel Syracuse - Syracuse
- 23-26 Annual Convention, Fall
Board of Governor's Meeting
Concord Hotel, Kiamesha Lake,
New York

NOVEMBER

- 13-14 Train-The-Trainer Seminar
Rochester Sheraton Inn -
Rochester

DECEMBER

- 4-5 Train-The-Trainer
Holiday Inn & Holidome - Suffern

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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Delmar, New York 12054

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