diens vo Retarded Children Can Be Helped

Association's **Annual** Convention Draws Record **Attendance**

Delegates adopt 1987 Legislative Platform, Honorary membership awarded to Banquet Speaker State Senator John Flynn, Candidate Andrew O'Rourke and Commissioner Arthur Y. Webb. representing the Governor, Address Delegate Assembly.



Banquet Speaker, Senator John E. Flynn, speaks to gathering on 1986 Legislative Session.



The largest attended NYSARC, Inc. Convention was held at the Concord Resort Hotel on October 23-26, 1986. Over 675 persons registered and were in attendance in what has been called "one of the finest conventions in the history of our Association". The thirty-seventh annual convention had as its theme, "Family and Friends -Volunteers Crucial to the Future'

Those present had an opportunity to participate in 47 different workshops. Included in the array of workshops were demonstrations of the Association's activities, programs and services. There also were some outstanding workshops and presentations by individuals outside of ARC. In addition to the workshops, a film forum and numerous exhibits were also part of the convention

On Friday night, October 24, 1986 a standing room only Delegate Assembly heard the beautiful and touching words of Alice Lee, representing the Ulster County Chapter.

The Delegate Assembly heard a stirring message from Mrs. Nicola Schaefer. The author of "Does She Know She's There?", is a parent of a young adult who is severely disabled. Her presentation was well received and set the tone for the convention. Her message reinforced to all, the purposes and objectives of our Association.

Election of Officers and Board of Governors to the State Association was carried continued on page 5

Delegate Assembly Adopts 1987 NYSARC, Inc. Legislative Platform

At its thirty-seventh Annual Convention, the Delegate Assembly representing the membership of the NYSARC, Inc. sixty-five chapters approved the Association's 1987 Legislative Platform. Commenting on the adopted platform, the Chairman of the NYSARC, Inc. Legislative Committee, Mr. John Bryant, said "the platform as approved by the Board of Governors and ratified by the Delegate Assembly represents the most important elements of legislation that our chapters feel should be presented to the Legislature during the 1987 session."

The following is a brief overview of the adopted NYSARC, Inc. 1987 Legislative Platform. The issues are not listed by order of importance and each area reflects either long-term concerns or new initiatives for our Association.

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Board of Governor's Respond to Key State Initiatives

The Board of Governors, the policy-making body of the NYSARC, Inc. at its October meeting at the Concord Resort Hotel reviewed and responded to two key state initiatives effecting New York's programs and services for persons who are mentally retarded and developmentally disabled.

The Association's 119 Board of Governors representing 65 chapters and over 51,000 members approved of a motion to oppose any attempt by New York State to transfer the Sheltered Employment Program (SEP) from the State Education Department to the State Office of Mental Retardation and Developmental Disabilities (OMRDD). SEP is a \$23,000,000 a year program which subsidizes services to persons with disabilities working in sheltered employment settings.

The Sheltered Employment Program was the subject of considerable discussion between the Governor and the Senate during the close of the 1986 legislative session. In attempting to reach a compromise on the ORS issue, the Governor proposed that SEP be transferred to OMRDD. For its part, the Senate proposed the establishment of an independent council to oversee the function-

ing of the state's rehabilitation system. Though no compromise was finalized, the possible transfer of SEP to OMRDD has remained alive for consideration, either in a special session or when the Legislature reconvenes in January.

Clearly, from NYSARC's perspective, the transfer of SEP to OMRDD was seen as extremely controversial. Many individuals throughout NYSARC including both employees and board members, questioned whether or not such action would undermine the administration of SEP. Perhaps at the heart of this concern is a belief by many persons affiliated with NYSARC that transferring SEP to OMRDD would subject SEP to a regulatory system which is overwhelmingly bureaucratic and top heavy with paperwork requirements. Also of concern was whether or not such transfer would result in the elimination of exempt income.

The final position adopted by the Board on ORS and the transfer of SEP called for NYSARC to "continue to support the removal of OVR from SED and the creation of a separate ORS" and "to oppose any attempt to

continued on page 5



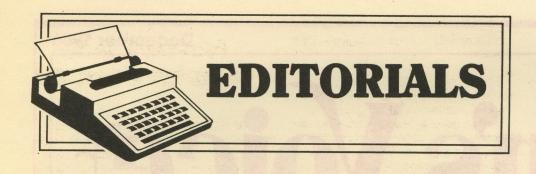
Master of Ceremonies. Commissioner Irene L. Platt, presides over **Banquet Cere-**



Nicola Schaefer, parent and author. gives the keynote general session.



Employer of the year, Craig Harman with Onondaga Chapter at Awards Luncheon.



An Inequity Within New York State's Family

On Tuesday, November 4, 1986 the voters of New York State gave a tremendous vote of confidence to Governor Mario M. Cuomo by re-electing him by 65 percent of the voting electorate. Almost every major issue that the Governor has brought before the State Legislature has his chosen theme "The Family of New York State".

The Governor has, during his first four years of office, demonstrated his compassion concerning issues relating to the disabled. In his January 1986 State of the State message, the Governor stated, "Together, we have provided more services for people who are disabled, the frail elderly and others who are less fortunate. We have made progress, but, within the real limits of our fiscal capacity, we must do more."

In support of his message, the Governor has indeed signed a number of bills into law which are of major significance to persons who are mentally retarded. Most noteworthy was the signing of the NYSARC initiative establishing a Bill of Rights for individuals living in community residential programs, the signing of legislation providing summer school services for certain children with disabilities and the signing of a bill which authorizes provider reimbursement of interest on loans used to purchase personal

The Governor's push to allow the awarding of annotated diploma for students with handicapping conditions was accomplished when the State Education promulgated regulations allowing for such diplomas to be granted. Perhaps the most significant event concerning the disabled was the Governor's ability to bring all the disabled together to rally for his proposal to establish a separate Office of Rehabilitation Services (ORS) in the Executive Branch of Government.

The Governor's first term of office, while demonstrating his concern for the disabled, has also raised a number of concerns. While the first four years of the Governor's term had positive aspects, it did produce a climate of uncertainty for not only NYSARC, Inc. but to the entire not-for-profit voluntary agencies.

Examples of this climate of uncertainty began in the early days of the Governor's term. The co-location of Craig Developmental Center with a correctional facility still is a vivid memory. To this day, the

Association has been unsuccessful in its attempts to have the Legislature address this issue. The Governor has not adopted a policy against co-location and the issue is still very much in the forefront of concern.

The development of Small Residential Units (SRUs) on the grounds of developmental centers was another issue which clearly demonstrated a lack of a state policy dealing with the real residential needs of persons who are mentally retarded.

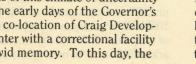
The proposed OMRDD's 1115 Medicaid Waiver which, if approved by the Federal Government, would result in the transfer of substantial discretionary authority over medicaid funds to OMRDD was never fully disclosed with the field until it was officially applied for. In addition, the proposed policy papers and major programmatic and funding shifts proposed by OMRDD has left the field in shock as to the complexity and immediate need for such dramatic and revolutionary change.

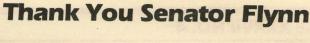
Furthermore, over the last four years, a trend towards unequal treatment between the state and voluntary sectors has widened. While state approved union contracts have consistently included healthy pay hikes for state employees, pay for not-for-profit employees has been the target of cost containing rate and fee setting methodologies. Incentive programs like the "Health Corps" act of 1985, intended to attract badly needed clinical professionals to the human services field, have been enacted solely for the benefit of state-operated programs.

Clearly it seems, the voluntary sector has been left on its own to remedy the unequal treatment which is has been accorded. When the Governor submitted his 1986-87 budget request to the Legislature last January, funding for the Hepatitis B vaccination program and monies to comply with new federal life safety code standards were requested but only for the benefit of the state sector. Only after it was pointed out to the Legislature by NYSARC and other provider organizations that similar essential funding was not requested for not-for-profit providers was such funding finally appropriated.

The Governor's actions during his first four years in office have indicated his genuine desire to serve persons who are developmentally disabled. However, it will fall to the not-for-profit sector to remind the Governor over his next term in office that the best possible means of ensuring quality care is to vigorously address the inequities that exist in the current system. Only we, members, employees, and friends of organizations such as NYSARC, can give the Governor this message.

> Commissioner Arthur Y. Webb representing Governor Cuomo at the General Assembly.





When the New York State Legislature begins the 1987 legislative session, there will be a number of familiar faces missing. One of the most popular and highly respected state senators will be among the few in the Legislature who have decided not to return. After serving ten terms representing the 35th District for Westchester County, Senator John E. Flynn, had decided to retire at the

While in office Senator Flynn has distinguished himself as an advocate for the concerns and issues facing New York State's disabled community.

Among committees that the Senator had served on, he has since June 25, 1981, chaired the Senate Select Committee on the Disabled. In this capacity, the committee under the direct guidance of the Senator has effectively established open lines of communication with disability groups and individuals who were seeking assistance for themselves or family members. Senator Flynn has held numerous public hearings during his years with the Senate on such subjects as vocational rehabilitation services, preschool and twelve month educational programs and the underserved population such as persons with epilepsy and autism.....

In order for the committee to be appropriately informed about key issues regarding the disabled, Senator Flynn appointed two advisory committees, the Upstate Advisory Board and the Metropolitan Board which is made up of persons with disabilities and parents.

Many pieces of legislation have been introduced and signed into law as a result of the hard work and dedication of Senator Flynn. The following are but a few:

- 1. In order to assist families whose children are leaving the educational system, three bills were signed into law over a period of three years that set up a referral process that would aide in the transition between school and work.
- 2. In 1984, a bill was passed to require the training of impartial hearing officers engaged in due procedures for children with handicapping conditions.
- 3. Senator Flynn took the lead in gaining a law that prohibited the State Education

Department from imposing a fee on parents when they appealed a decision made by a hearing officer.

- 4. Over a period of several years, the Senator has worked to gain Civil Service positions for persons with disabilities who were unable to gain those positions through competitive means. To date, there are 900 of those positions available within the
- 5. Non-driver identification cards to persons over the age of eighteen are now being issued to persons unable to pass a driv-
- 6. Senator Flynn was a driving force in obtaining the Bill of Rights for persons in community residences.
- 7. In 1984, Senator Flynn was very active in obtaining legislation that requires the state to pay interest on monies owed to contractors and suppliers which are not paid within 45 calendar days.

Other legislation that the Senator has sponsored, in the past has been the diploma bill, preschool and summer school, provision of health care in the event of catastrophic illness, establishing the Office or Rehabilitation Services and the allowing of tax credits for expenditures made for construction repair, and alteration of buildings and structures to make them more accessible to persons with disabilities. Again, these are but a few of a lengthy list of items pursued by the Senator in order to improve upon the lives of persons with disabilities and their

On announcing his retirement, Senator Flynn stated, "During my 20 years as a Senator, one of the most satisfying and important parts of my work has been on behalf of our disabled citizens." Senator Flynn's presence will be missed. He left behind, however, a record of accomplishments that will enable New York State's disabled community to have a better quality of life. Because of Senator Flynn's advocacy efforts and non-partisan philosophy, his accomplishments will not only be long remembered but will have the benefit of being the law in New York State. Thank You Senator Flynn for a job well done. We miss you already.

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

Published quarterly by the New York State Association for Retarded Children, Inc. a non-profit, tax exempt organization of parents and friends of the mentally retarded, chartered by the State of New York in February, 1949.

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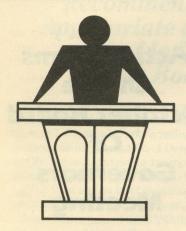
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The President Speaks

It is hard to realize that a full year has again passed. During 1986 much has transpired both within our Association and from outside, which effects the lives of persons who are mentally retarded and developmentally disabled. It was, at times, a difficult year, with the usual frustrations and set backs that somehow have become a routine of our actions.

As President, I believe that the Association is in an excellent position to address any and all issues which face us. While all of us seem to agree that some changes are needed in our internal structure, we have made many efforts to improve the communication process between our chapters, regions and state organization. As I pointed out in my remarks to the Board, issues that face our Association are being prioritized and one by one are being discussed, reviewed and acted upon.

Our strong visibility as a statewide Organization can be documented in a hundred different ways. This past legislative session more than indicates NYSARC's strong role in influencing the direction of legislation and budget matters relating to persons who are mentally retarded.

While the Governor vetoed a bill developed by NYSARC concerning the manner in which OMRDD regulates our programs, it brought the issue to the forefront. The Assembly Committee on Mental Health conducted a hearing on the matter and both the Senate and Assembly were in agreement with the Association's position. The issue more than demonstrates the positive workings of our Association. The chapters bringing forth the current meaningless regulatory process to the Board for discussion and action produced a legislative initiative which will ultimately bring change - positive change.

The veto by the Governor was disappointing but our successes in other areas found the long standing Association initiatives of summer school funding and the awarding of high school diplomas passed into law and/or regulation.

Close to twenty NYSARC bills were introduced in the Legislature. All of the bills were a direct result of our Legislative platform which was developed by our Legislative Committee through the input of NYSARC's Chapters and committee structure.

Much of this issue of OCV is devoted to our recently held Convention at the Concord Resort Hotel. Close to 700 individuals came from all over N.Y.S. to participate in this event. It was indeed a most productive and successful convention.

While I feel extremely proud of the organized manner in which our Convention carried out its affairs as well as the quality and quantity of issues that were responded to, I must admit I am somewhat disappointed. My disappointment is over the fact that the Board of Governors could not act favorably upon the recommendations of the Ad Hoc Committee to Review and Make Recommendations on the Structure of NYSARC, Inc. At the October, 1985 Convention held at Grossinger, N.Y., I formed such a committee.

The need for the establishment of such a committee was shared by many in the Association. I appointed an Ad Hoc Committee whose members were drawn from all parts of the state and had no vested interest in the structure of NYSARC except that which would best serve the interests of our clients in the long run.

The committee actually held eight meetings and produced an interim report. This report was reviewed in detail at four separate regional meetings.

Attendance at these regional meetings was excellent. Each region had Chapter Board Presidents and Executive Directors as well as many other interested Chapter Board members. The overwhelming sentiment expressed at these regional meetings was that the interim report was too weak and did not address the real concerns of the chapters.

The Ad Hoc Committee once again met and reviewed the comments of the regional meetings as well as correspondence received from Past Presidents of the Associations as well as others in the Association who took the time to comment. Out of the information gathered a final report was written which more accurately reflected the feelings of the chapters.

The recommendations were bold and would have produced a major change in the internal organizational structure. The recommendations, however, did reflect the concerns of the chapters and most certainly the regional meetings. At the October Board of Governors meeting the final report was discussed and voted upon, recommendation by recommendation. Almost all of the recommendations, certainly the main ones, were voted down.

Perhaps the complexity and diversity of our organization can best be portrayed by what took place. Our Board of Governors has the responsibility of setting policy and the direction of the Association. The effectiveness of this process, no matter what the size of the board composition is, and no matter how often the board meets, will only be measured by chapters sending individuals to accurately represent their chapters interests.



As president I was hoping for a change in the structure not because it is currently not working but because the size and complexity is growing and within the near future some change will be essential if we are to remain the strong advocacy organization we are today.

While I am disappointed that no change has occurred I can't help but feel very positive concerning the direction we are headed in. It has been, in my opinion, a most productive year. I look forward to serving the Association in my capacity as President and wish all our members and friends the very best of the New Year.

David B. Lettman

Newark D.C. Chapter Formed

At the beginning of the Thursday night October 23, 1986 Board of Governors' Meeting, the President of the Association, David B. Lettman, informed the Board that Newark Developmental Center Chapter has officially become the 65th Chapter of NYSARC, Inc. The Chapter will officially call themselves the Newark Parents and Friends Chapter of the New York State Association for Retarded Children, Inc.

On June 14, 1986 the Chairperson of the Association's Developmental Center Committee, Bernice Volaski, and State Association Executive Director, Marc N. Brandt, visited with the founders of the Chapter. They toured Newark D.C. and the newly developed SRUs on the Newark campus.

The first officers of the Chapter are:

President - Dwight Goodwin Vice President - Arvilla Wilson Treasurer - Arnold Weaterstone Recording Secretary - Suzanne McGovern

Directors elected at the June 14, 1986 meeting were:

Pat Peterman, Regina Krolak, Wesley Tomion and H. "Stu" Stillwell

President David B. Lettman commented at the October Board Meeting that the Association "is proud to have Newark D.C. as our newest Chapter. We welcome the Chapter into the Association."

Attention OCV Readers

Beginning with the first issue of OCV in 1987, advertisements will be included in the publication. Advertisements sought will be from companies/organizations whose services and/or products contribute to the education of our readers, apprising them of developments, improvements and availability of services and products for persons who are mentally retarded and developmentally disabled.

For more information concerning OCV advertising policy and cost, please fill out the form below and mail it to the State Office.

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John Bryant (R) and Ben Golden lead workshop on Legislation.



Dr. Harriett Cooper from the Institute for Basic Research discusses the Fragile X Syndrome



Dear Editor:

I would like to express, through your pages, our profound thanks to the many, many who expressed concern about Barbara's condition

We would like to answer each one personally but there are too many. Barbara has been home since August 21 and improving very, very slowly.

She joins me in expressing our thanks and love to all. God bless you one and all.

Sincerely,
Joseph T. Weingold

Dear Editor:

Just a note to let you know how much I enjoyed the June copy of "Our Children's Voice"; I am certainly looking forward to receiving future editions.

Please convey my congratulations to your staff for a job well done.

Very truly yours.

James M. Walsh Director Staten Island Boro Developmental Services Office

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 to right to limit the amount of letters printed.

Quote Of The Quarter

"We are faced with a proposed reorganization of the field of mental retardation in New York State that is well intended but extremely problemmatic in its implementation... Please note that what may seem to be a highly technical and complicated matter may very well have significant impact on the availability of appropriate services for your children and siblings."

Michael Goldfarb Executive Director Association for the Help of Retarded Children - N.Y.C. Chapter

David B. Lettman Re-Elected As President

Commissioner Irene Platt Installs Association's Officers and Governors

At the thirty-seventh Annual Convention the Delegate Assembly representing the sixty-five chapters and the over 51,000 members of NYSARC, Inc. elected the Officers and Board of Governor members of the Association.

At the banquet held on Saturday night, October 25, 1986, the Immediate Past President of NYSARC, Inc. and current Commissioner of the New York State Commission on Quality of Care for the Mentally Disabled, Irene L. Platt, installed the State Association's Officers and Board of Governors.

David B. Lettman was unanimously reelected as President of the Association. In his acceptance speech Mr. Lettman urged the Board to continue to review the current Board size and to remain active during the coming year.

The Officers elected for a one-year term are as follows:

David B. Lettman President Eileen Patricia Madison John Bryant Warren Heilbronner Sr. Vice President Kay Nogai Monroe Vice President - Central Region Elliot Aronin Nassau Mary L. Caniano Vice President - Northeast Region Patricia Peterman Newark D.C. Audrey Strickland Blanche Fierstein Vice President - Western Region George Hirsch Bernice Volaski Betty Pendler Vice President - Southeast Region Walter Redfield New York City George G. Hirsch William Hughes Niagara Robert Taylor O.D. Heck D.C. Carroll F. Stowell Shirley Fredenburg Assistant Treasurer John Schuppenhauer Ontario Sadieann Mazzotta Jean Black Secretary Orange The following individuals were elected Audrey Strickland Orleans to serve on the Board of Governors for the Bettye Hughes 1986 - 1988 term of office Dr. John Readling Oswego Albert VanderLinde Ellie Pattison Rensselaer Ida Rios Bronx D.C. Francis Turner Rome D.C. Robert Salankiewicz Broome-Tioga Patricia Campanella Ethel Card Cattaraugus Anne Marie Giorgi St. Lawrence Helen Emerson Carroll Stowell Judith Fox Cayuga Bella Stuart Schenectady Joseph Trusso, Jr. Chautauqua Steve Cole William Fowlston Chenango Jean Emerson Schoharie Jeanne Coffin Clinton Bonnie Baker Schuyler Lois Fairclough Columbia Paul Greenfield Steuben Beverly Epstein Community Fred Salzberg Suffolk Florence Siegel League (Wassaic Elizabeth Radzieski Sullivan John Keller Syracuse D.C. Sandra Bullis Delaware Joseph Pecora Ulster Celeste Rudberg Dutchess Bernice Volaski Welfare League Donald Enslin (Letchworth David Essrow Erie Village D.C. Jane Meier Hector Dowd Henry Valerych Genesee Charles Kingsley Catherine Hagan Greene Robert Meltzer Westchester Leonard Boas Judith O'Rourke June McCarrell Herkimer Ellen Owens West Seneca Cheryl Englert Livingston-Wyoming David B. Lettman raises his right hand to take an oath as Commissioner Irene Platt officially in-

Action Items Of The October Board Of Governors Meeting

The governing body of the NYSARC, Inc., The Board of Governors, met on Thursday and Friday, October 23 and 24, 1986 and again on Sunday, October 26, 1986. Much of the discussion that took place at the Thursday and Friday meetings related to the structure of the Association. The Sunday meeting had a number of issues which the Board took action on.

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

- Welcomed Newark Developmental Center Chapter.
- Reviewed and recommended to the Delegate Assembly for approval of the 1987 NYSARC, Inc. Legislative Platform.
- Adopted the 1987 Board of Governor Goals.
- Elected John Bryant as Senior Vice President.
- Elected Warren Heilbronner, Ellen Maroun and Judy O'Rourke to be Members at Large to the Executive Committee.
- Approved an Honorary Membership be given to retiring State Senator, John Flynn.
- Reviewed and discussed the recommendations of the Ad Hoc Committee to review and make recommendations on the structure of NYSARC, Inc.
- Recommended to the Delegate Assembly a change in the By-laws stating that a simple majority of the Board of Governors shall consist of parents or blood relatives of persons who are mentally retarded.
- Recommended to the Delegate Assembly a change in the By-laws regarding the composition of the Executive Committee.
- Recommended to the Delegate Assembly a change in the By-laws that the Treasurer shall serve as the Chairperson of the Budget and Finance Committee.
- Approved the use of the rose as symbol for the NYSARC, Inc. statewide media campaign.
- Approved action that NYSARC, Inc. should be on record opposing the OMRDD 1115 Medicaid Waiver as currently proposed.



David B. Lettman presenting Tom Glair, Executive Director of Genesee, with Certificate of Appreciation.

stalls him as President

of the New York State

Association for Retarded Children, Inc. for 1986-



Johnathan Swick performing at the Awards Luncheon



Mr. Weingold makes a point at the Board Meeting.

- Adopted guidelines for NYSARC, Inc. Chapters concerning AIDS.
- Adopted the Position Paper on "The Critical Care Index".
- Adopted a policy statement concerning the humane placement for persons residing in developmental centers.
- Adopted recommendations of the NYSARC Insurance and Pension Committee regarding changes in the Minimum Insurance Standards and Pension Policy.
- Approved the Prevention Committee's Introduction to Prevention Strategies
 "Tips on Prevention".
- Approved the continuation of support for a separate Office of Rehabilitation Services (ORS) but not the transferring of the Sheltered Employment Program (SEP) to OMRDD.
- Approved at the Sunday meeting a change in the By-laws concerning representation on the Executive Committee by developmental center representatives. The proposed change will be transmitted to the 1987 Delegate
- Approved an additional meeting of the Board of Governors to be held during February.

New York State Department Of Labor To Regulate Payment Of Subminimum Wages To Handicapped In Industry

The New York State Department of Labor recently filed a notice of proposed rulemaking in the State Register which, effective 1/1/87, modifies the State's eight general industry minimum wage orders to allow minimum wage requirements to be met through the "...payment of compensation to an individual employed as part of an approved rehabilitation program." The full impact of the proposed amendments is unknown at this writing since the Department plans to address the details of the changes in guidelines which have yet to be developed. However, NYSARC believes the amendments are intended to govern all handicapped individuals paid less than minimum wage, other than those individuals who work in sheltered

In a related matter, NYSARC has received a verbal report of a recent DOL investigation in Otsego County which may indicate that the Department intends to govern the payment of subminimum wages to handicapped individuals in supported work programs and other work programs where work is performed outside of the sheltered workshop program. NYSARC finds this action most curious given the October 3, 1986 letter from the Department, wherein we were assured that Section 651.5(j) of Article 19 of the New York State Labor Law provides an exemption from the payment of minimum wages to handicapped individuals working in or for a not-for-profit rehabilitation agency. NYSARC was also informed that while each

case would be judged upon its own merits, the exemption would apply where the not-for-profit rehabilitation agency has the handicapped worker on its own payroll and directly supervises the work of such individuals.

NYSARC has not received written notification of the Otsego case and therefore urges chapters to maintain the status quo for all offsite work programs unless advised otherwise through a chapter bulletin update.

NYSARC will file recommendations on the proposed amendments and will provide extensive input regarding the development of guidelines for the implementation of the proposed regulations. Chapters may wish to contact the State Office for additional information.

Board of Governor's continued from page 1

transfer SEP to OMRDD" since "such action would position SEP in a needlessly burdensome regulatory environment." NYSARC has been severely critical of OMRDD's regulatory enforcement practices which have been the subject of legislative hearings.

The Board of Governors also voted to oppose OMRDD's 1115 Medicaid Waiver proposal. Such proposal, if approved by the Federal Government, would result in the transfer of substantial discretionary authority over medicaid funds to OMRDD. Again, the perceived tendency of OMRDD to over administer and over regulate programs was a factor in this decision. One NYSARC official stated that "given OMRDD's inclination to abuse its authority to regulate our programs, how can we reasonably be expected to support attempts by the Office to obtain substantially more authority from the Federal Government?"

In this presentation on this issue before the Board, Marc N. Brandt, NYSARC's Executive Director, pointed to OMRDD's failure to clearly explain how the Medicaid Waiver proposal would work and what it would mean for New York State's developmentally disabled citizens. Mr. Brandt stated that in the absence of such explanation OMRDD's frequent reference to competitive bidding and for-profit providers must be viewed with alarm by all persons who want to ensure that individuals with developmental disabilities are not made the subjects of ill conceived state experiments in cost containment. Mr. Brandt concluded by stated that following the upcoming elections, NYSARC would arrange to meet with Senator D'Amato to voice its concern.

Annual Convention continued from page 1

out. As reported elsewhere in OCV, David B. Lettman, was re-elected President of the Association.

One of the most important business items transacted at the General Assembly was the review and adoption of the Association's 1987 Legislative Platform. The platform was introduced by the 1986 Legislative Chairperson, John Bryant. The platform is reported in detail in the issue of OCV.

Both candidates running for N.Y.S. Governor were invited to address the Delegate Assembly. The President of the Association, David B. Lettman, requested in correspondence to Governor Mario Cuomo and Mr. Andrew O'Rourke the addressing of four key issues. These issues represented a broad range of philosophical and practical concerns impacting the care and treatment of persons who are mentally retarded and/or developmentally disabled.

The four issues presented to Governor Cuomo and Mr. O'Rourke were:

- 1) The Role of the Parent and Guardian versus the role of the State.
- 2) The issue of Co-location.
- 3) Equality of Service Provisions (Equity of Funding).
- 4) The salary issue (discrepancy between the public and voluntary wage and benefit scales in human service fields).

On Saturday morning, October, 25, 1986, Mr. Andrew O'Rourke addressed the Delegate Assembly. Mr. O'Rourke in addition to addressing the four issues also spoke about his concerns with the present system of delivery of services to persons who are disabled. Representing the Governor, Commissioner Arthur Y. Webb of the Office of Mental Retardation and Developmental Disabilities spoke about the accomplishments of the past three years.

A new process of Resolutions found a lively discussion with a great deal of input by the delegates representing their respective chapters. The most significant action concerning the Resolutions was the Delegate Assembly's vote changing the NYSARC position on the development of Small Residential Units, known as SRU's, on the grounds of developmental centers. A full reprint of all the resolutions can be found in this issue of OCV.

The convention festivities were high-lighted at the Annual Banquet. This year the banquet speaker was the Chairperson of the Senate Select Committee on the Disabled, Senator John Flynn. Senator Flynn will be retiring this year from the State Senate after ten years of distinquished service on behalf of persons in N.Y.S. who are disabled. President David B. Lettman presented to Senator Flynn a plaque from the Association. The Association also has awarded to Senator Flynn an Honorary membership in NYSARC.

The Immediate Past President of NYSARC and one of the current Commissioners of the N.Y.S. Commission on Quality of Care,

Irene L. Platt, was this year's master of ceremonies. Commissioner Platt did an outstanding job on conducting the business of the banquet. Mrs. Platt at the beginning of the banquet introduced Robert Edwards who eloquently gave an invocation. Welcome remarks were given by Richard Montgomery representing the Ulster County Chapter. Mrs. Platt again this year installed the officers and Board of Governors.

The President of the State Association, David B. Lettman, commented that the "1986 ARC Convention was one of the most productive and well organized conventions ever for the Association. There are many people who should be thanked for their efforts; our staff, our various committees who participated in the planning and those volunteers who helped at the Convention."

Next year's Convention will be held from October 15 to October 18, 1987 at the Hotel Syracuse in Syracuse, New York. ■

Keynote speaker, parent and author, Nicola Schaefer, gives keynote address at General



Bonnie Bowes,
President, Schoharie Chapter, accepts Certificate
of Appreciation on
behalf of Harva
Company.



Board members review policy decisions.



GUEST COMMENTARY

(From time to time, OCV will feature a guest commentary. The contents of these guest articles will be reflective of the author and does not necessarily represent the views or opinions of the NYSARC, Inc.)

An Important Priority

by: Helen Kaplan

Throughout the state, difficulty is being encountered in the regulation of the Community Residence program as well as other programs certified by OMRDD. The following is a commentary which appeared in the Nassau News, a publication of the Nassau County Chapter, NYSARC, Inc. The author, Helen Kaplan, was an early pioneer in the care of the mentally retarded and has been instrumental in the growth of the New York State Association for Retarded Children, Inc. Mrs. Kaplan is a founder and executive director emeritus of the Nassau Chapter of the Association for the Help of Retarded Children.

October is our birthday month and since we organized in 1949, we are now 36 years old. As one of the founders, I was present the night AHRC was voted into an organization and according to the minutes, I second the motion that created the Long Island Chapter. Shortly thereafter, we realized that Long Island was too large a geographic entity, so we split and Suffolk became an independent chapter and I became the first president of the Nassau County Chapter. I have the memory of when we opened each of our services and how we acquired our facilities but I don't want to retrace all the steps of our journey, nor do I want to rehash all the bills that were written and passed by the Legislature.

However, there is one program I want to write about because it is certainly one of the most important and I am wary of the changes that are impacting on that program and since I refer to the Community Residence program, let me begin with a description of how the program was established.

In 1966, Governor Rockefeller was campaigning for re-election and he was scheduled to speak at a labor luncheon in Hempstead. Since our sheltered workshop was in Hempstead at that time and it was located close to where the Governor would be speaking, we invited him to visit the shop. He accepted the invitation and after walking through the first two floors, he came down to the lobby and said to us, "I know what's troubling you and the parents, so let me say that if I am re-elected there will be an administration bill to establish the hostel program with an appropriation of \$500,000 to get it started." After that, he shook my hand and said, "You have my word for it.

You know that Governor Rockefeller was re-elected in 1966 and when the Legislature convened in 1967, he kept his promise. After the bill was signed, he appointed the following task force: Tom Coughlin, now Commissioner of Corrections; Jerry Weingold, then Executive Director of NYSARC, Inc.; Gus Jacobs, then Chairman of NYSARC Legal and Legislative Committee; Leo Fixler, attorney who was president of the Parent's Association of Wassaic and myself. The com-

mittee was charged with establishing standards that would replicate the home the person came from to the degree that was possible. In other words, the Governor's charge was that we create as home-like an atmosphere as possible. A few years later, the state bought us our first home in Hempstead and since then the program has grown to include 20 houses plus two blocks of apartments for adults who are capable of living alone with the aid of a supervisor who lives in an apartment within the apartment complex. We bought 10 of the houses and the state bought the remainder. From the start of the program, there were two modes of operation: one was the shift model where each set of personnel worked an eight-hour shift. The other model called for houseparents who would live in their own apartment within the house and have the weekend free with relief house-parents on

Now, the goals of the program are in reverse gear and instead of having homes that replicate family homes, we are gradually becoming mini-institutions by order of OMRDD.

Murray Fried assumed the directorship of the program after the first house was opened and since he was certainly experienced in the field of retardation, he designed the training programs for houseparents and for the administration of medication, etc. using whatever outside professional assistance the program required. The houses were opened as homes and since we have had visitors from a number of states as well as from Europe and Asia — all of whom commended the program, we felt secure in



the knowledge that not only were the residents well cared for and happy but that our model was respected by people who had visited similar programs in a variety of other states and countries.

Now, the goals of the program are in reverse gear and instead of having homes that replicate family homes, we are gradually becoming mini-institutions by order of OMRDD. Housemothers are now managers pushing paper; the regulations for the administration of medication and safety, etc. need a battery of Philadelphia lawyers to interpret. The standards for the size of the rooms, the height of the ceilings, the width of stair treads, etc. have all become more important than the welfare of the people who live in the houses.

There is scarcely a day that a barrage of mail does not arrive with a list of citations of what is wrong with every house. All of it is a hodge-podge of nitpicking gobbledygook and only rarely is any comment related to the welfare of the individual. The "inspectors" for the state obviously do not care about the people who live in the homes - all they want to know is how we record information and that the information is written according to their prescription without regard for the fact that an alternative way would serve the same purpose without the wholesale waste of time of the people who were hired to care for the residents.

As much as I object to the enormous waste of time and money under the guise of accountability, what angers me most is that the orders come from the same authority responsible for the administration of our state institutions (developmental centers) and New York has never run a first rate institution. In 1985, this state refunded \$33 million to Medicaid because the institutions involved did not pass federal review. When that occurred, the other institutions of the state did a quick clean and policy job that passed the cursory inspection by the Feds. However, this year the Long Island Developmental Center fell under the Medicaid gun, and they have been ordered to make programmatic changes or the Feds will withdraw their money. LIDC has a very conscientious director so I am sure he will do his best, but I must repeat that although I have seen excellent institutional care in Europe, it has never existed in New York. If OMRDD thinks it is the quintessential expert in the operation of homes, then they should provide evidence of that experience by cleaning up their own act before they reduce the voluntary residential programs to the level of the state institutions.

It is no secret that the voluntary sector always provided far better programs than the state. Nevertheless, we are the target of their buzz-saws while the programs that are the direct responsibility of the state remain sub-standard. Whenever I have made note of the fact, I am reminded by OMRDD that we spend tax dollars and that they are accountable to the taxpayer. From my perspective, a large part of that billion dollars plus operation of OMRDD, headquartered in Albany, is also supported by tax dollars, and since all of us are part of the "family" of taxpayers who pay their salaries, it seems to me that their case that only we are accountable is a specious argument and that they should be just as accountable to us as we are to them. Within their frame of reference, one of our large chapters recently told me that they did an audit of their annual paperwork and that the cost was \$100,000. Another organization gave me similar advice so I can only conclude that the waste of \$100,000 a year on meaningless paper that ends up in our files and in a morgue in Albany is just too big a price to pay for any commissioner's obsession with accountabil-

We have the money to expand our housing program which is difficult in our country because of an acute shortage of houses and land, but, and speaking personally, it bugs me to invest huge sums of money in a program knowing that a considerable percentage of our privately earned dollars will be wasted on an endless amount of "correction of deficiencies" and concomitant paperwork that will not add one iota of benefit to the mentally retarded.

The commissioner can fashion a procrustean bed, but we have no obligation to pay for the right to be the victims.



Banquet Speaker, Senator John E. Flynn, speaks to gathering on 1986 Legislative Session.



Richard Montgomery, assisted by staff member welcomes gathering at Banquet on behalf of the Ulster County Chapter.



Executive Director Marc Brandt addresses banquet.

NYSARC Statewide Awareness Campaign

Many chapters of NYSARC will be participating in a statewide effort offering Valentine Rose arrangements to emphasize the care and love which is being made possible through NYSARC chapters for individuals who are mentally retarded.

Representatives from about twenty-five chapters have been working the past six months through the Public Information Committee, in the development of the event and its theme, Legacy of Love.

Initial reports from the participating chapters indicate that the Legacy of Love Rose will be offered to the public in a variety of ways. Volunteers will be selling the arrangements at shopping centers, banks, railroad stations, athletic events, as well as other places where people gather. In addition, some local chapters are making arrangements to offer the Valentine Rose at meetings of other organizations such as the Rotary, Lions, and Kiwanis.

Chapters have been provided with suggested formats for participation and publicity.

The Valentine Rose arrangement has been designed by the Cayuga Chapter, which is producing the product in their sheltered workshop program. The arrangement which includes two polyester roses, together with baby's breath, will be sold to the public at \$3.50 each. Orders for the arrangements must be received by the Cayuga Chapter no later than December 5th to ensure delivery during the later part of January.

The statewide event is anchored to a special time of the year — Valentine's Day — which has an important connotation of love and caring.

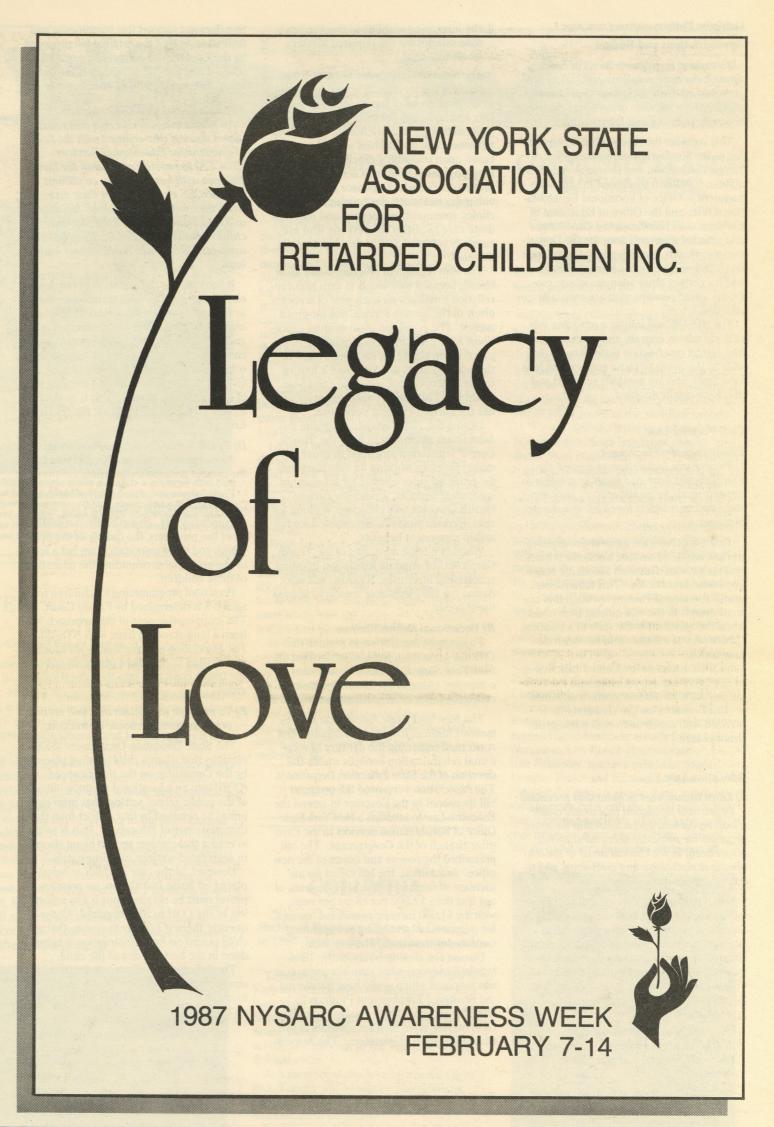
Additional details can be obtained by calling Susan Lyons, NYSARC's Public Information Coordinator, at (518) 439-8311.



NYSARC Public Information Coordinator, Susan Lyons (right), visits the Cayuga workshop where the Valentine roses are being assembled.



Workshop supervisor, Sue Waby (left) demonstrates how to make the Valentine Rose arrangements to be sold by chapters during the "Legacy of Love" event.





Robert Edwards giving Invocation at Saturday Banquet.



Well attended workshop gathering.



Roll call of Chapters.

Appropriations and Budget

To support appropriate levels of funding through the appropriations and budget processes of all State programs that affect affirmatively the lives of persons who are mentally retarded and their families.

This includes the reviewing and responding to the appropriations for the Office of Mental Retardation and Developmental Disabilities (OMRDD) the State Education Department — Office of Vocational Rehabilitation (OVR), and the Office of Education of Children with Handicapping Conditions; and selected appropriations for the Departments of Health, Social Services, Commission on Quality of Care for the Mentally Disabled and for certain other agencies whose programs affect persons who are mentally retarded.

The NYSARC will initiate a pro-active role that will advise, educate and encourage positive budget construction that will be responsible to the needs of those residents of New York State who are mentally retarded and developmentally disabled.

Civil Practice Law

Client TransferPlacement

To promote legislation to amend the Civil Practice Law and Rules in relation to appeals made by public officers to obtain stays on court orders for client transfer or placement.

This bill deletes the current provision of the law which allows that a state or municipal agency can obtain an automatic stay in any lower court order. This legislation would also amend current law such that the court must hear the case quicker than usual when the appellant is the state or a political subdivision of the state and has been denied a stay.

NYSARC successfully obtained sponsorship of S.8386 (Padavan) which passed the Senate and A.11333 (Connelly) which remained on third reading on the Assembly floor. NYSARC will continue to seek passage of this measure.

Education Law

A) Loan Repayment Scholarship Incentive

To promote legislation that would create a loan repayment and scholarship incentive program for professionals and students respectively in the clinical areas of speechlanguage pathology and audiology, physical and occupational therapies.

The New York State Association for Retarded Children, Inc. continues to experience difficulty in the recruitment and retainment of qualified licensed professionals, and in their compliance on a consistent basis with regulatory requirements in this regard with the State licensing boards of the State Education Department. In brief, the difficulty arises in:

 the inability to attract to rural areas, qualified licensed professionals in such areas as speech, physical and occupational therapy and psychology. the increasing inability to meet competitive salaries for the required Master's level individual.

The Association proposes to create a loan repayment and incentive scholarship program in the professions of speech-language pathology and audiology, physical therapy, occupational therapy and psychology. These loan repayment and scholarships will be awarded based upon committed practice of the specified profession in human services, not-forprofit agencies which sponsor and operate either day treatment, day training, workshop, clinics, community residences, and intermediate care facilities for persons who are mentally retarded and/or developmentally disabled.

The loan repayment program would allow already licensed individuals to earn loan cancellation privileges for each year of service given in the human service, not-for-profit agency. The expansion of an existing educational loan program would include a 10% cancellation clause for each loan year. In this way, agencies need not wait a four or five year period until potential employees graduate. This would enable agencies to use the current existing work force.

During the 1986 legislative session, the Association attempted to have the "Health Corp's" legislation amended in order to make clinicians working for voluntary not-for-profit agencies eligible for scholarship repayment benefits. Under the current Health Corp Act only clinicians working for state operated programs are eligible for scholarship repayment benefits.

Whether it is the amending of the "Health Corp's Act" or separate legislation granting scholarship incentives, NYSARC will work during the 1987 legislative session to address these needs.

B) Vocational Rehabilitation

To promote legislation to remove the Office of Vocational Rehabilitation from the New York State Education Department to a separate office in the Executive Branch called the Office of Rehabilitation Services.

The New York State Association for Retarded Children, Inc. has consistently been concerned regarding the delivery of vocational rehabilitation services under the direction of the State Education Department. The Association supported the program bill sponsored by the Governor to amend the Executive Law to establish a New York State Office of Rehabilitation Services in the Executive Branch of the Government. The bill prescribed the powers and duties of the new office. In addition, the bill called for an increase of funding to the SEP Program of not less than \$2,500 per client per year, with the \$1,000 increase considered "exempt" for purposes of calculating net operating costs under the Mental Hygiene Law

During the closing hours of the 1986 legislative session a last minute compromise was proposed which would have transferred the Sheltered Employment Program to OMRDD and would have established a council to oversee rehabilitation activities in the State Education Department. The Associa-

tion does not support this compromise and feels strongly that the original bill proposed by the Governor to establish a separate office in the Executive Branch is the only alternative to the existing structure.

C) Least Restrictive Environment

To promote legislation that will require school districts who contract with the Board of Cooperative Educational Services (BOCES) to provide education for their children with handicapping conditions to host BOCES classes, within their district, when appropriate. Furthermore, legislation will be sought to prohibit the placement of children into segregated facilities based upon lack of space in public school buildings.

It has come to the attention of our Association that children with mental retardation as well as other developmental disabilities are finding themselves being educated more and more in segregated settings such as church facilities, office buildings, vacant school buildings as well as centerbased BOCES buildings because of a growing lack of space in public schools. This is no doubt a clear violation of the Least Restrictive Environment.

D) Provision of Preschool Programs

To promote legislation that will address the area of preschool education.

Early intervention on behalf of children with developmental disabilities is a well-documented fact. However, the availability of the programs, the quality of the programs, and the transportation are but a few of the problems surrounding the education of these children.

Preschool programming for children from ages 0-5 is determined by Family Court. The inappropriateness of this approach has been a long-standing issue with NYSARC. The Association will continue to work for the transferring of preschool programs out of the family court and into the educational system.

E) To promote legislation that will require prior approval for home instruction.

The State Education Department (SED) requires that when a child is being placed by the Committee on the Handicapped (COH) into an educational program outside of the public school setting, that prior approval be obtained by that district from the Commissioner of Education. This is so as to ensure that children are not being placed in segregated settings inappropriately.

However, in the case of children being placed on home instruction, no prior approval must be obtained nor is any reporting by the COH to SED required. Consequently, there is not way to ensure that a child placed on home instruction is being done in the best interest of the child.

The Association will seek legislation to amend the education law to require COHs to obtain prior approval when placing a child on home instruction.

F) To promote legislation regarding the selection of hearing officers.

Impartial hearing officers who conduct hearings on behalf of parents and/or school districts are appointed by the local Boards of Education. That fact alone brings into question how "impartial" that person really is. Additionally, attorneys and law advocates working on behalf of parents have identified specific instances that support concerns for the present method of selection of these individuals.

The Association will seek legislation that would alter the school district's current right to be the sole determinant of who the hearing officer will be.

Mental Hygiene Law

A) Admission Criteria

To promote legislation that will eliminate current practices of discrimination which allows for placement decisions into community residences based upon whether a person currently resides at home or in a developmental center.

Placement into a community residence should be made based upon clinical decisions considering such things as age, sex, medical condition and functioning level to name but a few. Placement should not be made upon where someone resides.

During the previous legislative session, S.813 and A.2511-A were introduced. Our Association requested the amendment of these bills using the following wording "Admissions criteria for community residential placements shall not discriminate on the basis of prior residence in developmental centers or in family homes."

We will continue to oppose existing language in present bills and work toward the acceptance of our proposed language.

B) Rate-Setting Methodology

To promote legislation that will mandate that final rates be established for community residences prior to the opening of a community residence.

Community residences are now funded through a rate-setting methodology. Serious financial problems of considerable magnitude continue to plague our chapters as a result of having the final rates established well after the residence has opened up.

Two bills were introduced during the 1986 legislative session at the request of NYSARC with regard to this issue. S.8712 by Padavan was held in the Senate Mental Hygiene Committee while A.11210 by Connelly was held in the Ways and Means Committee.

While neither bill was passed by the Legislature, NYSARC's active promotion of this legislation caused both houses to recognize a "final rate" issue. Legislative staff assured NYSARC that if OMRDD does not resolve this problem administratively, NYSARC's final rate bills would be passed during the next legislative session. In this respect, OMRDD has informed NYSARC that the office is now developing guidelines to enable providers to obtain final rates prior to



The Swick family partaking at the Saturday Awards Luncheon.



Mary Brady, Director of Day Services, Ulster Chapter, accepts Certificate of Appreciation on behalf of Campus Auxiliary Services.



Senior Vice President, John Bryant, pauses to reflect.

the opening of residential programs. If in fact the new OMRDD administrative procedure addresses the concerns of our chapters it may not be necessary to reintroduce the final rate bill.

C) Equity of Funding

To promote legislation that will eliminate imbalances of funding between persons residing in the community and those with a history of institutionalization.

The existing local assistance funding system creates incentives to serve persons who have had a history of institutionalization at the expense of individuals without such history.

During the 1986 legislative session, the Legislature eliminated the imbalance in funding between persons with and without a history of institutionalization for individuals who are mentally ill. The same proposal has been advanced for persons with developmental disabilities but to date, nothing has been done.

The Association will seek legislation to consolidate chapter 620 funding and local services funding.

D) Land Reimbursement

To promote legislation to have the cost of land reimbursed for community residences.

Providers are not reimbursed for the cost of land used to establish community residential facilities. This has reduced development particularly in regions of the state where the cost of land is high.

The Association successfully obtained the introduction of S.8851 (Padavan) and A. 11293 (Kremer) requiring that fees established for ICF/MRs and Community Residences include the cost of land for newly established residential facilities.

S.8851 remained in the Senate Mental Hygiene Committee. A.11293 was held by the Assembly Rules Committee.

According to legislative staff, this legislation was held in committee since reimbursement of land costs for any type of health care facility is unprecedented. However, staff in both the Assembly and Senate recognized the problems which this legislation addressed and agreed to continue discussions regarding the reimbursement of land costs for possible legislative action next year.

E) Regulatory Enforcement

To promote legislation which would require OMRDD to submit a plan to the Legislature with respect to regulatory practices conducted by the office.

The OMRDD regulatory enforcement system seeks stringent provider compliance with both trivial and important regulations. This approach is needlessly burdensome (i.e. paperwork, staff time) to providers and uses resources which could otherwise be devoted to client care.

NYSARC successfully obtained the introduction of S.8714 (Padavan) and A.11209 (Connelly) to require that OMRDD submit a plan to the Legislature with respect to regulatory practices conducted by the office. Such plan was to have distinguished critical areas of client care, such as client health and safety from non-critical areas. Based on such distinctions, OMRDD was to have established separate visitation schedules for all regulations.

S.8714 was passed by the Senate and Assembly respectively and sent to the Governor who subsequently vetoed the bill.

In his veto message, the Governor stated that OMRDD has "vigorously initiated" regulatory reform "over a year ago."

The Association will once again raise this issue with the Legislature.

F) Timely Response to Rate Appeals To promote legislation requiring the timely response to rate appeals.

OMRDD response time to rate appeal applications is often unreasonably slow. As a result, providers do not know what costs will be reimbursed. This may disrupt services.

NYSARC successfully obtained the introduction of S.8716 (Padavan) and A.11238 (Connelly) requiring that OMRDD and the Division of the Budget respond to completed rate appeals within 90 days.

S.8716 passed the Senate while A.11238 was held by the Assembly Ways and Means Committee.

Legislative Staff assured NYSARC that if OMRDD did not resolve this problem administratively, this legislation would be reconsidered next year.

G) Prohibition of Co-location

To promote legislation prohibiting the colocation of persons who are mentally retarded and developmentally disabled with persons incarcerated in correction facilities or other facilities detrimental to the wellbeing of developmentally disabled persons.

The policy of co-locating persons who are mentally retarded with other individuals who are in custody of the criminal justice system commits a gross injustice against those who are mentally retarded. Our Association has worked diligently over the years to educate society to the fact that persons with mental retardation are not people to fear. To locate these individuals side by side on the same campus with persons in the criminal justice system only reinforces a very negative message and consequently does a great disservice to persons who are mentally retarded.

Additionally, having these persons in such close proximity to those incarcerated poses a possible threat to their personal well-being and physical safety.

Co-location continues to be a major issue for the Association. Existing legislation, however, does not prohibit co-location from occurring. Rather, it provides a process to determine whether a particular proposal for co-location should take place. In our view, such legislation does not adequately protect D.C. residents and needs to be strengthened

The Association will be proposing stronger legislation on this subject during the 1987 legislative session.

H) Establishment of an Ombudsman Position in Developmental Centers.

To promote legislation that would establish an independent advocacy position in developmental centers.

It has become apparent to this Association that there is a great need to address particular concerns that arise in a more timely fashion. Parents and residents of developmental centers as well as those residing in the community on legal status, need an independent person who they will be able to approach in dealing with matters of concern that they do not seem to be able to resolve through normal channels.

NYSARC was successful in having S.8857 (Padavan) and A.11483 (Connelly) introduced to require the establishment of a client advocate — an "Ombudsman" — at each developmental center. Details of the bill were carefully worked out with OMRDD. A.11483 passed the Assembly. However, S.8857 was held by the Senate Rules Committee and thus could not be voted upon by the full Senate.

NYSARC will again seek passage of this bill.

I) Notification to Concerned Persons Regarding Suspected Cases of Client Abuse.

To promote legislation requiring OMRDD facilities to notify parents, guardians and correspondents of suspected instances of client abuse.

Parents, guardians and correspondents often do not have access to complete information regarding alleged instances of client abuse. As a result, the ability of these persons to advocate on behalf of the affected client is limited. It is often unknown, for example, whether or not the alleged perpetrator remains in contact with a client that they may have abused.

NYSARC will work for passage of a bill requiring notification to be given when suspected cases of client abuse occur.

J) Employee Verification

To promote legislation which will enable providers to thoroughly review backgrounds of prospective employees.

It has repeatedly come to the attention of NYSARC that the inability of providers to check the background of prospective employees has led to the hiring of individuals who have a history of criminal behavior. Such persons constitute a danger both to clients and other employees. In order to avoid these situations, providers should have the ability to assess the full background of prospective employees.

Public Health Law

A) Medical Consent

To promote legislation that would allow a legal guardian of a person who is mentally retarded to sign for medical or dental consent.

Current laws are unclear as to the rights of legal guardians as they pertain to medical or dental consent. Consequently, regula-

tions promulgated by the Office of Mental Retardation and Developmental Disabilities do not recognize the authority of an adult client's legal guardian to give such consent.

This has in the past resulted in undue suffering on the part of many individuals who have had to await medical treatment while permission has been obtained through the courts. Furthermore, this lack of clarification has caused a great deal of frustration on the part of many parents who have gone to the trouble and expense of obtaining legal guardianship on behalf of their adult children only to be told that they cannot provide medical and/or dental consent.

Bills were introduced in the Senate and Assembly clarifying the authority of guardians to give medical or dental consent. A.8072 (Connelly) passed the Assembly. Despite intense efforts by NYSARC, S.7283 (Padavan) was held by the Senate Rules Committee.

The Senate's precise reservations concerning this bill are unknown. OMRDD vigorously opposed the bill on the grounds that clarifying the right of a guardian to give medical consent might lead to the abuse of such authority.

The Association will again during the 1987 legislative session raise this issue.

B) Prevention of Lead Poisoning

To promote legislation which will increase public awareness and will increase the number of existing screening centers to prevent lead poisoning in children.

It is a well-documented medical fact that one of the leading causes of mental retardation is the ingestion of lead by young children. Lead is everywhere in the human environment as a result of industrialization. Hence the sources of lead are many including air, water, food, paint and gasoline. Increase public awareness is essential in the prevention of childhood lead poisoning. Therefore, it is vital that the general public be better educated regarding this most serious problem. Additionally, it is most important that the screening centers which now exist be expanded so that many more children can be tested for lead poisoning.

C) Fetal Alcohol Syndrome (FAS)

To promote legislation to amend the alcoholic beverage control law in relation to warnings regarding the ingestion of alcoholic beverages while pregnant.

Research has now documented that a leading cause of mental retardation is the ingestion of alcohol by a pregnant woman. Legislation will be sought which will mandate that warnings be placed in appropriate places. As with warnings on cigarette packages regarding danger to one's health, it follows that such warnings should also be required as to the inadvisability of consuming beverages containing alcohol while pregnant.



N.Y.S. Advocate, Francis Berko leads workshop on Advocacy.



The Schuyler ARC crew gets advice from Albany ARC.



Senator John Flynn, President David Lettman and the Edwards Family enjoy the cocktail party.

CONVENTIO

Delegate Assembly Adopts Nine Resolutions

Delegate Body Overturns NYSARC

Policy Regarding Small Residential Units (SRU's)

Jonathan Swick Plays At Awards Luncheon

Close to seven hundred people had the pleasure of hearing Jonathan Swick play the piano at the Awards Luncheon at the NYSARC Annual Convention held at the Concord Resort Hotel on Saturday, October 24, 1986.

Jonathan is 16 years old and is a freshman in a BOCES class at the Bethlehem Central Senior High School in Delmar, New York

Jonathan had attended preschool at the Montessori School of Albany, and then was mainstreamed into the Bethlehem Public School System through the seventh grade. He completed his middle school years at the Farnsworth School in Guilderland, New York

For six years Jonathan has studied piano with an outstanding Albany teacher, Mary Alice McCullen Senecal. Although his train-

ing in music is primarily classical, his enjoyment of it includes rag time, popular, gospel and rock.

On September 21, 1986, Jonathan gave a mini-recital at SUNY, New Paltz as an invited guest of the Director of Wassaic Developmental Disabilities Service Office, Mr. Hollis W. Shaw.

At the Awards Luncheon, Jonathan thrilled the audience with the following selections:

Songs Without Words, Op 30 No 3 "Consolation" - Mendelssohn L'Amoure de L'Apache - Offenbach-Ely Lesperles - Burgmiiller Für Elise - Beethoven■



Jonathan Swick performs at the Awards

his enjoylar, gospel

On Saturday, October 25, 1986, the Delegate Assembly, representing the NYSARC, Inc. 65 chapters and 51,000 members, voted on nine resolutions. A tenth resolution submitted by the Education Committee was withdrawn.

The most controversial resolution pertained to the OMRDD policy of developing Small Residential Units (SRU's) on the grounds of developmental centers. The NYSARC, Inc. was not opposed to the development of SRU's contingent upon five conditions. These conditions were as follows:

- 1. Persons placed into SRU's had to be continued to be counted within the developmental center census.
- 2. The process of utilization review had to be continued to ensure that individuals placed in SRU's are appropriate for this level of care.
- 3. That vacant buildings on the grounds of developmental centers could not be co-located with persons in custody of the Criminal Justice System or any other inappropriate population.
- 4. That the Governor of the state and the Commissioner of OMRDD shall ensure that a good faith effort be made in order to maximize the continued pace of community development for residential and day programming.
- 5. That the Commissioner of OMRDD be directed to incorporate within the SRU concept an appropriate community res-

pite service and a capacity to admit individuals in need of such placement.

The NYSARC, Inc. By-laws provide that any action of the Board of Governors may be revised, altered or rescinded by affirmative vote of the delegates present at the annual convention. The Delegate Assembly overturned the adopted Board Policy on SRU's and the official NYSARC, Inc. Policy relating to SRU's is now in opposition.

The nine resolutions as adopted by the Delegate Assembly are as follows:

RESOLUTION NUMBER 1: TERATO-GEN REGISTRY IN NEW YORK STATE

WHEREAS, recent scientific evidence shows that many environmental agents may be teratogenic and have the potential to seriously disrupt normal embryonic and fetal development leading to mental retardation. Chemicals of several categories, including substances found within the general environment and those substances used because of personal habits and for medicinal purposes, may also be damaging to the unborn fetus. Such environmental chemicals including, but not limited to, additives, pollutants and contaminants are a major public concern because of their ubiquity and incidiousness, and most importantly overexposure to them. Examples of some suspected teratogens are heavy metals, insecticides, anti-convulsive drugs, alcohol, cigarettes and carcinogens and a host of other substances.

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1987 Committee Goals Adopted by Board of Governors

At the Annual NYSARC, Inc. Convention held at the Concord Resort Hotel in Kiamesha Lake, New York on October 24, 1986, the Board of Governors reviewed and adopted the 1987 goals for the Association's committees. These goals were developed by the various NYSARC committees and reviewed by the Executive Committee of the Board of Governors.

The purpose of developing these goals is to assure that the NYSARC, Inc. committees are focusing their attention and energies on Board of Governor priorities. In addition, the Board of Governors are responsible for developing, reviewing, passing and implementing policy for the Association. It, therefore, follows that the Board of Governors should develop and implement goals and objectives for the coming year as well as on-going objectives.

It goes without saying that underlying the committee goals is our commitment to advocate on behalf of all persons who are mentally retarded and developmentally disabled, wherever they live. Our Associa-

tion has spoken loudly and clearly for over thirty-seven years, articulating their goals and needs; therefore, our advocacy efforts will continue to be the driving force behind all of our Association activities.

The following are the goals and objectives as adopted by the Board of Governors:

Area:

Adult Services

With the development of the proposed medicaid waiver as well as the direction that government is moving towards it is essential that the Association develop a "white paper." The purpose of this paper would be to set forth the goals and objectives of the Association as it relates to the delivery of services to persons who are mentally retarded and developmentally disabled.

While the Committee only proposes one goal, the "white paper", it would be a major undertaking and would involve the input from the other NYSARC committees. The "white paper" would serve as the Associa-

tion's response to the current government initiatives as well as providing the Association with a philosophical base in which to function.

Area:

Community Residential Services

- A) To develop guidelines which will be useful to chapter board members in assessing the quality of life of individuals living in the chapter residential program.
- B) To review and survey medication administration and related issues affecting persons who are mentally retarded residing in CR's and ICF's.
- C) To review and make recommendations on the OMRDD 1991 Plan: reconfiguration of Residential Services 1985-1986/ 1991.
- D) To assist in the development of a manual on CR and ICF rate setting and rate appeals which will be useful to the fiscal managers of our chapters.

Area

Developmental Center

- A) To conduct a re-survey of the developmental center chapters' perspective on the quality of care given to persons residing in New York State's developmental centers.
- B) To conduct an in-depth review and analysis on the staffing patterns in a sampling of three developmental centers (West Seneca, Rome and Wassaic) to determine if actual staffing ratios are consistent with legislative mandates.

Area:

Education

- A) Continue to publish the Edu-Letter
 - Research and develop articles that address vocational education for schoolaged persons. This article will not only be printed in Edu-Letter but will be used as a reprint.

continued on page 16



The President, "hard at work".



Counsel for OMRDD, Paul Kietzman leads workshop on Medical Consent.



A moments break for NYSARC state office staff.

N HIGHLIGHTS

WHEREAS, many states have already established teratogen registries in cooperations with poison control centers and hospitals. These registries can provide physicians and the general public with any up-to-date information on teratogens and many of the effects to be expected after exposure.

WHEREAS, because New York State at present does not have a teratogen registry and because discussions with the New York State Department of Health and several state hospitals and poison control centers have begun to address the need for such a registry.

NOW THEREFORE BE IT RESOLVED, that NYSARC become responsible for collaborating with other agencies, organizations and individuals to establish a teratogen registry in New York State.

RESOLUTION NUMBER 2: CLIENT ABUSE

WHEREAS, no person should be deprived of any civil right solely by reason of receipt of services for a developmental disability, and

WHEREAS, persons receiving services for a developmental disability are entitled to receive such care and treatment which is best suited to their needs and administered with full respect for their human dignity, and

WHEREAS, those persons receiving services for a developmental disability may be subjected to instances of physical harm caused directly by an employee of the organization providing such services during the course of administration providing such services, and

WHEREAS, those persons who receive services for a developmental disability are entitled to equal protection of the laws.

NOW THEREFORE BE IT RESOLVED, that the New York State Legislature be commended for passage of Section 13.21(b) of the Mental Hygiene Law which states, in part, that in instances of alleged patient abuse or mistreatment "if it appears that a crime may have been committed, the director shall give notice thereof to the district attorney or other appropriate law enforcement official as soon as possible, and in any event within three working days."

RESOLUTION NUMBER 3: CO-LOCATION OF DEVELOPMENTAL CENTERS

WHEREAS, the Association has historically and consistently been opposed to co-location and recognizes this issue's importance, especially in view of existing SRU development on the grounds of several developmental centers; the New York State Association for Retarded Children, Inc. continues to have the utmost concern about the lives of institutionalized children and adults who are mentally retarded and the living conditions, management policies and practices which are evidenced in New York State's developmental centers; and the Association is strongly opposed and continues to be in forefront in advocating against the co-location of buildings, programs or services for persons who are mentally retarded and developmentally disabled, such as an SRU, next to buildings, programs or services for persons who are in custody of the criminal justice system.

NOW THEREFORE BE IT RESOLVED, that the New York State Association for Retarded Children, Inc. forcefully reaffirms its opposition to co-location and stands philosophically for the appropriate placement and humane movement of New York State's developmental center population which specifically and totally excludes co-locating persons with developmental disabilities with incarcerated persons.

RESOLUTION NUMBER 4: PRESCHOOL EDUCATION

WHEREAS, the need for early intervention on behalf of children with developmental disabilities is a well-documented fact, and

WHEREAS, the provision of these services can sometimes eliminate and/or reduce the severity of the disabilities.

NOW THEREFORE BE IT RESOLVED, that NYSARC will continue to promote legislation that will address the needs of children with handicapping conditions between the ages of 0-5.

RESOLUTION NUMBER 5: CLASS-ROOM SPACE VS. LEAST RESTRICTIVE ENVIRONMENT

WHEREAS, NYSARC has always promoted and enforced the Least Restrictive Environment in the education of children with handicapping conditions, and

WHEREAS, Part 200 of the Commissioner's regulations specifically defines Least Restrictive Environment as "education of the pupil to the maximum extent appropriate with other pupils who are not handicapped", and

WHEREAS, the growing lack of space in public schools has caused the removal of certain children with handicapping conditions from public schools and thus leads to their placement in church facilities and other non-educational type structures, away from the mainstreaming;

NOW THEREFORE BE IT RESOLVED, that NYSARC will continue to seek legislation to prohibit placement of children in segregated facilities based solely on the lack of space in public school buildings.

RESOLUTION NUMBER 6: SMALL RESIDENTIAL UNITS (SRU'S)

WHEREAS, several key factors support the position of opposing the development of small residential units. The central issue is segregation versus integration.

WHEREAS, the concept has already been tried and proven unsuccessful, i.e. "cottages" in Massachusetts or "modular units" in Pennsylvania.

Many other states have constructed 10 to 15 bed units on the periphery of the institution grounds, some as recently as the 1970's. In Connecticut, Massachusetts and Pennsylvania, these units are being phased out. Further, in the Pennhurst dispersal order, Judge Broderick did not discriminate

between these facilities and the large wards in ordering deinstitutionalization.

WHEREAS, most service providers can, and will, respond to residential development needs. While some providers have chosen not to expand to serve more severely disabled individuals, many are impeded only by the lengthy, confusing and difficult development process required by OMRDD. This opinion was shared by members of other area chapter boards and by area and statewide representatives from the Executive Director's Association.

WHEREAS, other options could be pursued, i.e. ICF/MR programs or the "Medicaid Waiver" provisions of the Consolidated Omnibus Budget Reconciliation Act (PL99-272). This legislation, signed by President Reagan in April of this year, permits a maximum of 36 month phase-out of sites not in compliance with Medicaid regulations as an option to capital improvements or ongrounds construction. Instead of a plan of correction to address cited deficiencies, the act also allows for submission of a written plan for reducing the number of certified beds at the location in question within the specified time frame.

WHEREAS, while certainly slowed, ICF/MR development does continue and could also be more fully employed. Finally, broadening of this continuum of care could allow easier client transition toward greater independence and create a positive flow from more staff intensive services to less supervised, more flexible community-based options.

NOW THEREFORE BE IT RESOLVED, that the New York State Association for Retarded Children, Inc. actively oppose the construction of new facilities on the grounds of institutions (developmental centers) and support the right of people with developmental disabilities to live in the community.

RESOLUTION NUMBER 7: 620/NON-620

WHEREAS, New York State operates on a deficit funding basis, i.e. gross costs, minus revenue reduced by exempt income*, equals

net operating costs or deficit.

FUNDING

*Exempt income is contract sales amounts after direct costs are subtracted, donations, membership fees, fundraising results, nonspecific grants, etc. In general, self-generated income of all sorts.

WHEREAS, funding is based on two contracts and two types of participants 620 and non-620. 620 participants are those individuals who were institutionalized for at least five (5) years prior to January 1984. Non-620 participants are almost everyone else enrolled in a non-Medicaid funded day program. (Some programs do have Direct Workshop contracts which do not depend on this categorization, though these arrangements are increasingly being diminished and/or phased out). At the time of the Willowbrook Consent Decree, "620's" were backed by 100% state funding to promote deinstitutionalization. They still are so funded. "N-620's" are backed by 50% state funding. At least in theory, the remaining 50% is split equally between the county in question and the agency's self-generated

revenue (exempt income) and other sources of funding (i.e. OVR, etc.).

WHEREAS, the split in costs between these two contracts is usually determined by units of service. A unit of service is simply one day. Under a client-specific revenue allocation method, costs and revenue which can be specifically assigned to each client, by category, are so allocated. Non-specific costs (e.g. transportation) remain spread on a units of service formula. Only two variables exist: census (total number of participants) and rate of utilization (number of days those participants actually were in attendance).

Due to substantial local need (typically N-620) and a diminishing and increasingly disabled 620 population, N-620 units of service often exceed 620 delivered units. Layoffs or part-time N-620 participation are clearly unfair as a means to balance units of service. Limiting local access to services also unfairly impedes service provision to community participants. The resulting funding balance created by full participation and free access, however, often cannot be borne by the agency.

Additional revenue and/or reduced spending does not address the problem, since revenue and costs must still be split according to contract. Revenue specific allocation is not always effective in realizing a better spread of expenses.

NOW THEREFORE BE IT RESOLVED, that the New York State Association for Retarded Children, Inc. actively investigate, initiate and support legislation which would abolish the present 620/N-620 funding formula for day training and sheltered employment in favor of a more equitable, realistic method of allocation.

RESOLUTION NUMBER 8: APPRECIATION OF NYSARC STAFF

WHEREAS, the NYSARC annual convention provides a vital opportunity for its membership to become more informed and actively participate in improving the quality of life for MR/DD persons,

NOW THEREFORE BE IT RESOLVED, that this delegate body applaud the work of NYSARC staff and all other persons responsible for making this convention a most valuable experience.

RESOLUTION NUMBER 9: CONVENTION IN MEMORY OF RUTH GROSS AND MINNA BOBER

WHEREAS, it is extremely important to recognize and acknowledge the efforts and dedication of our volunteers throughout the NYSARC family,

NOW THEREFORE BE IT RESOLVED, that this 37th Annual Convention held at the Concord Hotel, be closed in memory of Ruth Gross, Past President of Nassau AHRC and Past President of the NYSARC, and Minna Bober, Past Vice President of the New York City Chapter and member of the New York City Board of Directors for 36 years.

RESOLUTIONS COMMITTEE Maryann Bryant, Chairperson Mary Caniano Seymour Rubin



"Keep those placards High!"



What the "Heck" another vote!



A point of information being raised.

CHAPTI

BROOME-TIOGA

Broome-Tioga Holds 32nd Annual Dinner Dance and Awards Banquet

The Broome-Tioga ARC held its 32nd Annual Dinner Dance and Awards Banquet on Saturday, September 13, 1986. Over 350 clients, parents, staff, board members and dignitaries were in attendance making this one of our largest and most successful banquets.

The program included the presentation of the 1986 Community Service Award to the Reverend James Leeper whose personal and professional contributions over the past 20 years have almost single-handedly helped to change the nature, scope, availability of services and subsequently the lives of the disabled in Broome County. Six other awards were presented to program participants, staff and the company of the year given for support of the workshop program.

Broome-Tioga was honored to have a long and distinguished guest lost of state and local dignitaries including representatives, James Tallon and Richard Miller from the New York State Assembly; David B. Lettman, Marc N. Brandt and John Bryant from NYSARC; Carl Young, Broome County Executive and representatives from the Broome DDSO, OVR and County Mental Health Departments.



N.Y.S. Assemblyman James Tallon speaks to guests at the Broome-Tioga ARC Annual Banquet.

SUFFOLK

Scholarship Fund Expanded to Assist Needy Clients

Suffolk Chapter's Board of Directors recently voted to expand the Robert Sansone Scholarship Fund to include financial assistance to needy clients for leisure time activities. Some clients lack the financial means to take advantage of agency leisure time offerings such as weekend resort trips, theater outings, adult education, camping activities and other beneficial leisure time pursuits. It was determined, therefore, that proceeds from the Robert Sansone Scholarship Fund would also be used for this important purpose. Since its inception, the fund has been used to provide college tuition help to students planning careers in the field of special education.

The first scholarship recipient will accompany a group of clients on Friday, November 28 when Leisure Time Activities will sponsor "The Ultimate New York Experience" featuring the Christmas Show at Radio City Music Hall, luncheon at Mamma Leone's Restaurant and a tour of St. Patrick's Cathedral.

WAYNE

Wayne Chapter Visits New York State Fair

Ninety-four clients from the Wayne County Chapter, New York State Association for Retarded Children's sheltered workshop, Key Industries enjoyed a day at the New York State Fair, courtesy of Ames Department Store, Newark, New York.

Ames provided the tickets, bus fare and refreshments to the clients and staff who all showed their appreciation by writing letters to Ames thanking them for their generosity.

O.D. HECK D.C.

Parent Appointed to Board of Visitors

The O.D. Heck Chapter is pleased to announce the appointment of Shirley Valachovic to the Board of Visitors. She is the only parent representative of a resident at O.D. Heck.

At our last meeting on October 7, 1986, Paul Shields, Ph.D. discussed "Normalization, How it Relates to the Mentally Handicapped at O.D. Heck". ■

Thank you. Very truly yours, Pamela M. Sorocco

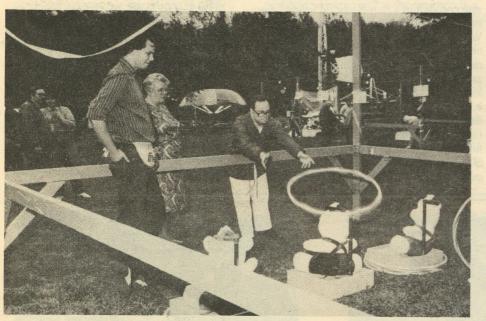
SCHENECTADY

Family Carnival is Great Success

There was something for everyone at Schenectady ARC's Family Carnival, September 26-28 — twirling and twisting upside down on a midway ride, eating a hot dog, finding a bargain at the rummage sale or trying your luck at a game booth. It was all a matter of choice.

Although the weather was not too cooperative, the event was a successful fund-raiser and served to enhance public awareness of the ARC within the community.

The many hours of volunteer work by staff, parents and board members provided an enjoyable way for everyone to become better acquainted. It was all a lot of hard work but workers and carnival goers alike had lots of fun!



Mrs. Carroll Stowell watches her son, Robert, try to "ring a bear" during Schenectady ARC Family Carnival.

MADISON

Madison County ARC's Annual Pumpkin Fest Sets Another Attendance Record

Two days of sunny weather on October 18 and 19 after weeks of rain, was a major factor in bringing out the tremendous crowds to support and celebrate Pumpkin Fest '86.

Estimated attendance for the weekend of pumpkins, food, music, hay rides, pony rides, entertainment and contests was 3,000 on the grounds of the Madison County ARC main facility in Oneida.

The annual celebration began in 1983 when Alex Penna, a local farmer and parent of a client, offered to donate pumpkins to the agency while suggesting an event of some kind be organized around their sale. As a result, the Pumpkin Fest was developed and has grown annually in size and significance to the community ever since.

Although still primarily intended to provide a weekend of wholesome family fun while sharing their facilities with the community, the Annual Pumpkin Fest has become the agency's most successful fundraising special event. The first Pumpkin Fest netted the Madison County chapter a whopping \$48, the proceeds grew to \$1,700 at the second annual Pumpkin Fest '85, resulted in more than \$6,000 and this year it is estimated that the Madison County ARC will benefit to the tune of \$10,000.

HERKIMER

Alternative Measures Offers Training to Herkimer County

The Alternative Measures Program, sponsored by the Herkimer County Chapter, New York State Association for Retarded Children, Inc. is a new and innovative concept in a rural community such as Herkimer County. It has, therefore, been necessary to generate interest and information about the developmentally disabled offender to the criminal justice system in order to facilitate referrals to the program. To achieve this goal, it was decided to hold a series of comprehensive educational seminars for criminal justice professionals, police and magistrates in the area. The seminars will consist of a slide presentation reinforced by written material and discussions of recognizing the developmentally disabled client and how to deal with him/her. Also included will be an explanation of the Alternative Measures Program. These training sessions were held at the local community college in early October.

A brochure containing a description of Alternative Measures and facts regarding developmental disabilities has been prepared for distribution.

Alternative Measures has made inroads in making service providers for the developmentally disabled population aware of the program. At the completion of the training seminars, this awareness will be enhanced and Alternative Measures will be a viable resource for this target population in Herkimer County.

RNEWS STATE



A special initiative by members of the New York State Senate made possible a grant of \$25,000 to the Nassau AHRC. The funds, which were used for the purchase of a truck, honored Helen Kaplan's retirement. Present at the symbolic presentation were (left to right) Ed LaJoie, Nassau AHRC President; New York State Senator Michael J. Tully; Helen Kaplan and New York State Senator Norman J. Levy. Also instrumental in the funding were New York State Senators Dean Skelos, Ralph Marino, John Dunne, Frank Padavan and Michael J. Tully.

YATES

Yates Chapter Hosts Five-County Dinner Dance

On October 9th, the Yates County Chapter hosted the fourth annual Five-County Dinner Dance sponsored by Seneca, Schuyler, Ontario, Wayne and Yates Chapters of the New York State Association for Retarded Children, Inc. Dr. Michael Marge, Professor of Special Education and Rehabilitation at Syracuse University, addressed the gathering of 160 people about "New Federal Initiatives for Disabled Persons", a report of the National Council on the Handicapped. Dr. Marge is a presidential appointee to the Council and has served on it for four years.

Dr. Marge summarized the report of the Council which was submitted to the President earlier this year. He highlighted the priority areas as determined by the Council. They include total equal opportunity for the handicapped population, employment without discrimination, disincentives to work, prevention, transportation, housing, independent living, education from birth to adulthood, personal assistance and coordination of services to the handicapped. Legislation has been enacted just this year on independent living and education from birth to adulthood, based on the recommendations made by the Council. Dr. Marge did much to dispel the "ivory tower" image which many of us hold of presidentially appointed Councils.

Dr. Arthur Kirk, President of Keuka College, was Master of Ceremonies introducing the guests at the head table which included, in addition to Dr. Marge, the Board Presidents from each of the five county chapters; Marc N. Brandt, Executive Director of NYSARC, Inc.; and David B. Lettman, President of NYSARC, Inc. All at the head table were accompanied by their spouses. Mrs. Lauren Snyder, Board President of the Yates Chapter, welcomed everyone and both Mr. Brandt and Mr. Lettman briefly addressed the group.



David B. Lettman welcomes dinner guests at the fourth annual Five-County Dinner Dance sponsored by Seneca, Schuyler, Ontario, Wayne and Yates Chapters. Left to Right: Mr. and Mrs. Alan Snyder, Dr. Arthur Kirk, David B. Lettman, Marsha Lettman, Marc N. Brandt and Lynn Brandt.

ALBANY

Albany County's Transition Program

The Albany County Chapter, New York State Association for Retarded Children, Inc. through the assistance of federal grant monies and sponsorship from their present Sheltered Workshop program, North Country Industries has developed and implemented a Transition program. Suitable for candidates from a BOCES class or Day Treatment program, the Transition program integrates components from these programs with those of the Sheltered Workshop. As a result, participants receive a well-rounded rehabilitative program to meet their special behavioral and skill needs which better prepares them for a successful transition to a total Sheltered Workshop setting.

Located within their Sheltered Workshop, the group consists of 12-13 clients supervised by one work supervisor. The services offered by the Transition Group Rehabilitation Counselor and the Basic Education Instructor are also an integral part of this program.

Production in conjunction with structured learning activities similarly linked with the mechanisms of the Sheltered Workshop constitute the client's day. To date and after ten months from inception, three clients have successfully met the program's exit criteria and are now productive workshop employees.

As the Albany County ARC's Transition program develops and matures, plans for continued success in terms of client movement to the total workshop setting along with increased comprehensive services to those individuals aging-out of the educational system and, in general, to the underserved populations of their community are underway.

COLUMBIA

Sheltered Employee Chosen to Compete in 1987 International Summer Special Olympic Games

Tommy Sanders, 23, of Philmont, New York has been selected to represent the New York State Special Olympics at the 1987 "International Summer Special Olympics" in South Bend, Indiana at Notre Dame University. He entered in the one mile Track & Field event.

As a member of the Area 10 Special Olympics, Tommy will be representing Albany, Schenectady, Greene, Rennselaer, Schoharie and Columbia Counties.

Tommy, a sheltered employee at COARC's Community Workshop, has been training in Track & Field for the past four years.

Tommy has also been nominated for New York Special Olympic's "Athlete of the Year."

COMMUNITY LEAGUE - WASSAIC D.C.

Community League Holds Luncheon for Officers and Board Members

All the preparations were made for the free brunch and installation of officers and board members and the day finally arrived. The day was September 14, 1984, the place was the Vista Hotel and you were the distinguished guests who made this brunch a time we will long remember.

President Florence Siegel spoke about the legislative victories, the battles of legislation yet to be won and the need our residents at Wassaic have for the organization. Director Hollis Shaw spoke of the new innovations at Wassaic and the letter one of our members sent to various legislative people. Director Shaw challenged us to do even more than we already do and we accepted his challenge as we always do more than expected and always are there when we are needed.

President Florence Siegel presented former Acting Administrator, Peter T. Lasher, with a plaque for his long and lasting dedication to the quality of care to our residents. Mr. Lasher has left Wassaic for another position but still remains a dedicated member and a dear friend of Community League.

Director Hollis Shaw administered the oath to our incoming officers and board members. They are: Florence Siegel, President; Beverly Epstein, Vice President; Pamela LaSala, Recording Secretary; Sarah Greenburgh, Corresponding Secretary; Seymour Epstein, Treasurer; Ruth Zeins, Financial Secretary; Jeanette Kozak, Secretary. Board members installed were Hilda Benjamin, Leo Fixler, Harry Schuster, Lillian Schuster, Sadie Steele, Abe Siegel, Dorothy Fixler and Michael LaSala.

As for the food as always, there was more than enough even with the many people who had seconds and thirds. These extra helpings prove my point, the food was excellent. We all had a very enjoyable afternoon.



Tommy Sanders, an employee of the Columbia Vocational Rehabilitation program will represent several counties at the Special Olympics International Summer games.



DUTCHESS

Dutchess ARC Develops New Program With Local BOCES

In a move to aid in the transition from classroom to workshop, Dutchess County ARC and the Dutchess BOCES have inaugurated a one year pilot program for five young adults who are either mentally retarded or have autistic-like behaviors.

The program is designed for the aging-out or near aging-out child; that is the child nearing or at age 21 when their formal school program ends.

The program at DCARC currently has five young adults, ages 18-20, a teacher and a teacher's aide in addition to a staff member of DCARC. They have a classroom at the DCARC's facility and initially will be doing workshop jobs in that room. Eventually, as they age-out, they will move onto the work floor.

In cases of autism, it is important for children to have consistency in their program and persons working with the young adults. The teacher, Martha Schultz, has been with this same class for three years while the teacher's aide, Kathy Johnson, has been with them for ten. Both Martha and Kathy are employed by BOCES. Mary Ellen Bohan, DCARC's Evaluation Supervisor, provides the link to the adult service system.

While the students are transported from their homes to DCARC, they spend part of the morning at BOCES. The balance of the day is spent at DCARC in classroom and transitional workshop settings.



Dutchess County Chapter Executive Director, Lynn Smith, with clients from their programs at the first annual client/staff picnic at James Beard Park.

NASSAU

Nassau's Active Fall Calendar

The Nassau Chapter began its fall schedule with a membership Luncheon and Fashion Show which was attended by about 1,000 paid up members.

During the fall, the chapter held its annual Walk-or-Jog Athon, an event which has been growing steadily through the years and held at four different locations in the county.

In early November, the chapter sponsored its annual Bazaar, a giant sale event which fills an entire armory floor and attracts several thousand browsers and buyers.

Nassau dedicated a new community residence in Woodmere, a town on the south shore of Long Island and has announced plans for the addition of an intermediate care facility which will be opening around the late summer of 1987 in Plainview.

During the holidays, there was a variety of activities contributed by the community organizations, including holiday dinners and parties at the various AHRC facilities as well as the organization's Brookville campus.

YATES

Yates County Chapter is on the Move!

The Preschool Program, inaugurated in September 1985, is experiencing a space squeeze. Currently, the program is housed at the Branchport Elementary School. The program has grown to include, in addition to the full-day preschool program, a toddler program and an infant home-based program. With growth in enrollment, space requirements for classrooms and therapists have increased at the same time as the needs of the school district have expanded. Possible sites in Yates County are being looked at either to relocate the entire program or to open a second site.

Strategic planning is another big topic at the Yates ARC. In September, Fred McDonald of the McDonald Management Training Group conducted a workshop on strategic planning for Board members and staff. Lauren Snyder, Board President, has appointed John Rathfon, Board member, as Chairman of the Steering Committee. Other Board members appointed to the Committee include Allis Weaver, Robert Maxwell and Walter Guild. Four staff members will round out the Committee. The goal is to develop a long-range plan to give direction to the development and expansion of the Yates ARC.

CHAUTAUQUA

Arrival of Residents for Resource Center's New ICF

The enthusiasm was high among The Resource Center staff as the two chartered planes touched down at the Jamestown area airport. Almost 20 staff were there to greet the residents who will occupy one of the new ICF facilities recently opened by The Resource Center.

Formerly of the Terrance Cardinal Cook Health Care Center, the plane trip and move became an exciting new experience for these four disabled clients. The staff rushed to bundle the clients with blankets and ready them and their belongings for the trip from the airport to their new home.

Upon their arrival each client was given an exclusive tour, their eyes clearly expressed their amazement. As one client entered his room with the big sunny window which looks out on the marina and lake, he smiled and gave a squeal of joy. Their family will be complete with eight more newcomers scheduled to arrive soon.

CHEMUNG

Chemung ICF Dedicates ICF To a Very Special Person

October 4th was a very special evening for the Chemung County Association for Retarded Citizens when a board recognition dinner was held to honor both past and present board members. For one former board member, Lucille Houck, the evening was even more memorable, not to mention surprising. Unbeknownst to Lucy, the true purpose of the dinner was to dedicate our Children's ICF in her name. Lucy served on the Chemung County ARC Board more than 20 years; serving as secretary and involved in several committees. She has always had a special interest in the Residential Programs and was particularly instrumental in the planning and development of our Children's ICF home that opened last December.

In appreciation of Lucy's many years of devotion and support, the ICF was dedicated to her. A bronze plaque reading, "Lucille R. Houck, in recognition of her many years of devoted service as a member of the Board of Directors of the Chemung County Association for Retarded Citizens", will be placed on the ICF. As a personal gift from the board, a painting of the ICF was presented to Lucy during the dinner.



Maryann Bryant, Board President of Chemung County Chapter (left) watches as Lucille Houck is presented with a painting of the "Children's ICF".

RNEWS

CHAUTAUQUA

Resource Center Holds Awards Banquet for Softball Team

The second annual awards banquet for The Resource Center's Softball Team was held this year at Restivo's Alibi Restaurant on September 4th. Everyone came dressed for a night of dinner and special presentations of awards.

The featured speaker this year was Mr. Donald Reinhoudt, Jr. Chautauqua County Youth Bureau Director, once named the strongest man in the world. Mr. Reinhoudt spoke of the importance of sports in his life and what it means to him to be an athlete.

A presentation was then made by Special Olympics Committee member Mr. Frank Hyer to the Resource Center team and to Coach Diane Haase. After which awards were presented to each player who participated in this years games by Coach Haase and volunteers Helen and Charles Bryner and Donna and Norris Whitford. In all, 34 players attended the games, the largest group ever.



Mr. Donald Reinhoudt, Jr. "pins" Special Olympic Coach, Diane Haase.

MONTGOMERY

Montgomery Chapter Receives Award

Liberty Enterprises, the vocational arm of the Montgomery County Chapter of the New York State Association for Retarded Children, Inc., has been selected by the Montgomery County Chamber of Commerce as the 1986 "Industry of the Year".

The annual award was established to honor a business or industry that has made a positive economic contribution to the county's business climate.

The chapter will be honored at the chamber's annual "Industry of the Year" dinner on Saturday, December 13, 1986 at the Fulton-Montgomery Community College.

The Montgomery County Chapter employs more than 350 full and part-time staff making it one of the largest employers in the county.

President of the chamber, Michael C. McKenney, states that "Liberty, in an effort to provide employment and services to the area's disabled has become a major manufacturing center with annual sales exceeding \$3 million dollars."

SARATOGA

Saratoga County ARC's Alpha Industries Hosted a Luncheon for Area Employers Hiring the Handicapped

"People at Work" was the theme of a special luncheon gathering of the business community and ARC's Alpha Industries. Alpha, a Sheltered Workshop for persons with disabilities, provides training programs for client workers preparing for competitive employment. As part of the national "Hire the Handicapped" activities this month, Alpha's Job Placement Program proposed to establish a "networking" with businesses who are seeking client workers for their work place.

Objectives of the luncheon held on October 9th at an area restaurant were:

- To express appreciation to employers who have established outstanding programs and records of hiring people with disabilities:
- To encourage those employers who have not hired a worker with a disability to look at the abilities, not the disabilities; and
- To salute the achievements of people with disabilities who are contributing to their communities and to society through their jobs.

Special recognition was awarded to Hugo Matson, owner of four area McDonald's restaurants, who during the past year has hired several young people who were clients in Alpha's janitorial training program. Other employers recognized included:

Alpha Industries; C.B. Sports - Glens Falls & Mechanicville; Phelan Brothers Restaurant - Clifton Park; Saratoga Capital District State Park & Recreation; Gideon Putnam - Saratoga; Ramada Renaissance - Saratoga; Albany Public Market - Pyramid Mall; Saratoga National Park - Stillwater; Price Chopper - Saratoga; Moreau Lake State Park; Norstar Cleaning Service at Service Master; Headstart Volunteer Training Program and Janitronics.

ALLEGANY

Allegany ARC Sells "Angels"

Each year, Laszlo Ispanky, an internationally known sculptor, creates a sculpture of love representing a different country. The ceramic angels are made by mentally handicapped adults as part of an independent work program at the T & M Ranch in Indiantown, Florida.

The angels are presented in a gift box containing a brochure regarding the artist and the ranch. Locally, the angels are sold through the Allegany County Chapter with proceeds to benefit their many programs.

A limited edition of angels for 1986 combined with the support of Edward James Olmos (national honorary spokesman for the Angels of The World Foundation and the unsmiling police, Lt. Martin Castillo from the hit show "Miami Vice") delivering a public service announcement on television, will make Antonio an extremely collectible item for gift giving.

FULTON

Fulton ARC Holds Autumn Leaves Dinner

The Fulton County Association for Retarded Children's Lexington Foundation had everyone in the Glove City's talking and nearly everyone dancing this year when it held its annual Autumn Leaves Dinner at the Revolutionary War site, the Fort Rensselaer Club in Canajoharie. Catering and decorations were planned by the dinner committee and executed by local firms and the musicians, the Harlem Blues and Jazz Band (called by one reviewer from the Schenectady newspapers, the "East Coast version of the Preservation Hall Jazz Bank") came especially from New York City for the occasion. Greens and candles were everywhere and everyone agreed that the authentic museum-quality rooms on the first floor of the Fort were the perfect place for cocktails and later for after-dinner coffee and pastries. Over 100 patrons wore black tie or long gowns, sequins glittered and everyone enjoyed the evening which raised money to help support the work that the Fulton County Association for Retarded Children does with the children and adults of Fulton County who are retarded. Committee members are already planning next year's event scheduled for October 10th at the Hall of Springs in Saratoga.



Assemblyman and Mrs. Glenn Harris, two of the evening's Honorary Chairpersons were among the many who enjoyed the music at the Fulton County Association for Retarded Children's Autumn Dinner.

CLINTON

Clinton County Chapter Awarded Transitional Employment Program Grant

The Transitional Employment Program (TEP) of Clinton County ARC is funded through a Day Services Initiative Grant by OMRDD. The program began August 14, 1986 and is projected through June 30, 1987. This program has enabled Champlain Valley Industries, the Vocational Service Division of the Clinton County ARC to implement social work and long-term follow-up services. These services were designed to provide clients who have been competitively employed or are being considered for competitive employment with the necessary life support services to ensure their permanent and successful job placements.

Transportation was found to be the number one obstacle for employment of "job ready" clients. The TEP provides temporary transportation subsidies to allow clients to be placed until permanent cost reasonable arrangements can be made. A main goal of TEP is to maximize the number of clients placed in competitive employment and the length of time they are competitively employed. The clients who are placed are provided with support services through this grant. These clients are expected to earn at least minimum wage.

Many clients are currently benefiting from this program. Support Services consist of nutritional counseling, money management, financial assistance, family assistance, companionship, driver's license, recreational services, additional work hours/higher wages, better medical care/mental health, transportation and adult basic education. Social work services also involve locating clients who were once competitively employed, but are now un-employed. Support in daily living skills and community awareness may enable these clients to become re-employed and lead to a successful job placement.

Thus far, Champlain Valley Industries feels that the TEP services have already proven to be invaluable and looks forward to its continuation.



Clinton County Chapter opens its first Intermediate Care Facility (ICF) in October of this year.

Committee Goals continued from page 10

- Develop article on Regents Action Plan and its implication on special education. This article will not only be printed in Edu-Letter but will be used as a reprint.
- B) Conduct two to three regional workshops using the "theme" approach. The committee will decide upon a topic that they feel is worthy of focusing upon at workshops around the state. This topic will then become the theme of all workshops conducted under the auspices of the Education Committee including the convention workshop during 1987. The theme will be selected at their meeting at the convention.
- C) Continue to develop education liaisons/ committees within various chapters and to provide on-going technical assistance.

Area:

Guardianship

- A) To complete the development of an audiovisual presentation for dissemination to assure consistency of information regarding the Association's Guardianship Program.
- B) To ensure that all chapters have active Guardianship Committees.
- C) To ensure viability of the NYSARC Guardianship Program, there will be exploration and examination of alternative service models for guardianship programs and potential funding sources.
- D) To review and revise the NYSARC Policies and procedures on Guardianship in order to be consistent with the goals stated above.

Area:

Prevention

- A) Develop a bibliography of Prevention of MR/DD related materials for NYSARC library.
- B) Implement Prevention Committees in a minimum of five (5) NYSARC chapters.
- C) Develop a maximum of three public service Announcements (PSAs) for radio and television regarding prevention of MR/DD efforts.
- D) Initiate interagency coordination of prevention of MR/DD efforts.

Area:

Public Information

- A) Conduct three meetings/workshops for Chapter Public Information Resource Group.
- B) Expand participation of Chapter Public Information Resource Group to include a minimum of 30 chapters on an active basis.
- C) Foster chapter participation by holding a minimum of two workshop/meetings in areas not readily accessible to Albany.
- D) Distribute a minimum of two informational packets to chapters.
- E) Implement statewide special event for chapter participation.

- F) Organize and conduct workshop for 1987 NYSARC convention.
- G) Provide and staff Public Information exhibit at 1987 convention.
- H) Develop access for chapters to specialists within resource group for assistance in communications and fundraising needs.
- I) Provide help to develop "Our Children's Voice" as an advertising medium.

Area:

Supplementary Recreation and Special Olympics

- A) Provide a minimum of two regional workshops on innovative recreational programs and special olympics.
- B) Develop and distribute a minimum of two informational bulletins regarding recreational programs in the New York Special Olympics (NYSO) and NYSARC newsletters.
- C) Establish a section in the NYSARC library on recreation and special olympics.
- D) Conduct a workshop at the 1987 convention in addition to having an exhibit booth.

Area:

Youth

- A) Formalize organizational structure of Y.O.U.T.H. ARC.
- B) Provide technical assistance to local chapter regarding Y.O.U.T.H. programs and activities.
- C) Produce a new brochure on Y.O.U.T.H. to be distributed to all interested chapters.
- D) Produce a short newsletter to be provided to Y.O.U.T.H. groups at least two times a year.
- E) Conduct a minimum of two regional workshops in areas with little or no involvement in youth related activities.
- F) Revise Y.O.U.T.H. ARC organizational manual to meet the needs of todays program.
- G) Formalize chapter Y.O.U.T.H. advisory group which will meet once a year.

Recognized at Annual Convention

Each year, Chapters throughout New York State are encouraged to recognize an individual, corporation or business in their communities that have demonstrated outstanding support and assistance in providing services and job opportunities to individuals who are mentally retarded and developmentally disabled.

After the chapters submit their nominations for consideration, the Scholarship and Awards Committee makes a determination as to the winner basing its decision on the information provided to its members by the individual chapters that participated in the competition.

As reported in this issue of OCV, the 1986 Employer of the Year Award went to Mr. Craig Harman, Director of Residential Dining Services at Syracuse University. In addition to the Employer of the Year Award, ten other businesses and individuals who have contributed to enriching the personal growth of persons who are mentally retarded and developmentally disabled and have helped to foster their acceptance in their respective communities were recognized at

the Awards Luncheon at the recently held NYSARC Annual Convention.

Certificates of Appreciation went to the following businesses and companies:

- 1. Biel's Microfilm Nominated by Erie County Chapter
- 2. Pepsi-Cola Bottling Corporation Nominated by Genesee County Chapter
- 3. Ponderosa Steakhouse Nominated by Herkimer County Chapter
- Cazenovia Greenhouse/Charles Pace,
 Owner Nominated by Madison County
 Chapter
- 5. Skyview Graphics, Inc. Nominated by Nassau County Chapter
- 6. Pavion Ltd. Nominated by Rockland County Chapter
- 7. Harva Company Nominated by Schoharie County Chapter
- 8. Pines Hotel Nominated by Sullivan County Chapter
- Campus Auxiliary Services Nominated by Ulster County Chapter
- 10. Saga Nominated by Westchester County Chapter

Congratulations to these businesses on a job well done.

■

Craig Harman Recipient of 1986 Employer of the Year Award

Craig Harman, the New York State ARC's 1986 Employer of the Year, has demonstrated his commitment to employment opportunities for mentally retarded persons in a variety of ways.

In his position as Director of Residential Dining Services and Commissary Operations at Syracuse University, Mr. Harman has supported the hiring of mentally retarded persons for competitive jobs. During 1985, Monarch Industries, a division of the Onon-

daga County Chapter, placed two persons into non-food handling jobs with Residential Dining Services. They are permanent employees and members of Local 200 Service Workers International Union.

Mr. Harman feels very positive about the work of these employees and other disabled workers hired by his division. "We are very happy with their performance," he told *Our Children's Voice*. "We've fou:.. that they are very reliable employees who pull their own weight. Once they are trained in a job, they do very well."

One reason for the success of the Monarch Workers has been the cooperation between Mr. Harman and his staff and the Monarch Industries community placement staff. After a worker is placed into a competitive job, a lot of follow-up work is done to ensure that the worker succeeds in the job.

In addition, Monarch and Residential Dining Services are collaborating on a training program to further facilitate the placement process. Monarch workers ready for competitive work have received training in food handling at a dining hall.

Lastly, Mr. Harman has served on the advisory board of Projects With Industry (PWI), a group that brings together representatives of Syracuse area rehabilitative agencies and businesses to discuss the placement of disabled persons. He provided assistance when PWI, Monarch and other agencies were putting together a career day for persons who are mentally retarded. Syracuse University was a co-host for the event.

In reflecting on the Employer of the Year award, Craig Harman commented that "I'm pleased and flattered. One thing I want to emphasize is that this has been a team effort. A lot of credit goes to our dining hall managers and other staff."



Craig Harmon (center) proudly displays a plaque honoring him as this year's Employer of the Year, presented to him by David B. Lettman (left) and Scholarship and Award's Chairperson, Kay R. Nogaj (right).



Jan Gile and David Lewis enjoying the cocktail party.



Kay Nogaj, chairperson of the Scholarship and Awards Committee presents the Employer of the Year Award at the Saturday Luncheon.



Participants of the Special Olympics workshop.

Recommended Guidelines for the Appropriate and Humane Placement of Individuals Adopted by Board of Governors

The Board of Governors at their October 1985 meeting requested the Developmental Center Committee to "take a realistic look at the declining population of Developmental Centers to Ascertain an appropriate response to the 1986-1991 OMRDD Program-Capital Plan and to offer guidelines for acceptable and human placement."

The Chairperson of the NYSARC, Inc. Developmental Center Committee, Bernice Volaski, held two meetings and at the meeting of July 25, 1986 a paper entitled, "1986-1991 OMRDD Program-Capital Plan - Summary Report on Developmental Centers" was presented and reviewed. The position paper was reviewed and moved to the Board of Governors by the Executive Committee.

The Board of Governors at their meeting held on October 26, 1986 adopted the recommended guidelines. The Board of Governors stated that "Upon review of the OMRDD 1986-1991 Program-Capital Plan which explains anticipated developmental center capital needs and projects, the movement of people currently residing at each center and the placement of persons between New York State's developmental centers, the following guidelines are strongly recommended by the New York State Association for Retarded Children, as benchmarks for future policy decisions by OMRDD for the appropriate humane placement of individuals:"

- The Association urges OMRDD to carefully plan the future use of developmental center buildings which are reconfigured or displaced by the development of SRUs so as not to allow co-location of persons who are mentally retarded/developmentally disabled with those persons who are in custody of the criminal justice system or other negative external influences.
- The Association recommends that the development of SRUs and their operation adhere to the language included in the 1986-87 New York State Budget so as to improve the living conditions and opportunities of current developmental center residents beyond that which is evident in existing New York State institutions.
- The Association recommends that the movement of people from developmental centers to alternative placements be made according to the client's individual needs such that placement into a less restrictive environment is assured.
- 4. The Association recognizes that placements ideally should be in the geographical area of next to kin or guardian but recommends that the programmatic needs of the individual take precedence in placement decisions.
- 5. The Association recommends that movement of clients between developmental

centers be specifically noted to parents and/or guardians and correspondents six months in advance of transfer. It is further recommended that this notification include: who, what, when, why and how.

- 6. The Association recommends that OMRDD develop a publication describing the process of client placement from developmental centers as well as any appeal process, and that such publication be distributed to parents, guardians or other interested persons.
- 7. The Association strongly recommends the Commission on Quality of Care and the Mental Hygiene Legal Service to receive copies of all six month notifications on transfer and placement.
- 8. The Association recommends that OMRDD support the passage of S.8857 (A.11483A), or subsequent bills, which establish an on-site client advocate known as an ombudsman to work with parents, guardians and other interested persons in attempting to resolve their concerns regarding the daily care and treatment rendered to individuals residing in developmental centers.
- The Association recommends MHLS and the D.C. ombudsman attend meetings with the D.C. director and/or his designated staff on all transfer plans as well as at the receiving residential unit for persons without parents or guardians.
- 10. The Association recommends the transfer/placement plans of all residents from downstate facilities to upstate D.C.'s be reviewed by the respective Board of Visitors for comment and recommendation.
- 11. The Association recommends that the developmental center director have the on-going responsibility to inform the Board of Visitors on census projections at regular intervals to ascertain recommendations on resource needs and limitations. Additionally, recommendation is made that specific written reports from the director on special needs populations to reside or currently residing at each center be forthcoming to each Board of Visitor member for their recommendation. This includes elderly persons, persons with autism, behavioral problems, criminal involvement, AIDS victims, etc.
- 12. The Association recommends that the Board of Visitors be assured of updated reports from respective developmental center directors on the status of retrofitted and reconfigured buildings and their use. Further, it is recommended

President Reagan Signs Education of the Handicapped Act

Special Education programs for 3 to 5 year olds will become mandatory within four years.

On October 8, 1986, President Ronald Reagan aboard Air Force One, signed S.2294 which is a bill reauthorizing the Education of the Handicapped Act (EHA) for five years.

The bill reauthorizes existing EHA discretionary programs and amends P.L. 94-142, the Education for all Handicapped Children Act, to include grants for states to educate handicapped children from birth to age 2 and from 3 to 5 years old.

The significance of this bill, in addition to the reauthorization of EHA, according to NYSARC Executive Director, Marc Brandt, is that "Special Education Programs for three to five year olds will become mandatory within four years".

The reauthorization of the Education of the Handicapped Act, signed by the President, would fund programs for preschoolers who are handicapped at a level of \$180 million so that states could provide mandated special education services for children ages 3 to 5. Programs for children from birth to two would be funded at \$50 million.

NYSARC Calls National NRE Meeting

NYSARC took the lead in calling a national meeting in "Least Restrictive Environment" LRE. This meeting was held in Washington, D.C. on October 16 and 17, 1986.

Having come to the realization last year, that New York State is in serious violation regarding the placement of students with handicapping conditions into the LRE, NYSARC filed a complaint with the Office of Special Education and Rehabilitative Services (OSERS) of the U.S. Department of Education charging the N.Y.S. Education Department with having failed to appropriately implement LRE. In gathering documentation to be included in the complaint, it was determined that the requirements found in P.L. 94-142 under LRE not only were not being implemented in New York but in fact all over the country.

In speaking with various representatives of national and state organizations, the feedback was that LRE was not being enforced not because the law or the regulations were not clear enough but that OSERS had failed to monitor and/or implement the law appropriately.

Some of the issues that were raised during this meeting were that in many states, the manner in which special education is funded, act as fiscal disincentives to placing children in the LRE; that OSERS had no formal complaint policy, (that is, what needs to be included in such a complaint, what constitutes a valid complaint, and what are the same time lines); that the way in which data is collected and provided to OSERS does not allow for documenting where children are being educated (in segregated or nonsegregated settings); in regard to reviewing and approval of state plans, the question was raised as to whether there was any coordination between those reviewing, those doing the monitoring and those handling complaints.



Dr. Bellamy discussing the issue of least restrictive environment from the perspective of the U.S. Department of Education. Left: Tom Bellamy, Director Office of Special Education

Programs, U.S. Dept. of Education Right: Marilyn R. Wessels Director of Advocacy Services NYSARC, Inc.

The group agreed that they would support OSERS in withholding funds to those states that were not in compliance with LRE.

A number of positive outcomes have come out of this October meeting. (1) Madeleine Will, Assistant Secretary for OSERS has agreed to develop a formal complaint process to be used when filing a complaint through her office; (2) that sometime in November a Policy Manual will be coming out of OSERS that will be provided to all state education departments for dissemination to the local districts as well as to the advocacy organizations who were in attendance, that will specify what districts must consider when placing children; and (3) the participants at the meeting unanimously voted to remain committed to the full implementation of LRE until such time that all children will be appropriately integrated into public schools.

The next meeting of this group will be in Washington in February, 1987.

that opportunity is provided for Board of Visitor comment on all developmental center capital project improvements including information on monies appropriated for such so to prompt recommendations for the allocation of monies.

The Board also requested that the above guidelines be transmitted to the Commissioner of OMRDD, the Commission on Quality of Care, the Governor, the Legislative Committees on Mental Health and Mental Retardation and to each of the Board of Visitors of the State Developmental Centers.



A beaming President, David Lettman with daughter Linda and Robert Edwards.



Bernice Volaski presents Guidelines for Humane Placement.



The Welfare League Chapter joined by Anne Kraus.



NEW PUBLICATIONS

"TIPS"

Document Available

The President's Committee on Mental Retardation in 1978 stated "Americans cannot afford to shrug off mental retardation as something largely beyond their control. Much of it is controllable through legislation, through common sense, and highly important, through greater knowledge of the problem." TIPS or "The Introduction To Prevention Strategies" is a recently written and approved document put out by NYSARC, Inc. which explains the meaning of the term prevention, explores some causes of mental retardation and suggest possible prevention strategies for the initiation of local programs.

There are over 200 known causes of mental retardation. It has been estimated that if all the scientific knowledge now available were applied, 30% of the disability of severe mental retardation and possibly even a higher percentage of mild mental retardation disability could be eliminated.

The document stresses prevention of the occurrence of future disabilities and gives practical, useful information. It is a helpful resource to agencies who wish to develop public information or want to obtain ideas for local programs.

Many ARC chapters are already involved in tertiary prevention which minimizes the long-term disability or at least mitigates some of the effects. This is accomplished through specific comprehensive community-based services for persons with mental retardation. Learn how your agency can build on this concept by exploring primary and secondary prevention strategies.

This well referenced document was prepared with the assistance of Dr. Harriett Cooper and Dr. Donald A. Snider from the New York State Institute for Basic Research in Developmental Disabilities. Please write today for your copy to the NYSARC State Office.

New SSI Publication Available

New and revised 1986 editions of Social Security Supplemental Security Income (SSI) publications are now available. The reprints have simplified language and graphics making the content more readily understandable.

The revised SSI publications are:

- SSI for Aged, Disabled and Blind People.

This booklet explains who can get SSI, the income resource limits, and how to apply. Explanation of food stamps, medicaid, and other help available to SSI recipients is also contained in the booklet.

- What You Have to Know About SSI

This publication explains what changes may affect the amount of our eligibility for checks. It tells recipients how and when to report changes and gives them other important information about receiving checks.

- A Guide to SSI

This booklet is for use by organizations that deal with SSI recipients. It gives a detailed explanation of eligibility conditions, provisions to help recipients work, payment, amounts, state services, and periodic reviews. It also explains how SSI claims are processed and briefly describes the recipients responsibilities.

Copies of the above mentioned publication can be obtained free of charge at any local Social Security Office.■

Summary of Federal Appropriations

On October 18, 1986, the 99th Congress adjourned, two weeks past the scheduled adjournment date. Any legislation not enacted into law before adjournment has expired and must be reintroduced during the 100th Congress beginning in January.

Of significance to NYSARC, the House and Senate conferees on September 30 agreed on a bill that would provide a \$19.3 billion appropriation for the U.S. Department of Education in FY 1987, approximately \$1.4 billion more than the FY 1986 post Gramm-Rudman level, and several "high priority" programs even received significantly higher increases. As an example, the handicapped education funding increased by 29 percent with the inclusion of funding for two new programs, and vocational education was increased by 8.5 percent.

The House and Senate on October 17 passed the conference agreement on the FY 1987 Budget Reconciliation Bill needed to avoid a potential Gramm-Rudman across-the-board cut. The reconciliation bill cuts approximately \$12 billion from FY 1987 spending and thus meets the Gramm-Rudman deficit target of \$144 billion for this year.

The Education of the Handicapped Act Amendments of 1986 was signed into law by the President on October 8, 1986. P.L. 99-457 reauthorizes existing handicapped education programs for five years and creates two new programs to assist handicapped children aged birth to five.

The FY 1987 Education Department appropriate bill contains \$50 million for the new early intervention program created under P.L. 99-457 to assist handicapped infants aged birth to two. States electing to participate will receive incentive grants to develop birth to two programs.

The appropriation bill also includes \$180 million in new funding for a program to provide handicapped education services to children aged three to five. States are mandated under the act to have a program for preschool handicapped children fully in place by 1991.

The House and Senate have approved and sent to the President a compromise version of H.R. 4021, the Vocational Rehabilitation Act Amendments of 1986.

The bill reauthorizes existing vocational rehabilitation programs through 1991 and authorizes a new \$25 million grant program to assist states in providing supported employment services for individuals with severe handicaps. The bill also reduces the federal share of funds provided for vocational rehabilitation programs from the current 80 percent to 75 percent by 1993.

A reauthorization of several social services programs, including Head Start, Follow Through, Community Services and Dependent Care Block Grants and the Low Income Energy Assistance program was signed into law by the President on September 30, 1986.

In Memoriam

Minna Bober Pioneer Member

On August 18, 1986 the NYSARC, Inc. lost one of its most staunchly loyal supporters and advocates. A Board of Director of the New York City Chapter, Minna Bober for more than 36 years contributed her boundless energy, commitment, and creative skills as advocate, creator, planner and consummate fundraiser for our N.Y.C. Chapter.

Minna became a member of the Association and ultimately served without interruption on the N.Y.C. ARHC's Board of Directors from 1951 to 1986.

She will be missed by all who knew her.



The Columbia County Association for Retarded Citizens recently had a ground breaking ceremony for the construction of a ten bed residence for handicapped adults in Stockport as part of COARC's expanding residential services program.

Left to right: Harvey Whitbeck, COARC's Land Search Committee; Kay Day, President COARC's

Left to right: Harvey Whitbeck, COARC's Land Search Committee; Kay Day, President COARC's Board of Directors; Carol Anderson, COARC's Executive Director; Peter Stillman, Kenneally-Stillman Associates; Raymond deRis, Architects Group.



Commission on Quality of Care Counsel, Paul Stavis, and Commissioner Irene L. Platt, review Surrogate Medical Decision making.



One of the many Convention displays.



Ed Licence make a point.

Upcoming Conferences

(1) 2nd National CEC Conference on **Effective Utilization of Technology**

January 15-17, 1987

Place:

Radisson Mark Plaza Hotel Alexandria, Virginia

For More Information Contact:

Michael M. Behrmann George Mason University 4400 University Drive Fairfax, VA 22030

(2) New York Association for the Learning Disabled Annual Conference

Theme:

"Transition - A Lifelong Process"

Date:

April 2-3, 1987

Place:

The Americana Inn Albany, New York

For More Information Contact:

NYALD

155 Washington Avenue Albany, New York 12210

(3) National Industries for the Severely Handicapped (NISH) Annual Conference

Date:

April 5-8, 1987

Place:

Albuquerque, New Mexico

(4) Young Adult Institute (YAI) 1987 National Conference

"Transitional Issues for Community Coalescence: Promoting Integration and Dignified Services for People with Developmental Disabilities'

April 29 - May 1, 1987

Place:

New York City

For More Information Contact:

460 West 34th Street

New York, New York 10001

(5) University of Alberta Conference

Theme:

"Severe and Multiple Handicaps Alternative Futures Conferences"

Date:

May 6-8, 1987

Place:

Edmonton, Alberta, Canada

For More Information Contact:

Dick Sobsey, Conference Coordinator Dept. of Educational Psychology Faculty of Education University of Alberta Edmonton, Alberta

Committee **Chairs Named** for 1987

Immediately following the 1986 NYSARC, Inc. Annual Convention, the President of the Association named the Committee Chairs for 1987. Each Committee meets at least twice a year and is charged with the responsibility of addressing the goals and objectives of the Association as adopted by the Board of Governors.

The following are the Committee Chair appointments of the President for the October 1986 to October 1987 period:

Adult Services

Dr. David Keymer

Budget & Finance

Community Residential

Services

Developmental

Center

Education Guardianship

Incident Review

Insurance & Pension

Legal

Legislative

Nominating

Prevention

Public Information

Research

Resolutions Scholarship & Awards

Supplementary Recreation

Olympics &

Parent Outreach

Ellen Maroun

Bernice Volaski

Robert Lehr

Paul H. Dhalle Dr. Irving

Caminsky Marvin Liebergot

Warren Heilbronner

Michael

Limongelli

David Essrow Joan Edwards

Robert Katz

Dr. Robert Cooke

Maryann Bryant

Kay R. Nogaj

Maythorne

Winterkorn

and Special Youth

Ad Hoc Committee/

Barbara Levitz

A Special Farewell to Shirley Valachovic

Just a few weeks prior to the October NYSARC, Inc. convention, a letter of resignation was received from the Senior Vice President and Vice President of the Northeast Region, Shirley Valachovic. The reason for the resignation was due to the fact that Shirley was getting married on October 22, 1986 and would within a short period of time after her marriage be relocating to Florida.

For over eighteen years Shirley has been active in both the Schenectady Chapter and the New York State Association. She was a past president of the Schenectady Chapter and served on its Board of Directors for eighteen years. As Senior Vice President of the State Association, she represented the Association on numerous occasions on behalf of the President.

Her highly sensitive and humanistic approach led her to be one of the most respected Board members of the Association. Since Shirley was capable of any task or responsibility, she often chaired some of the most difficult committees. She most recently

chaired the Ad Hoc Committee to Review the NYSARC, Inc. Structure and two years ago chaired the Ad Hoc Committee on Real Estate Policies.

The President of the State Association, David B. Lettman, said that "Shirley has always demonstrated her capabilities and professionalism in the highest sensitive way possible. I will miss her very much.'

The entire Association joins collectively in wishing Shirley and her husband Roger Reubelt the very best of health and happiness. New York ARC's loss is Florida's gain. Best to you.







"And the Convention will be in Syracuse next

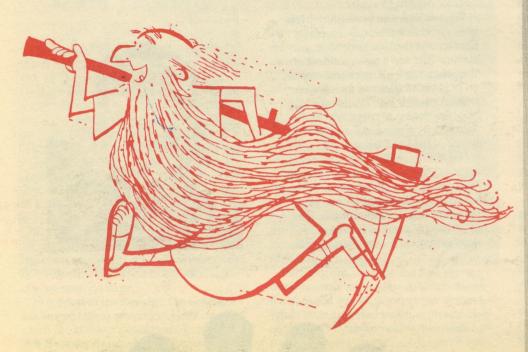


Henrietta speaks to the issue.



The Senator gets a kiss of appreciation.

Best Wishes For 1987





Special Association Dates 1987

FEBRUARY	7-14 20-21 (Fri.& Sat.)	NYSARC Statewide Media Campaign Board of Governors' Meeting Thruway House Albany, New York
MAY	1-2 (Fri.& Sat.)	Board of Governors' Meeting Thruway House Albany, New York
OCTOBER	15-18 (Thurs Sun.)	Board of Governors' Meeting and 38th Annual Convention Hotel Syracuse Syracuse, New York

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC. 393 Delaware Avenue

Delmar, New York 12054

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