

OUR Children's Voice

Retarded Children Can Be Helped

Ombudsman Bill Passes Legislature Governor Signs Bill into Law

STATE OF NEW YORK

A. 2455-A
Cal. No. 153

1987-1988 Regular Sessions

SENATE-ASSEMBLY

February 4, 1987

IN SENATE -- Introduced by Sens. SPANO, PADAVAN -- read twice and ordered printed, and when printed to be committed to the Committee on Mental Hygiene -- reported favorably from said committee, ordered to first and second report, ordered to a third reading, substituted for Assembly No. 2455, substituted, restored to third reading, amended and ordered reprinted, retaining its place in the order of third reading

IN ASSEMBLY -- Introduced by M. of A. CONNELLY -- Multi-Sponsored by M. of A. BOYLAND, COLMAN, DANIELS, DAVIS, DIAZ, GRABER, GREEN, HARENBERG, JENKINS, MCPHILLIPS, MURTAUGH -- read once and referred to the Committee on Mental Health -- passed by Assembly and delivered to the Senate, recalled from the Senate, vote reconsidered, bill amended, ordered reprinted and restored to third reading

AN ACT to amend the mental hygiene law, in relation to establishing an on-site client ombudsman in facilities operated by the office of mental retardation and developmental disabilities

... presented in Senate and Assem-

On April 23, 1987 Governor Cuomo signed into law chapter 57 of the Laws of 1987. The bill amends the Mental Hygiene Law and establishes an on-site ombudsman in each of the developmental centers operated by the Office of Mental Retardation and Developmental Disabilities.

The bill was sponsored for NYSARC in the Assembly by Assemblywoman Elizabeth Connelly and in the Senate by Senator Nicholas Spano.

During the 1986 legislative session, the Association was successful in getting the bill passed by the Assembly. The bill was held in the Senate Rules Committee and thus could not be voted upon by the full Senate. After many letters and discussion with Senator Warren Anderson's office, Senator Anderson was willing to let the bill go before the full Senate during the early part of the 1987 legislative session. The bill passed both houses unanimously.

The Association feels that the bill is of significant importance. The bill calls for an existing item in each of the state's 20 developmental centers to be used as an ombudsman. The ombudsman would provide to parents and residents of developmental centers on-site advocacy.

The need for such on-site advocacy is becoming more and more critical as five developmental centers are being closed and many others are being phased down. ■

The bill states that "The Legislature hereby finds and declares that a need exists for an individual to be available in developmental centers operated by the office of mental retardation and developmental disabilities to receive and respond to concerns, complaints, questions, inquiries and to have the ability to advocate for client needs, interests and well-being. The legislature recognizes that parents, relatives, guardians or other interested persons often do not know how or where to advocate for clients residing in developmental centers. The legislature intends to assist such persons in addressing their concerns with respect to the care and treatment of such clients by establishing the position of ombudsman in each developmental center facility listed in section 13.17 of the mental hygiene law. The legislature further declares that the ombudsman should be capable of functioning independently from the facility to which he or she is assigned and from the office of mental retardation and developmental disabilities."

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

Co-Location at Rome D.C. Rumored -- State to Close Facility Earlier Than Planned

Parents urge governor not to co-locate Rome D.C. until all residents are appropriately placed. Chapter requests NYSARC involvement.

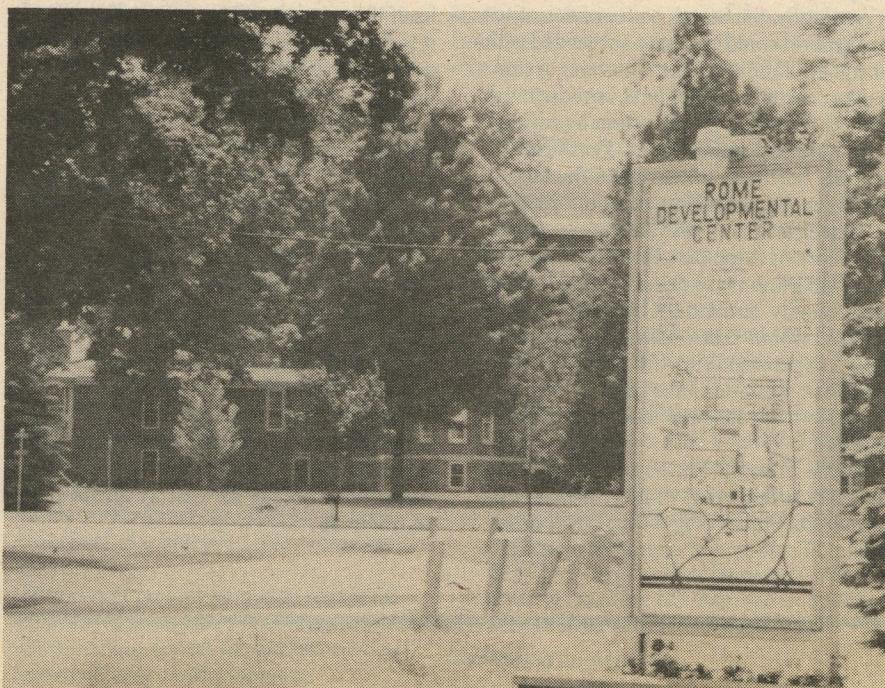
On April 10, 1987 the State Legislature and Governor Cuomo agreed on the NYS Budget for the April 1, 1987 to March 31, 1988 Fiscal period. Contained in that Budget was plans to close Rome Development Center by 1991. Within a few short weeks after the Budget was passed, rumors started to develop that Rome D.C. would be closed before the 1991 schedule and that a prison would be developed on the Rome D.C. Campus.

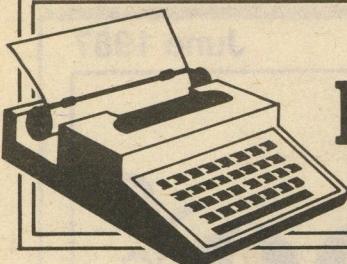
The current situation of overcrowding in State Prisons makes the campus of Rome D.C. attractive to partially resolve the prison crisis. NYSARC, Inc. has in the past and continues to vehemently oppose Co-location of developmental centers. Co-location is the establishment of programs for non-developmentally disabled populations on the grounds of developmental centers. The Association strongly feels that the establishment of such programs, commonly for the purpose of incarcerating prisoners, is highly detrimental to the care and treatment of persons with developmental disabilities.

Co-location of vulnerable persons with potentially dangerous populations not only increases the risk of bodily harm and injury to persons who are disabled but creates a substantial detriment to the therapeutic atmosphere which is essential to adequate care and treatment. The Executive Director of NYSARC, Inc., Marc N. Brandt stated in a letter to the leadership of the Legislature that "an environment which includes guards, barbedwire fences and violent criminals does not, we strongly feel, nurture the sense of security essential to the well-being of the residents of the facilities in question."

On Friday, June 5, 1987 the Deputy Secretary to the Governor for Human Services, Ms. Ilene Margolin and the Commissioner of OMRDD, Mr. Arthur Y. Webb toured Rome Developmental Center and met with the Board of Visitors, the President of the Rome D.C. chapter and two parents. The purpose of the meeting was to review the master closure plan and to discuss potential alternate uses of the Facility.

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EDITORIALS

Voluntary Salaries: A Questionable Partnership

On April 10, 1987 the Legislature enacted the final State budget for the FY 87-88 State fiscal year. Contained within the 41 billion dollar spending plan was \$7,000,000 to address the "salary issue". Though this appropriation was far short of the \$21,000,000 requested by the "Coalition for improving salaries" it represents the beginning of a solution to this most fundamental issue.

The \$7,000,000 is, however, only a beginning. The Legislature, choosing to leave out day programs, limited salary enhancements to those direct care and support staff working within residential facilities. Furthermore, provider groups all concluded that the annual increase for residential programs —estimated at an average of \$1,625.00 per FTE — still did not bring these salaries up to adequate levels.

Needless to say, there was general agreement that, unfortunately, the salary issue is still alive and well and that considerable work needs to be done before the concerns raised this issue are resolved. At the core of these concerns is the fact that in our labor intensive field, which requires staff with exceptional emotional and personal qualities, groups such as NYSARC must still compete with gas stations and fast food chains for employees. This fact underscores the seriousness of the salary issue and the imperative need to mount an on-going struggle to improve salary levels. This fact also serves to remind us that while we must compete with gas stations and fast food chains for employees we are in every other respect very different organizations. Unlike these for-profit organizations, groups such as NYSARC play an integral role in the development and implementation of state policy.

Specifically, the State's policy of deinstitutionalization could not have succeeded without the availability of the voluntary sector to either resettle D.C. clients or reduce the demand for institutionalization by caring for community-based clients. Furthermore, the State has made no secret of the fact that the most compelling reason for before the concerns raised this issue are resolved. At the core of these concerns is the fact that in our labor intensive deinstitutionalization is that quality care cannot be cost effectively rendered within these facilities. Even at an annual expense of \$90,000 per client, life within D.C.'s is often miserable at best and the subject of ceaseless federal oversight activities.

Clearly, from the State's perspective, the voluntary sector exists in large measure to assume the State's very difficult and costly burden of care and, of course, to save the

State money. In this context our struggle to enhance salaries cannot be viewed as asking for something for nothing. Rather, we are asking the State to give us the resources we need to appropriately care for persons who are mentally retarded; a task which we seek as dedicated service providers but also one which the State, for very practical reasons of its own, has asked us to perform.

The relationship between the State and voluntary sectors has often been described as a partnership. That's what it should be. Yet with anywhere from a 35% to 55% salary discrepancy remaining between State and voluntary salaries the "partnership" has become — to put it kindly — very unequal or perhaps nonexistent.

Clearly, the State's short-term ends, to run down developmental center populations as rapidly as possible and to save money, are served by this imbalance. However, the State's more enduring goals, to care effectively for those persons who cannot care for themselves, will undoubtedly suffer if this imbalance continues indefinitely.

Last year at this time OMRDD chose to pursue those "more enduring goals" Commissioner Webb recommended to the Governor that he adopt a budget for OMRDD during FY 87-88 that included a substantial salary enhancement proposal. As it turned out, had it not been for the Commissioner's proposal, there probably would have been no salary enhancement monies appropriated for FY 87-88 since the Legislature elected not to independently add such funding to the State budget.

While the Commissioner deserves out praise for his action, he also needs out encouragement since he will very shortly begin to prepare his budget request for the next State fiscal year. If recent history repeats itself this request will be critical. Therefore, it is incumbent upon all of us to take whatever opportunity we can to urge the Commissioner to recommend to the Governor a budget that further lessens the overwhelming disparity between State and voluntary salary levels and restores a public/private partnership that puts the needs of persons with mental retardation first.

A State budget for the next fiscal year that really deals with the "salary issue" can be enacted without substantially reducing the savings that have and will accrue to the State by having a strong voluntary sector. Further, whatever additional dollars are spent will be more than made up for by a renewed confidence in a government and administration that is truly interested in pursuing the "more enduring goals" that we all speak of so highly. ■

Guest Editorial

Show More Concern for Mentally Retarded

There has been a great deal of rhetoric in the newspapers about co-locating convicts on the Rome Developmental Center (RDC) Campus along with its mentally retarded citizens.

As parents of a profoundly retarded youngster who has resided at RDC for the past 19 years, we are compelled to speak out on this issue. Our position, along with all the parents we have spoken with to date, is that we are opposed to and will not tolerate prisoners living on the RDC Campus as long as one developmentally disabled citizen remains there.

Further, we are adamantly opposed to allowing the Department of Corrections to gain entry to the RDC Campus for any purpose, no matter how attractive the enticements, until every single developmentally disabled person has been appropriately placed in the community and small residential units with good programs.

On the one hand we tell society mentally retarded citizens make good neighbors, while on the other there are those in policy-making positions who, by promoting co-location, send out a conflicting message the convicts and the mentally retarded have something in common. We believe co-locating criminals and innocent mentally retarded citizens to be cruel and inhumane.

Parents spend a lifetime coping with the overwhelming problems associated with advocating for a mentally retarded child's rights. The unexpected closing of RDC has created a great deal of stress for us and now, in addition to our children becoming displaced persons, we learn about possible co-location. How much more stress are parents to endure? ■

Robert and Joan Taylor
1014 Millington Road
Schenectady

(continued from page 1)

The Director of Rome D.C. was quoted in newspapers as saying that discussions included concerns about a transitional Co-location of a prison on the Rome D.C. grounds. At that meeting the President of the Rome ARC Chapter, Mr. Joseph Parzych, told those present that the chapter is totally against Co-location of the facility.

On Sunday, June 14, 1987 State Association Executive Director, Marc N. Brandt accompanied by two State Office staff, John M. Kemmer and Susan Lyons, spoke to the Rome D.C. chapter parents. Mr. Brandt informed the chapter that NYSARC, Inc. will assist the parents "in whatever way possible to assure that all residents are appropriately placed and that all residents on the grounds of the Facility will be protected from Co-location with a prison population".

The Rome Chapter unanimously passed a resolution urging the State Association to take whatever action is necessary to assist the parents in assuring that the 617 individuals currently living at Rome D.C. will be protected against Co-location.

While at the time of the writing of this edition of OCV there has not been a definite decision to Co-locate the Rome Facility, we urge the Governor and the Legislature not to take such action. Rome D.C. is scheduled to be closed by 1991.

With proper and careful planning the Facility can be closed earlier. There is no humane reason why Co-location has to take place. ■



Ms. Joan Taylor addressing Rome D.C. Chapter

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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The President Speaks

Dear Governor Cuomo:

I am writing to you as both the parent of a mentally retarded child and the President of the New York State Association for Retarded Children, Inc.

(NYSARC). It has come to my attention that your office, in conjunction with OMRDD, has initiated talks with legislative leaders which would result in the eventual co-location of prisoners with the developmentally disabled residents of Rome Developmental Center. I must express both my very strong personal opposition and the opposition of NYSARC to any such undertaking. I am also distressed that our Association was never officially informed of the discussions concerning Rome D.C. and only learned of them by contacting your office to substantiate rumors which have persisted for the past few weeks.

Let me state that in our view the co-location of prison populations on the grounds of developmental centers, is highly detrimental to the care and treatment of persons with developmental disabilities. Co-location of vulnerable persons with potentially dangerous populations not only increases the risk of bodily harm and injury to persons who are disabled but more importantly creates a substantial detriment to the therapeutic atmosphere which is essential to adequate care and treatment. An environment which includes guards, barbed wire fences and violent criminals does not, we strongly feel, nurture the sense of security essential to the well-being of the residents of the facilities in question.

Finally, co-location with undesirable persons suggests that persons with developmental disabilities are dangerous misfits and should be forcibly separated from the rest of society. As a parent I can tell you that

this image has been shed only after a long and difficult struggle. I can also state that the prospect of renewing this struggle is a particularly painful one.

To date, the theme of your tenure in office has been "the family". Our Association will view the co-location of Rome Developmental Center with a prison population as a threat to the well-being of a significant number of New York State's family. It was only five months ago that plans were announced to close Rome and our Association as well as the parents of residents residing at Rome were told that the closure would be carried out over five years and that all placements would be made in the best interest of the individuals being placed. If plans are announced to renovate the buildings of Rome while it is still a Developmental Center, it will send a strong message of insensitivity to parents, advocates and professionals. We urge your consideration in understanding not only the legitimate concerns of the parents of Rome Developmental Center residents but the more basic issue of the human value and rights of citizens in New York State who are mentally retarded.

In conclusion, I must state the NYSARC, Inc. will do everything it can to ensure that co-location does not occur and that the well-being of those disabled persons who may be affected by such action is protected.

Thank you for your attention to this matter.

Sincerely,

David B. Lettman

David B. Lettman
President

Final 1987-88 N.Y.S. Budget Adopted

Legislature adds Budget language exercising oversight over the closure of Five Developmental Centers – Fails to increase funding for Salary Enhancements.

On April 11, 1987 the budget for the State of New York for Fiscal Year 1987-88 was agreed to by the Legislature and Governor. Though overall funding for programs serving persons with mental retardation appeared to be adequate the Legislature failed to increase funding requested by the Governor for salary enhancements. This was a major disappointment to NYSARC and the many other organizations which worked together on this issue. Nevertheless, NYSARC remains committed to working with both the Legislative and Executive Branches of government in order to obtain funding for decent salaries for our employees. Clearly, the efforts put forward by the many organizations involved with this issue over recent months have laid the foundation for ultimately resolving the salary crisis.

The following is an overview of the final state budget as enacted by the Legislature. This review contains a further elaboration of the salary issue and other matters of importance to NYSARC.

I. State Budget Highlights

Despite our disappointment over the salary issue the Legislature took significant action on a number of budget items of importance to NYSARC. These actions affected both proposed funding initiatives and budget language and were supported and actively sought by our Association. They are summarized as follows:

- Approval of \$7,000,000 recommended by the Governor to enhance the salaries of employees working for not-for-profit agencies serving persons with developmental disabilities.
- Deletion of budget language requiring that a special means test be constructed to target agencies for salary enhancements.
- Deletion of budget language requiring that voluntary agencies refinance existing mortgages to qualify for salary enhancements.
- Deletion of budget language which would have arbitrarily capped budget based fees paid to newly established ICF/MRs and Community Residences regardless of necessary costs.
- Addition of budget language requiring that salary enhancements be implemented through existing rate mechanisms.
- Deletion of budget language requiring that new projects designed after April 1, 1987 be based on prototype architectural designs developed by OMRDD.
- Addition of budget language establishing a mechanism for maintaining legislative oversight with respect to the closure of five additional D.C.'s.
- Addition of budget language establishing minimum staffing standards at non-Willowbrook class D.C.'s.
- Addition of \$3,460,000 to enhance D.C. staffing levels. This amount includes funds for 85 direct care staff to mitigate the effect of employee absenteeism at D.C.'s.
- Addition of budget language requiring that cost guidelines for community development reflect the actual "current regional" cost of development.

- An increase of building aid for the construction of special education program space from a maximum of \$2,000 per pupil to \$3,000 per pupil when such space is constructed within or connected to facilities serving non-handicapped children.

Other Legislative budget actions which are of interest to NYSARC though not necessarily supported by our Association include:

- An increase of \$1,350,000 to the budget of the State Education Department to increase the number of Occupational Therapy Assistants and Physical Therapy Assistants in facilities operated by OMRDD and OMH by training direct care staff.
- An increase of \$906,000 to restore the Youth Opportunity Program, which provides work for unemployed youth at facilities operated by OMRDD.
- An increase of \$1,000,000 for Family Support Services to fund additional respite care.
- A reduction of (\$92,000) in OMRDD's Division of Quality Assurance to reflect denial of seven new positions.
- A reduction of (\$300,000) to reflect the denial of funds requested to restore the Willowbrook Review Panel.
- An increase of \$421,000 to fund program enrichments for private schools serving adults with mental retardation.

II. Discussion of Selected Issues

The following includes a further elaboration of budget issues of critical importance to NYSARC.

1. Salary Enhancements for Voluntary Agencies Serving Persons Who Are Mentally Retarded.

Although the legislature did not approve of increased funding to enhance direct care salaries as proposed by the "Coalition for Improving Salary Levels" it did appropriate the \$7,000,000 originally requested by the Governor. In addition to eliminating certain language provisions as previously mentioned, the Legislature also made the following changes to the Governor's request:

- Limited the use of salary enhancement funding to increases in salaries for ICF/MR and Community Residence direct care and support staff.
- Added language stating that "the current region III intermediate care facility cost category standard salary level shall be, in so far as practicable, the upper level limit for all affected salaries"
- Stipulated that salary enhancements be made through "salary standards in the reimbursement methodology" for intermediate care facilities and community residences rather than through a separate means test as proposed by the Governor. Such salary standards are to be developed by OMRDD no later than August 1, 1987.
- Required that the Commissioner "continue to examine the factors that contribute to high turnover and to suggest

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Commission on Quality of Care to Conduct Hearing

The Commission on Quality of Care has announced that regional hearings will be conducted in five locations throughout New York State in the months of September and October, 1987.

The Commission has stated that the purposes of the hearings will be to:

1. provide the community at large an opportunity to provide feedback to the Commission on its progress in the ten year period since its establishment, and to help identify priority areas for the Commission's attention in the future; and
2. provide an opportunity to service recipients, advocates, family members and service providers to discuss individual concerns with staff from the various bureaus within the Commission (e.g. Client Assistance Program, Protection and Advocacy Programs, Quality Assurance Bureau, etc.)

The hearings have been tentatively planned for Buffalo on September 16, Syracuse on September 17, Albany on September 22, Nassau/Suffolk on October 7, and New York City on October 8. ■

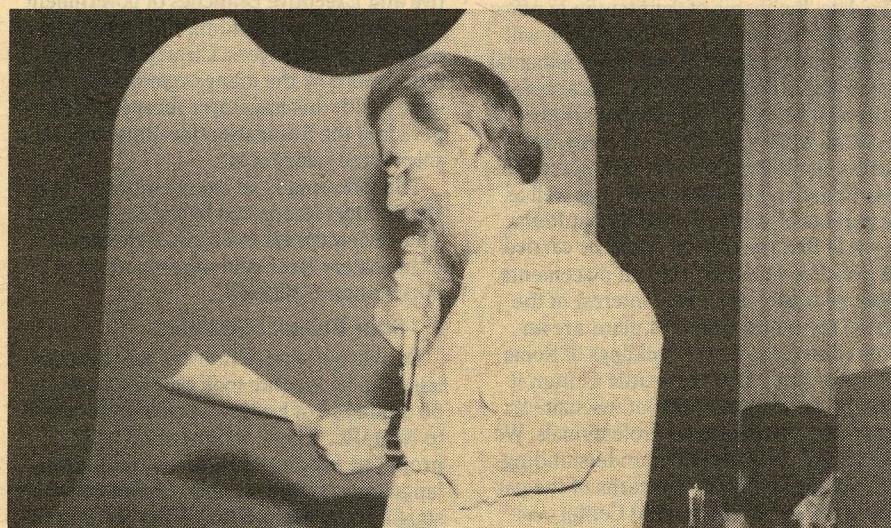
Highlights of Spring Board of Governors' Meeting

On May 1 and 2, 1987 the governing body of the NYSARC, Inc., the Board of Governors, met in Albany, New York. The 118 member governing board reviewed many issues, all of which affect the lives and well-being of persons who are mentally retarded. A summary highlighting the major actions of the Board of Governors' meeting are as follows:

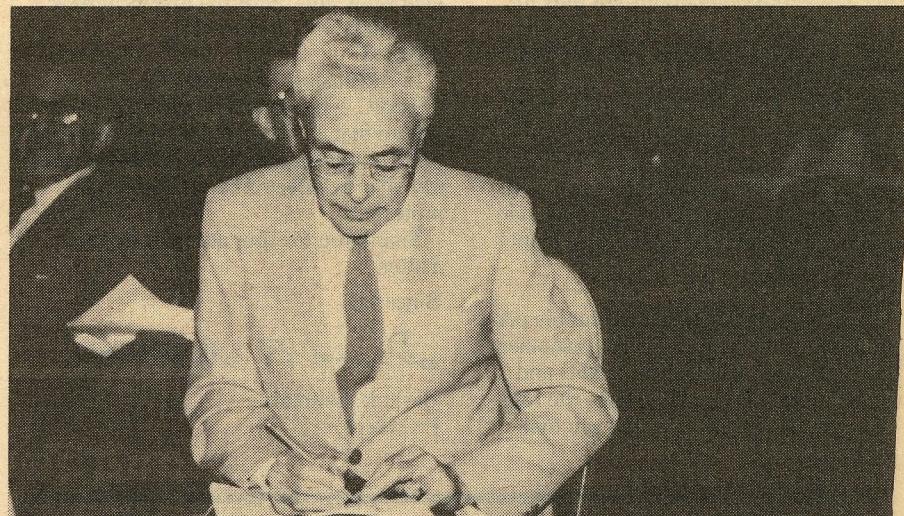
- Previewed a newly developed slide presentation depicting the work of the Association.
- Reviewed and adopted the Association's 1987-88 Budget.
- Reviewed the Final NYS Budget as it relates to programs and services to persons who are mentally retarded and developmentally disabled.
- Reviewed and approved the Second Annual NYSARC, Inc. report to the Commissioner of OMRDD on the Quality of Care in Developmental Centers: A Parental Perspective.
- Reviewed and Discussed the NYSARC, Inc. complaint filed with the Federal Office of Education regarding the educational space issue.
- Reviewed and adopted the revision to the NYSARC YOUTH Organizational Manual.
- Reviewed and adopted a change in the NYSARC Minimum Insurance Standards and adopted changes in the NYSARC Pension Policies.
- Approved an orientation program for newly elected Board of Governor members.
- Approved the supporting of proposed changes to Section 17A of the Surrogate Court Procedures Act.
- Approved a resolution authorizing the Albany County Chapter to use the Dormitory Authority for funding a new facility.
- Adopted a change in the Model Chapter By-Laws regarding composition of Board of Directors at local chapter level.
- Adopted a resolution to establish a Standing Committee on Family Support and Outreach Services. The resolution now goes before the Delegate Assembly in October. ■



The Treasurer, George G. Hirsch, presenting the Budget of the State Association for 1987-88.



Dr. Robert Lehr, Board Member from Cortland County Chapter and Chair of Education Committee presenting an update on NYSARC Federal Complaint concerning Education Space Issue.



Otsego County Chapter Board Member, Dr. Robert Porter, taking notes.



The Board of Governors voting to approve Second Annual Report on the Quality of Care in Developmental Centers.

(continued from page 3)

appropriate means of addressing staffing problems" and to report on the results of such examination to the chairmen of the legislative fiscal committees and the Director of the Budget no later than January 15, 1988.

It should also be noted that the Legislature retained the October 1, 1987 effective date originally proposed by the Governor for the salary enhancement program. Finally, it is estimated, that the salary enhancement program will increase affected salaries by an average of \$2,000 per employee in addition to funding required fringe benefit increases.

2. Closure of Five (5) Additional Developmental Centers

The Governor's announcement that five (5) additional developmental centers (Bronx, Craig, Manhattan, Newark and Rome) would be closed caused considerable concern for both parents and advocates. These concerns related to the appropriate placement of affected persons and the continued availability of essential services once facilities are finally closed.

The Legislature held hearings on this issue and in response to numerous concerns regarding the sufficiency of planning added budget language requiring that "The target date for the completion of the developmental center closings shall be subject to the development of sufficient and appropriate alternative community residential and day placements." Additionally, in order to exercise oversight over the closings, the Legislature added budget language requiring the Commissioner of OMRDD to submit quarterly reports to the Legislature. The reporting requirements of this language include the following items:

- the projected and actual number of developmental center clients placed into a community placement during the quarter;
- the projected and actual number of community clients placed during the quarter. The number of community clients shall not include those placed in Aging-Out or Special Ed beds;
- the projected and actual number of developmental center clients placed in state operated and voluntary operated residential facilities;
- the development of programs intended to address the special needs of the medically frail, including continuity of care;
- the development of programs intended to address the needs of special population groups currently residing in developmental centers;
- the number of developmental center clients placed outside of the catchment area of the developmental center where they resided prior to placement, delineated by type of placement;
- the change in the number of full time equivalents in the community and institutional service programs and the actual number of employees laid off during the quarter.
- the efforts projected and underway to assist employees impacted by closure in obtaining state employment or other job opportunities. Such efforts shall include fire and safety officers;
- the schedule for actual closure of each facility; and
- the status of alternative use plans for the land and buildings to be vacated by the developmental center and the procedures by which local governments and community organizations are involved in the process. This shall be in conjunction with the commissioner of the office of general services ■

Congress Proposes Bill to Limit Liability of Volunteers

Representative John E. Porter of Illinois and Senator John Melcher of Montana have introduced bills in Congress which would encourage states to enact laws to protect those who volunteer for non-profit organizations from being held personally liable in lawsuits against the organizations they serve. The Volunteer Protection Act of 1987 (H.R. 911) would exempt members of the board of directors and other volunteers of non-profit organizations from personal civil liability in suits against the non-profit entity.

The bill calls for the withholding of one percent of Federal Social Services Block Grant Funds from States that fail to extend such protection to volunteers. At this date, the bills are pending before the House Committee on Ways and Means and the Senate Judiciary Committee. ■

Quote of the Quarter

"Caution must be exercised to ensure that programs for students with handicapping conditions are not unintentionally displaced or assigned inadequate space. Federal and State laws and regulations require that students with handicapping conditions be provided a free appropriate public education in the least restrictive environment."

Gordon M. Ambach
Commissioner of Education
Before the NYS Assembly
Task Force on the Disabled

Second Annual Report on the Quality of Care in Developmental Centers issued by NYSARC

Survey of ten Developmental Centers finds significant improvement over first report but staffing issues and individual program planning are found deficient.

At the May 1-2, 1987 Board of Governors' meeting, the Developmental Center Committee presented to the Board their report entitled, "The Second Annual Report on the Quality of Care in NYS Developmental Centers: A Parental and Advocate's Perspective." From March 1984 to April 1985, the NYSARC, Inc. conducted its first annual survey on the quality of care in developmental centers. This effort culminated in a report which was submitted to the Commissioner of OMRDD in June of 1985. The first report produced a number of concerns and recommendations. It was the feeling of the Developmental Center Committee and the Board of Governors that the survey should be conducted on an annual basis in order to assure that the results and recommendations were being addressed.

The report was designed to reflect the parents, relatives, advocates and in the case of Syracuse Developmental Center, the consumers' collective opinions on qualitative aspects of care being rendered. The opinions were based on personal experiences and observations of the advocate or the resident's own involvement with the quality of life in developmental centers.

The study began with the development of a survey instrument divided into five (5) categories with a total of 30 specific questions. The survey instrument was written by the NYSARC Developmental Center Committee around areas of noted concern, those being: (1) staffing, (2) living conditions, (3) program, (4) food and clothing, and (5) medical and dental. Within each of these categories related questions were grouped.

The survey was then sent to ARC developmental center chapter presidents and presidents of non-ARC groups. The survey was then distributed to parents, relatives and advocates of persons living in developmental centers.

After the collection of all the individual survey responses by the chapter president or parent group, each president was instructed to hold a Board meeting for the purpose of discussing the chapter or group's response. Chapter and group presidents were then asked to write the summary report and send it with the individual survey responses to the NYSARC State Office. The total process for data collections took approximately five months from the beginning of November 1986 to the middle of March 1987.

Of the five categories explored, the area of staffing was most often commented upon. Themes of inadequate staffing, that is the number of staff on the living units and on evenings and weekends, thread through most of the developmental centers reporting. Across all developmental centers, living conditions in terms of cleanliness, homelike environment and safety and security categorically rated as much improved. Most centers were rated as adequate in these areas. In the areas of repairs, linens, availability of equipment and humidifiers, and physically accessible environment, the ratings were widely mixed in terms of adequacy, inadequacy, marginality or not knowing.

Categorically the program area had a diverse range of responses. Trends were not

easily identified in this instance, except for recreational programming being reported as uniformly inadequate. It's interesting to note that parents state that they know less about the actual Individual Program Plan (IPP) or Individual Education Plan (IEP) for their son or daughter. Comments focused on observable activities instead.

The area of food and clothing received much attention from parents. Perhaps this is because the items most indicative of quality care are often the most basic of the human condition. The areas of appealing food, adequate staff and time for meals, adequate staff time for clothes shopping, lost clothing and laundered clothing, accountability of personal items and adaptive clothing were largely rated as inadequate to marginal. Areas showing substantial improvement were (1) more appropriate dining rooms and, (2) age appropriate clothing. These areas were rated overall marginal to adequate.

The medical and dental category showed remarkable improvement overall from the 1985 NYSARC report. The report showed the ratings in the majority of cases indicated marginal to adequate functioning with only a few inadequacies noted. Three out of five noted inadequacy ratings dealt with community hospital relations which were described mostly as external to the developmental center problem.

From the findings of the survey the Board of Governors adopted four recommendations relating to the quality of care in developmental centers. The recommendations are:

1. It is recommended that OMRDD establish a time-limited statewide task force of parents, advocates, the anticipated ombudsman positions and appropriate administrative personnel to look into ways of improving problems of staffing, food, clothing and program issues at developmental centers as identified by this report.
2. It is recommended that OMRDD report to the Legislature on developmental center staffing by conducting an updated study on staffing allocation, deployment and personnel issues which are suspected as causing deficient staffing although legislative mandates may indicate adequacy in this area.
3. It is recommended that OMRDD's Public Information Office and its Education and Training Division establish public information material and training geared to educating medical professionals both in community hospitals and at large.
4. It is recommended that the Commissioner of OMRDD and the Legislature hold public hearings when developmental centers are in the planning stage for phasing down client populations, either for purpose of closing the developmental center or utilizing parts of buildings and grounds for other purposes.

The Board of Governors unanimously adopted the report and authorized the transmitting of the report to OMRDD, the Governor and the Mental Hygiene Committees of the Legislature. ■

GUEST COMMENTARY

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

Speech to Rehabilitation Workshop Marketing Association, May 28, 1987

Delivered by Lieutenant Governor Stan Lundine

The Lieutenant Governor of NYS, the Honorable Stan Lundine on May 28, 1987 delivered a Keynote address to the Rehabilitation Workshop Marketing Association. In his remarks the Lieutenant Governor emphasized the role and importance of sheltered workshops. The following was his address.

I want to congratulate you, first of all, for forming the Rehabilitation Workshop Marketing Association just seven months ago.

I'm honored that you chose me to be the keynote speaker for your first annual convention.

This is a group that's been needed for a long time, and I hope you'll be very effective in helping the disabled help themselves with jobs.

John Halvorsen has some ambitious goals for you to aim for, and I think his leadership will steer you in the right direction.

Your motto, "That Each Shall Have Work," really says it all.

Many disabled people are capable of holding down jobs, and are eager to do so.

Often, they turn out to be better employees — with less absenteeism and more dedication — than workers without disabilities.

To deny them the opportunity to work is simply wrong.

Wrong because it deprives the disabled of jobs they so badly need, and wrong because it deprives our economy of the valuable contributions they can make.

Without jobs, the disabled have no choice but to live entirely on public assistance benefits.

With jobs — even at the low-end of the payscale — the disabled can become at least partially self-sufficient, cutting the amount of money taxpayers spend to help care for them.

And with jobs, the disabled have something more, something at least as important as money.

They have a greater feeling of self-worth, a greater feeling of fitting in with the rest of society.

The disabled suffer enough without our adding to their suffering. To set up barriers that keep them from finding jobs they are perfectly qualified to perform is an act of senseless and needless cruelty, and of unjustified discrimination.

The barriers go up because employers concentrate so much on what the disabled CAN'T do that they overlook what the disabled CAN do.

The disabled are well aware of how much they can handle in a job. No one is arguing that they should be thrown into situations that are more than they can handle.

But I join with you in arguing that there are many, many jobs that the disabled can do — if only businesses will give them the opportunity.

You know this from first-hand experience. You see it every day when the disabled employees in your workshops prove again and again that they can do good work.

Just as it is wrong to discriminate against blacks, or Jews, or women, or other groups based on race, or religion or sex, it is wrong to build a wall of prejudice around the disabled.

We have a duty to make sure that the disabled never feel that they are somehow second-class citizens.

Like other New Yorkers, they must be given the opportunity to reach their fullest potential in the job market. It is their right.

Your group estimates that workshops employ more than 25,000 disabled New Yorkers around the state, and estimates that the workshops have a gross income of about a half-billion dollars a year.

This makes the disabled a significant part of the state's economy.

But the significance is unknown to most New Yorkers.

Part of your job is to let more people — especially people in business — know about the importance of the contribution disabled workers make.

Working for not much more than the minimum wage, the disabled perform unskilled and semi-skilled tasks — such as stuffing envelopes, sorting goods and simple assembly work — that might otherwise go to low-paid workers in foreign countries.

The non-disabled in this country often find such jobs boring and unattractive. The jobs often have a high employee turnover rate, and sometimes aren't easily filled.

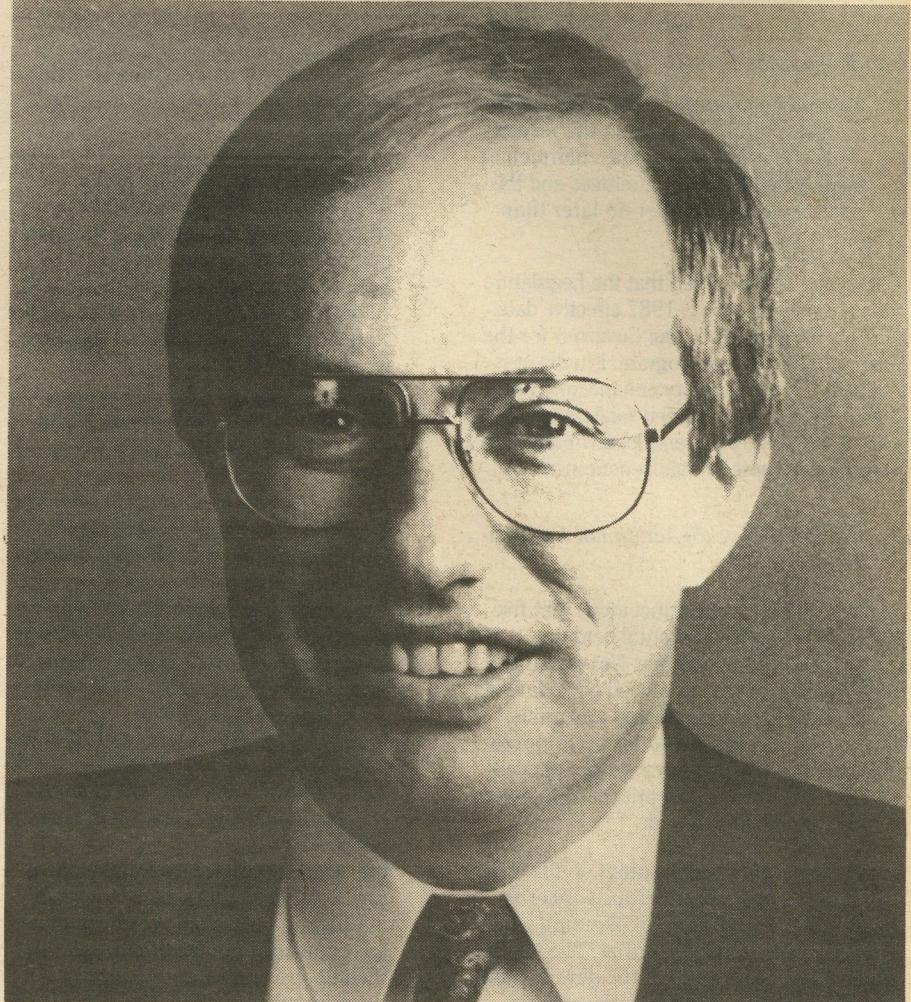
But for the disabled, long-accustomed to being turned down for work, the jobs are a godsend. They do everything in their power to hold onto the jobs and do good work.

In the Capitol Building where I work, the legislative messengers service has for years relied primarily on mentally retarded workers to serve as messengers.

Those messengers know the layout of the Capitol and the Legislative Office Building like the back of their hands, and do an outstanding job.

While visitors often get lost in the maze of corridors, the messengers always manage to make their deliveries of letters and documents and memos.

Without the service, legislators and their staffs would have a lot harder time communicating with each other and doing the work of government.



I want you to know that the Cuomo administration is just as eager as you are to help disabled workers.

Laws dealing with handicapped parking, Braille markings on elevators and similar aids to the disabled all make it easier for them to hold jobs.

Just as it is wrong to discriminate against blacks, or Jews, or women, or other groups based on race, or religion or sex, it is wrong to build a wall of prejudice around the disabled.

The Division of Marketing, Outreach and Placement in the Office of Vocational Rehabilitation works hard to help you achieve your goals.

Our proposal to establish an independent Office of Rehabilitation Services within the executive branch of government is designed to improve and enhance the delivery of vocational and other rehabilitation services to the disabled.

And of course, our wide-ranging program to aid business in the state also benefits workshops for the disabled that try to sell goods and services to those business.

Just last month, the governor signed into law a measure that will cut personal income

taxes by \$11 billion in the next four years — the largest tax cut in the state's history.

This tax cut will help keep business in our state, help attract new business and help businesses expand. As a result, you will have more opportunity to deal with them.

We believe that our approach of tax reduction, coupled with balanced budgets and regulatory relief, is the best way to create a favorable environment for investment.

In addition, we are aiding our economy by the governor's decision to make education his top priority.

Our education programs cover all children — the disabled as well as the non-disabled.

You can be sure that disabled youngsters will get the best special education we can provide, to ready them in later years for entry into the workforce and to help them live lives that are as full as possible.

We firmly believe that special education is a right — not a privilege.

All of you here today face an ambitious task.

Just as the loss of manufacturing jobs has hurt other workers, it has deprived disabled workers of jobs.

Your challenge is to emphasize a market approach — identifying a product or service that the public needs and then filling that need.

You know very well that you can't depend on businesses to simply feel sorry for your workers and send over a token amount of work.

Instead, you need first-class production facilities that can turn out high-quality goods, as well as the ability to provide first-class services, in order to attract business.

I know that the meeting you are having here will give you a chance to share your ideas and learn from each other.

I wish you luck in improving your marketing programs, and in giving more disabled New Yorkers the chance to go to work. ■

1987 SCHOLARSHIP RECIPIENTS NAMED

Once again our Association is pleased to announce the names of those individuals who were recently awarded scholarships offered by NYSARC, Inc. These individuals were selected among a group of candidates who have demonstrated outstanding achievements in their work in the field of mental retardation and/or for their distinguished academic records and excellent recommendations made by their sponsoring chapters, developmental centers and college faculty.

The Scholarship and Awards Committee of NYSARC, in conjunction with the entire Association, wishes to extend their appreciation to those chapters, schools and nominated individuals who participate in this year's scholarship program.

Our heartiest congratulations to the following recipients and our continued best wishes

Recipients of the 1987

Jonathan Weingold Scholarship

Northeast Region Barbara A. Goodspeed
Sponsoring Chapter: Saratoga

Southeast Region

Bruce P. Mortenson
Sponsoring Chapter: Sullivan

Central Region

Joseph A. Gonyea
Sponsoring Chapter: St. Lawrence

Western Region

Dennis N. Carter
Sponsoring Chapter: Monroe

Recipients of the 1987

Joseph T. Weingold Scholarship

Mary C. Von Bargen
College: State Univ. of NY at Plattsburgh
*Nancy Jean Carguello
College: State Univ. of NY at Brockport
*Michelle A. Shaw
College: State Univ. College at Buffalo
NOTE: Recipients tied for the scholarship.

Recipients of the 1987

James F. Reville Scholarship

Sue E. White
Sponsoring Chapter: Monroe
Cheryl Ann James
Sponsoring Chapter: Warren Washington

NYSARC Annual Convention

"NYSARC Advocacy - Strategies for Transition into the 90's"

October 15-18, 1987
Hotel Syracuse
Syracuse, New York

Watch for More Information in the Next
Issue of OCV!

Exceptional Artworks 1987

Each year a very special exposition of art, crafts and other fine workmanship by citizens with developmental disabilities is proudly displayed at the Empire State Plaza in Albany.

This year over a dozen NYSARC chapters participated in the "Exceptional Artworks" program which is sponsored by the New York State Office of Mental Retardation and Developmental Disabilities.

Involvement in "Exceptional Artworks" has many advantages. For the Artist, it demonstrates the high level of craftsmanship,

originality and productivity of the individuals who exhibit, and recognizes the work and fosters growth in self-esteem through the display of each individual's work in a prime exhibition area.

For the Agency Staff members, it provides an opportunity to work with individual students on artistic skills and social interaction; gives exposure to new art mediums and fosters creative exchange and collaboration with other art therapists and support staff. It also emphasizes the importance of art programs and enhances the professional status of the teachers and therapists.

And for the participating agencies, involvement presents an opportunity to exchange public awareness — fosters community support for the organization and provides an important affiliation on an extremely positive project with state and voluntary agencies throughout New York State.

Governor Mario Cuomo states that "Exceptional Artworks" enlarges and enriches our appreciation of the arts, and celebrates the cultural diversity in our state — a heritage that embraces all of our citizens" ■

Staff from the Albany Chapter take time out to pose with some unusual "friends" at the "Exceptional Artworks" exposition.



Oneida County Chapter participates in the 1987 "Exceptional Artworks"



Schenectady Chapter sells plants at the "Exceptional Artworks" exposition.



Monroe Chapter displays silk flower arrangements created by their program participants.



CHAPTER NEWS

IGE

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DUTCHESS

Dutchess ARC Presents Volunteer Awards

Each year the Association for Retarded Citizens, Dutchess County, New York presents an award to two outstanding volunteers within its organization. These awards are presented at the annual meeting, which took place on Thursday, April 9.

The awards are named for volunteers who devoted much time to the organization of ARC in its early days. The recipients are as follows: The Frank Pessia Award to Carolyn Draiss and the Mimi Stambrook award to Frank Shanny for their continued dedication to the agency. ■



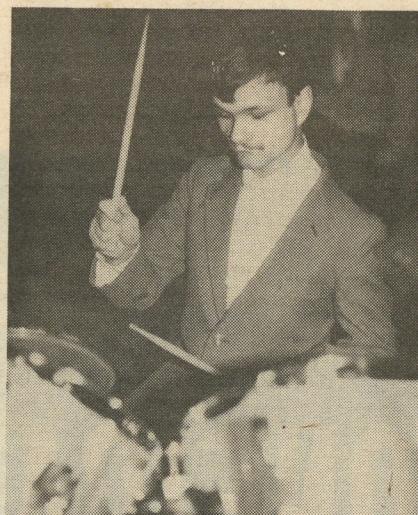
Carolyn Draiss, recipient of 1986-87 Frank Pessia Award for her volunteer work with the agency.

FULTON

Fulton Residents and Staff Enjoy "Hoedown"

Johnstown... Residents and staff of the Fulton County Association for Retarded Children Community Residence at 175 South Main Street in Gloversville sponsored a country western "Hoedown" dance for clients of the various programs sponsored by the ARC, and for the general public. Over 100 attended to enjoy music by the Renegades, directed by Staff member Ed Kafer, and decorations appropriate to the country feeling.

A special feature of the evening was a performance by David LaGrange, a Lexington resident from a home in Johnstown, who, although blind, is an excellent drummer. The idea for the dance, which they hope will be an annual special event, came from the community residence, and were coordinated by house parents Rick Morrison and Beverly Dodson. ■



David LaGrange, Fulton County ARC resident warms up the evening at the Annual Country Western Hoedown, held at the Day Treatment Building Gym in Gloversville.

SUFFOLK

Mammolito Appointed Deputy Executive Director for Administration

Joseph Mammolito has been appointed Suffolk Chapter's Deputy Executive Director for Administration. He succeeds Norma Pitcher, who retired in January after 30 years of dedicated service.

Prior to his promotion, Mammolito served four years as Controller and Chief Fiscal Administrator of the Chapter. He managed the AHRC accounting staff in the maintenance of financial records, and was responsible for the preparation of all certified financial statements and budgets in accordance with State and Federal regulations.

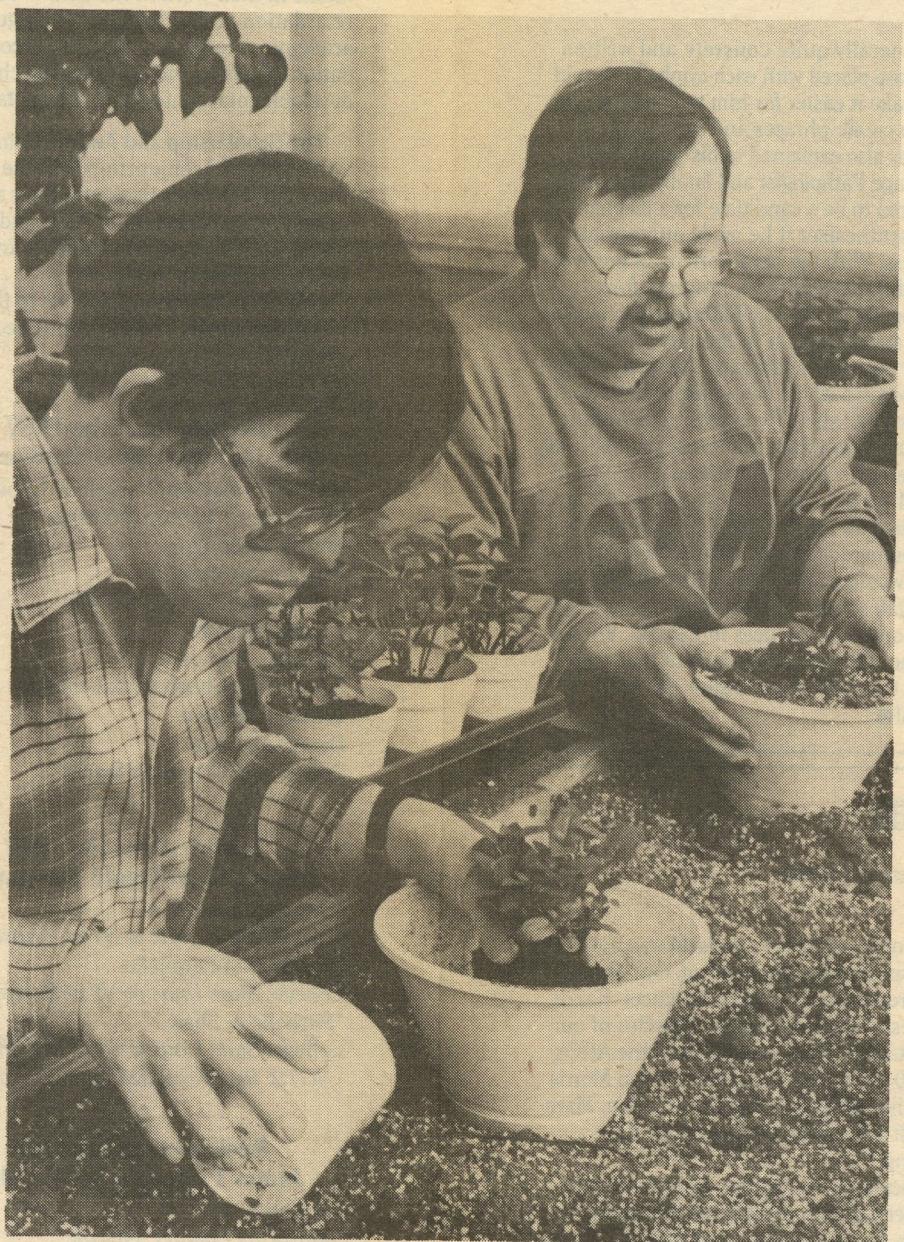
In his new position, he will continue being responsible for the Chapter's fiscal affairs as well as managing its daily operations.

"Joe brings to his new position a wealth of fiscal training and experience along with real administrative aptitude in decision making and leadership," said Bob Sansone, AHRC Executive Director.



NASSAU

Spring is a time for planting and at the Nassau AHRC horticultural program the young men were hard at work nurturing the young plants, proving again that plants and people grow with tender loving care.



ALLEGANY

First Annual Benefit Auction Big Success

The Allegany County Association for Retarded Citizens recently held its first Annual Benefit Auction on April 5, 1987. Fifty-five celebrities sent items for auction including Dyan Cannon's personally worn gold sandals and an autographed tongue depressor from Jamie Farr. Tom Selleck and Nancy Reagan's autographed photos were two of the items that brought top dollar. Over 400 merchants and individuals donated items and services bringing in a net profit of approximately

Mart, and Mr. & Mrs. David Haskins of Wellsville.

Chris Koehler, Chairman of the event commented "We could not possibly have had a successful event without the generosity of our community. Their continued support is responsible for our present and future success and growth."

We also extend our appreciation to Carl Rigby, the auctioneer and his men who all

CHEMUNG

Chemung ARC Receives Check for \$1,300

Members of Empire State Grotto, meeting in Elmira for their annual spring convention, presented a check for \$1,300 to Chemung County Association for Retarded Citizens on April 24.

The funds will purchase specialized equipment for the ARC Preschool in Elmira.

Presenting the gift was Garfield Jones, Jr. of Syracuse, President of Empire State Grotto. He was accompanied by Michael Yuskowatz of Dearborn, Mich., deputy grand monarch of the Grottoes of North America, Joseph F. Davis of Horseheads, treasurer, and Paul Sundberg of Warren, Pa., chairman of the Humanitarian Committee, Empire State Grotto, and Dennis Oldroyd, monarch of Cashmere Grotto in Elmira.

In accepting the check, Dr. Michael A. Doherty, ARC Executive Director, said the funds will be used for special therapeutic cushions called Grasshoppers plus helmets and saddles for the Preschool's Horseback Riding Program.

"One of the great problems for severely disabled children is muscle weakness," Dr. Doherty said. "Grasshopper sets allow our staff to position the child with the aid of variously shaped cushions. We're coaxing the muscles into straightening out the body's misalignment and with repeated use we tone the muscles as well."

Dr. Doherty said the riding program has therapeutic benefits as well; helping the child to sit erect and to develop a sense of balance and equilibrium.

Chemung ARC really likes the riding program because of the side benefits. "all of us know how three-year olds and five-year olds love to be around and on horses. That part of it is a real treat for our kids."

But totally unexpected, he said, was the reaction of one child classified as non-verbal. "She really identified with that horse and uttered her first word while riding."

The word?
"Whoa..." ■

DELWARE

Senator Charles Cook Gets the Ball Rolling for Delaware County Chapter's Annual Membership Drive

State Senator of District No. 40, Charles D. Cook of Delhi is the Delaware County Chapter's Honorary Membership Chairman for 1987. A letter from the Senator went out to all members asking them to join with him in renewing their membership. In addition, he offered to be photographed with members of the Chapter's Bowling Club to show how strongly he felt about "getting the ball rolling."

The first issue of the ARC Newsletter coincided with the membership drive and it was determined that the editorial thrust of the newsletter would be to develop new members. The Senator's photo and article served as the headline for the issue. All other editorial content included in the newsletter focused on different aspects of membership. Two noteworthy articles were featured in the newsletter, one was a success story by Lorri Platt, Placement Counselor, describing the success of a competitively employed client. The other was an interview by newsletter staff of the mother of a child in the chapter's Early Intervention Program. Both received rave reviews from the chapter membership. The articles not only called for membership but also gave real life examples of success that were made possible by the membership. Due to a super follow-through by those involved with the newsletter production, it was mailed on March 1 to all of the residents in Delaware County.

Overall, the response to the newsletter was very positive. At the half-way point of the drive the chapter received 432 members. The goal set by the state association for the chapter is 612 members.

The chapter wishes to extend many thanks to Senator Cook for serving as Honorary Membership Chairman and has learned a great lesson through developing such a theme newsletter. It is one that it hopes to repeat following its Fourteenth Annual Bike-A-Thon. ■



New York State Senator Charles Cook, 40th District, Honorary Membership Chairman for the Delaware County Chapter's Membership Drive "gets the ball rolling for membership" as Chapter Bowling Club members look on.

From left to right: Monte Bates, Fred Spicer, Ralph Robertson, Corinne Jones, Ed Ebmeyer (behind the Senator), Randy Palmer and Charles Burt.

CHAPTER NEWS

YATES

Yates ARC has Innovative Programs at Keuka Lake School

Last fall, Physical Therapists from the chapter's preschool program (Keuka Lake School) developed a method of staff training that has been both exciting and very useful. The staff as a whole was interested in learning more about early development. Our Physical Therapist suggested we form a study group so the staff could learn from one another. We decided to study development in periods of three months (i.e., birth to 3 months, 3-6 months, etc.). Each staff member contributed what she knew of the various aspects of development — cognition, social-emotional, language, and motor development. Disciplines represented by our staff are Psychology, Special Education, Speech Therapy, Physical Therapy, Occupational Therapy, and Nursing.

It was often difficult to visualize the movement patterns that the therapist described. The staff knew the vocabulary (flexion/extension, prone/supine) but found it difficult to formulate a picture. It was then that the Therapist had the idea of studying video-

tapes of babies in various stages of development. The staff asked friends and relatives to bring their babies in to be taped. At a separate session, the staff viewed the tapes together and discussed what they saw. They have found that this technique has helped to fine-tune their observation skills and has increased their ability to communicate across their various disciplines.

As they learn more about how children typically develop, they feel they are better prepared to set developmentally appropriate goals for children who may be experiencing difficulty in an area of development.

Mary Ann Christensen is the Physical Therapist and Mary Rzepski the Director of the Keuka Lake School, a program for children, age birth to five, with handicapping conditions. The program opened in September 1985 with an enrollment of nine and now serves twenty-five children in its various components — Home-Based Infant Program, a Toddler Program, and both a half-day and a full-day Preschool Program. ■

WESTCHESTER

Westchester ARC Receives Two Grants

Two grants from the Office of Mental Retardation make it possible for trainees in Westchester WARC's Day Training Program to experience work in industry, outside the Agency workshop. One grant, for the establishment of two work stations in industry, provides funding for a worksite coordinator, two foreman instructors and a van. As a result, there are now six trainees working under supervision at a discount apparel shop in White Plains and an additional six, with a supervisor, at Draf Industries in Bedford Hills. The second grant provides for a Mobile Work Crew, using clients from the Day Treatment Transitional Program, to do grounds maintenance on contract.

At present, five clients each form WARC's Hosmer and Katzenberg Centers are working on the grounds of the Hosmer Training Center in Mt. Kisco, with each crew working a half day. Grant money covers the cost of a grounds maintenance instructor, a van and extensive maintenance and landscaping equipment. The clients are now training at WARC's Golden Apple Greenhouse in preparation for fulfilling grounds maintenance contracts in the community.



Westchester ARC worker and store employee prepare garments for floor showing at the Apparel shop.

CHAUTAUQUA

ARC Purchases Voice Synthesizer with Help from Blue Cross/Shield

The Resource Center of Chautauqua County's Regional Communication Center (RCC) staff received FANTASTIC news this past February. After thirteen months of effort, news was received that Blue Cross/Blue Shield would fund 80% of the purchase price for a voice synthesizer, an amount close to \$2,400.

The lucky individual who soon will be "talking" is an 11 year old boy named John (not his real name), who lives with his family in Olean.

John first came to the RCC for testing in October 1984 and had been learning sign language in his home school district. The RCC Speech/Language Pathologists felt that signing was too limiting for John and very difficult for him to do, due to his fine motor problems. So, the Speech/Language Pathologists began to design a new program for John.

The first step in John's program was to introduce him to a picture/symbol board. A communication board would greatly improve John's ability to communicate with teachers, friends and family, as the picture/symbols

are generally quite concrete and written words are placed with each symbol. It would also make it easier for him to combine symbols to create phrases and sentences.

It was also explained to his school Speech/Language Pathologist and family, that John appeared to be a candidate for a mechanical voice synthesizer if he made appropriate progress. With the hard work of all involved, John did make enough progress for the RCC Speech/Language Pathologist to recommend such a system in January 1985.

The recommendation of the voice synthesizer began a whole new phase of hard work for the RCC staff. Even after appropriate documentation from numerous professionals involved with John, Blue Cross/Blue Shield denied the request. Undaunted, the RCC staff launched an appeal. After several months with numerous phone calls and letters going unanswered by Blue Cross/Blue Shield, the RCC staff sought legal assistance from Neighborhood Legal Services in Buffalo. Within one month, we receive news of their payment, thirteen months after the process began! ■

CORTLAND

Cortland County ARC Celebrates Its 20th Anniversary

In March, the Cortland County Chapter of NYSARC celebrated its 20th anniversary. There was an Open House at the ARC office and at both of our community residences. Residents helped to prepare refreshments that were served at the community residences.

We also held our annual Membership Drive in March. We are well on our way to achieving our goal of 300 members for this year! Cortland Mayor Francis Quinlan proclaimed March "Mental Retardation Awareness Month" and he also became our first member of the year.

Our 20th Anniversary Celebration and Annual Membership Dinner was held at the Cortland Holiday Inn on May 26th. Dr. William Hopkins, Associate Professor of

Psychology at SUNY Cortland was the Key-note speaker for the evening. Our Master of Ceremonies was Sam Forcucci. Karin Burgess, former Executive Director of our ARC, talked about highlights of the ARC's first 20 years. The Reverend Norman Morris gave the invocation and benediction. Marc Brandt was our special guest for the evening.

Officers elected at this meeting were: Chester Gigliuto, President; Alexander Longo, Vice-President; Kaye Kleisath, Secretary; Beverly Heath, Treasurer; Robert Lehr, Board of Governors Representative. We also presented awards to the Cortland Downtown Business Association and our Volunteer of the Year. ■



Cortland Mayor Francis Quinlan signs his check to become the first new Cortland County Chapter ARC member for 1987, as Doris Fitzpatrick, Cortland County Chapter ARC Membership Chairperson reads the Mayor's Proclamation of March as "Mental Retardation Awareness Month" for the City of Cortland.

Camp Arco - 20th season for Cortland Chapter's Summer Day Camp

Camp ARCO is the Cortland County Chapter's summer day camp for school-aged children (ages 5 through 21) with mental retardation or other developmental disabilities. Camp ARCO is also the oldest program operated by the Cortland ARC. In fact, the need for some type of meaningful recreation activities in the summer for children with mental retardation was the original impetus for the establishment of the Cortland County Chapter by parents and concerned teachers. The first Camp ARCO, held during the summer of 1967, was funded and staffed by parents and other volunteers. However, the Camp is now funded 50% through OMRDD local assistance monies, 25% by Cortland County funds and 25% through Cortland United Way and other private donations.

This year's Camp ARCO, its 20th season of continuous operation, is scheduled for July

However, the very effective structure for the daily and weekly camp activities which has evolved over many years will be continued. The general daily schedule includes all-camper activities at the beginning of each day, followed by individual group activities, break for lunch, swimming and all-camper activities at the end of the day. Each week's activities, including the weekly field trip and special events, are organized around "Health and Fitness," "Community," "Getting to Know You." One of the field trips, which has become an annual outing and is a favorite of the campers, is Special Kids Day at the Broome County Fair. The siblings of the campers are invited to attend camp for "Brother/Sister Day." The campers invite their entire families for the Open House and the end-of-camp Family Picnic and Awards Day. The camp's Mini-Olympics has a colorful opening ceremony with music and



Camp ARCO campers with their streamers in the Mini-Olympics parade of the athletes.

13th through August 14th. The Camp operates for 5 weeks, Monday through Friday, 9 a.m. - 2 p.m. each day. About 55 children of a wide range of ages and with a variety of needs are enrolled each year. Transportation is provided. The Camp's staff includes a camp administrative director, program director, speech therapist, three camp counselors (certified teachers), three assistant counselors (usually college students or teacher aides), and nine junior counselors (usually high school students). For children with severe or multiple disabilities who require one-to-one assistance, additional one-to-one assistants are hired. Parent volunteers are

streamers to accompany the parade of the athletes. The focus throughout the summer is on learning through experiencing and through fun, recreational activities.

ARC uses community facilities for the summer day camp. The camp is housed at a local elementary school, with daily swimming at two local city parks. The 3-day overnight camping experience is held at a nearby Girl Scout Camp on Song Lake in Tully, NY. The Girl Scout Camp (Camp Hoover) is used for the overnight camping experience because it has excellent facilities and is accessible. However, the ARC is working with the Cooperative Extension



Two Camp ARCO campers are hesitantly delighted with their first experience with goats and sheep on their field trip to the Broome County Fair.

also used to serve as monitors on the bus and for additional supervision on field trips. Under the direction of the new Camp Administrative Director, Stephen Yager, and new Camp Program Director, Karin Knabe, the 1987 Camp ARCO will include a stronger emphasis on outdoor and nature activities. ■

COLUMBIA

COARC officially in Stockport



A ceremonial ribbon is cut Tuesday at an open house at the Columbia County Association for Retarded Citizens new Intermediate Care Facility on Ravish Road in Stockport. From left, front, are Catherine Hurlburt, COARC director of residential services; resident Angela Ramdhammy; Kay Day, COARC board of directors president; resident Rebecca Bossert; Carol Anderson, COARC executive director; and Lisa

Gassstrom, COARC director of program operations; rear, Lawrence Berg; Columbia County director of health and community services; Stockport Supervisor, William Kosnick and Michael Mascari and Fred Finn, both of New York State Office of Mental Retardation and Developmental Disabilities. This is COARC's first new construction project. (Staff photo by Robert Ragaini) ■

STEUBEN

Lettman Honored Guest at Steuben ARC Annual Meeting

David B. Lettman, President of the New-York State Association for Retarded Children, NYSARC was the honored guest at the Steuben Association for Retarded Citizens (ARC) Annual Meeting held on Saturday, May 9th, 1987. The meeting was held at the Days Inn of Bath.

Steuben ARC's annual celebration included induction of incoming Board of Director members and special awards presentations.

Featured speaker for the evening of activities was Senator John R. Kuhl, Jr., of Hammondsport. Kuhl, a life resident of Steuben county, is a member in good stand-

ing of the New York State and Steuben Bar Associations, and a member of the American Arbitration Association. He represents the 52nd Senate District comprising Steuben, Schuyler, Chemung, Seneca, Yates and part of Ontario counties. He is Chairman of the Senate Standing committee on Agriculture, and serves on the Banks, Housing and Community Development, Social Services, Tourism, Recreation and Sports, and Transportation standing committees.

A highlight of the evening's activities were drawings for prizes as a result of a fund-raising project conducted by Steuben ARC. ■

HERKIMER

Herkimer ARC Involved in Innovative Program

Alternative Measures, an innovative program that began in Herkimer County in 1986, is a county-wide project that identifies, refers, and/or advocates for those individuals who are, or who are suspected of being, developmentally disabled in the Criminal Justice System. With the assistance of an Advisory Board, representing the Criminal Justice System, as well as local service providers, a coordinated network of services has been established. A single point of entry, known as "Alternative Measures" determines eligibility for services, offers alternatives to incarceration, and has proven its effectiveness in decreasing the return by those individuals to the Criminal Justice System.

Another component of the Alternative Measures Program, includes intensive train-

ing to the Criminal Justice professionals (including police departments, magistrates, attorneys and jail personnel.) This training sensitizes these individuals to the identification, management and special needs of persons with developmental disabilities, who become involved in this system.

With the intervention of the Alternative Measures Program, the following effects have been recognized:

1. The length of unnecessary incarceration for DD individuals has been shortened or eliminated.
2. The rate of recidivism has been reduced by the coordination of a comprehensive service delivery plan by the Alternative Measures Program. ■

Association of Cortland County on ways to fund renovations at the Cooperative Extension's 4-H Camp (Camp Owahta) so that this camp which is located within Cortland County could be used by the ARC and Cooperative Extension for integrated summer camp activities. ■

NYSARC's Response to Public Hearing on Future Directions for Preschool Children with Handicapping Conditions

On Tuesday, May 26, 1987 the Senate Education Committee and the Senate Select Committee on the Disabled held a joint public hearing on issues focusing on early intervention services for children from birth to age five who have handicapping conditions.

The purpose of the public hearing on Future Directions for Preschool Children with Handicapping Conditions was to give the Senate Committees an opportunity to evaluate the status of New York State's current educational programs for preschool children with handicapping conditions and to make possible recommendations for changes in the future.

The Executive Director of the NYSARC, Inc., Marc N. Brandt, represented the Association at the hearing. The following was the testimony given by Mr. Brandt.

My name is Marc Brandt and I am the Executive Director of the New York State Association for Retarded Children, Inc. I am here today to speak on behalf of our Association which consists of 65 chapters representing over 51,000 members. As you are well aware, our Association serves, on a daily basis, thousands of New York residents who are mentally retarded and developmentally disabled and their families in almost every county, community and developmental center. Our Association has for 38 years been advocating for the needs and rights of such persons who are mentally retarded and their families whether they are served directly by our Association or other voluntary organizations or through public programs. Currently, twenty-eight NYSARC chapters provide preschool programs and services to nearly 1,500 children.

Our Association wishes to sincerely commend the Senate Education Committee and Senate Select Committee on the Disabled for holding today's hearing. The fact that the committees are willing to take time from their busy schedules to meet with and hear the views and concerns of parents, providers and advocates is reassuring and deeply appreciated.

As previously stated in testimony before these committees, "it is heartening for us to be at a point when no one disputes the value of early intervention." Yet, the most frustrating problem facing our Association is the lack of a state mandated early intervention program and the lack of consistency and comparability of programs and services statewide for parents and preschoolers due to the lack of such a mandate. What could be more frustrating to parent and child than to move from one county of New York State to another, only to find that in the county of their new home, transportation, for example, does not include an aide or matron on the bus to protect the child or to assist the child on and off the bus, or that summer school is not available because all the classrooms are filled; or the child has regressed because the new classroom has fewer instructional personnel.

Within just a few short weeks, the Governor must make a very important decision as to whether or not to opt into the grant programs this year offered under P.L. 99-457. While it may be premature to advocate for New York State's participation in this new federal preschool program until such time

as detailed federal regulations are promulgated and the full impact of participation can be evaluated, this decision should not be based solely upon budgetary considerations. Our Association which historically advocated and fought very hard for the enactment of the P.L. 94-142 Education for all Handicapped Children Act recognizes and philosophically agrees with the principles embodied in P.L. 99-457. We believe that all handicapped children are eligible for a free and appropriate education. We believe that the procedural safeguards which are available to parents of children 5-21 should also be available for children 0-5 years of age. We believe that there should be a single state agency which is accountable for the funding and oversight of all education programs, not only for children 3-5 and 5-21 but also to include children from birth to age two. We believe that these should be the overriding factors to consider when evaluating whether or not New York State should opt into the grant programs offered under P.L. 99-457.

Quite frankly, as a citizen of New York State, I am deeply concerned that our state may ultimately extend these protections to handicapped children 0-5 and their parents "under the federal gun." While there is no question that making early intervention programs and services free and appropriate under the law will have a budgetary impact, the human cost for those children and their parents who cannot obtain services or the appropriate services and who must wait precious years in order to be guaranteed appropriate services under the law is immeasurable.

This is not to say, however, that NYSARC advocates for a radical overhaul of the current early intervention service system which has been established. On the contrary, I believe New York State contains many of the finest programs and services available to children age 0-5. Our Association wants nothing more than to assure the preservation of exemplary services already in existence. However, at the same time, our Association seeks guarantees under the law that what is available in one county is available in the next, that the process through which parents attain such services for their children is the same and contains procedural safeguards and that one state agency will be held accountable for the appropriateness and availability of such services in all of New York State. The one sad fact which cannot be ignored in this state is that despite our technology and our commitment to providing excellence in service and programs to preschoolers and their families, our system is hampered and frustrated by inconsistency of interpretation and implementation of the current laws and the lack of a single entity to resolve the many disputes which arise.

The question of which "single entity" should oversee preschool services is a controversial one. However, it is NYSARC's view that the most appropriate such entity is the State Education Department. We believe that 0-5 services are essentially educational in nature. Where preschoolers require other services SED can provide the proper coordination as the lead agency.

On the subject of reform of preschool services, there is once again proposed legis-

lation, Senate 44 and Senate 311 for which we have to thank both the Senate Education Committee, the Senate Select Committee on the Disabled, Senators Donovan, Kehoe and others.

Both bills recognize the educational nature of preschool services and appropriately places those services under the auspices of SED. In reference to Senate 311, NYSARC sincerely appreciates the recognition accorded by this bill to the importance and quality of private programs and services provided by our chapters and many other fine organizations. We agree that whatever changes eventually take place regarding the 0-5 population, the knowledge, expertise and input of private providers is essential to the success and quality of early intervention programs and services.

Senate 311 also provides for a very appropriate focus on the importance of primary family support services such as family counseling, family educational services and home management assistance while the current system requires a much more child-centered educational focus.

However, it appears that Senate 311, if signed into law, would have the effect of creating two parallel service systems both under the auspices of the State Education Department but one initiated through the Committees on Special Education and one initiated through newly created Early Intervention Committees appointed by the Board of Directors of the program provider. While Senate 311 embodies laudable philosophical principles, the establishment of early intervention committees will both duplicate the CSE process and complicate the transition out of preschool for many children.

Although Senate 311 recognizes the educational nature of services to preschool children, it is, as I have described, unnecessarily complicated. Senate 44, on the other hand, offers a more straight forward approach to structuring preschool services under the auspices of the State Education Department. I recommend building on the approach offered by this legislation by incorporating into it the best aspects of Senate 311 and by making certain technical changes.

For instance, the September 1, 1987 effective date for this legislation is unrealistic. This is critical. Assuming all of us have learned from our recent and current experience in implementing the 12-month education law, ample time must be given for regional training of the CSE's as to their new responsibilities. Additionally, time for local coordination and communication with parents, providers and CSE's must also be provided so as to bridge the gap during the transition period.

The problem of instituting any new system affecting vital services to many children and their families has been dramatically illustrated by the enactment of Chapter 683 of the Laws of 1986. I believe this is an unfortunate illustration of what happens to so many parents when they are for the first time confronted with a whole new set of rules governing educational programs and services for their children who have just turned age five. Again, with respect to the approach contained in Senate 311, why must we build separate systems under one

state agency which will continue to confuse and frustrate parents who must weave their way through each system to assure their handicapped child receives appropriate services? Children birth to age 21 can and should receive free and appropriate educational and related services through the CSE and under the auspices of one state agency — the State Education Department. Our Association supports the passage of Senate 44 as an intermediate step toward the eventual accomplishment of this.

Whichever approach is used to achieve a statewide and uniform system of preschool services it is critical to retain and enhance the best parts of the existing system. Thus, I want to state here that the quality and expertise of private providers can and should be recognized irrespective of whatever systemic changes take place. Historically, our Association began school programs in the absence of public special education programs in order to demonstrate that our children not only deserved an education but that with the right kind of education, they could benefit from such services. We did so initially on a demonstration basis with the long-range goal of turnkeying such programs to the public school where we felt they always should have been. While our Association generally continues in this belief, we recognize there are intervening realities and local factors which supersede our philosophical position. Educational programs and services to all children must be provided on the basis of quality and appropriateness in accordance with parental consent. These should always be the factors in determining where a child is educated and which entity or organization is the provider.

While I recognize testimony today is on the topic of preschool education, there are two additional and closely related areas I feel I must address: summer school for the four and five year olds in the year of transition; and summer school for children 5-21 who are not in their first year of eligibility for public school.

With respect to the transitions of 4 and 5 year olds to summer school programs, it is my fear that the problems which would have occurred had there not been the resolution through the state budget will indeed occur next year unless a permanent solution is adopted. Shortly, I will be convening meetings with representatives of our chapters to obtain their input in developing a recommendation which I will submit to the Senate Education Committee and Senate Select Committee. It is unfortunate that in the transition from the preschool education system to the school-age education system such gaps occur. However, it is unacceptable that for certain parents whose children may be deemed ineligible for summer school that there will be insufficient time to challenge the determination through due process, if necessary, and not have the outcome decided in time for participation in the summer school program.

With respect to summer school for children 5-21, while in the long run, I continue to believe we have made a step in the right direction with the passage of the 12-month education bill, as we originally indicated in our support for the bill, each change will bring its new problems. As I understand it,

this year some parents may not have sufficient time to take advantage of the procedural safeguards which deal with disputes over whether or not their child is eligible for summer school. I therefore request the Senate Education Committee and Senate Select Committee to take steps to assure that no child will be denied summer school until a parental objection has been heard.

You have asked several questions regarding existing preschool programs and services and the current statutory framework. As to the ability of preschool programs to meet the needs of children and their families and recommendations for improvement, I would like to note the fine work of Commissioner Ambach's Advisory Task Force which as established in accordance with Chapter 683 of the Laws of 1986 to recommend program and fiscal guidelines for the operation of preschools. This task force, on which NYSARC was represented, has developed a comprehensive set of recommended guidelines which, if adopted, would make significant improvements statewide in the overall funding and operation of preschools.

However the guidelines are simply GUIDELINES which will not have the same force and effect as law and therefore the major needs and concerns with respect to preschool programs cannot be addressed through these or any other guidelines. This is due to the fact that the major needs and concerns deal with the law itself — Section 236 of the Family Court Act which requires parents to petition the court for services; and, the lack of laws which would guarantee statewide comparability and procedural safeguards to parents by extending the right to a free and appropriate education to all children with handicapping conditions and to designate the State Education Department to oversee such services.

Our Association has for years stated its philosophical opposition to requiring parents to petition the court for services. We believe it is time to enact new, more appropriate laws governing the manner in which preschool and early intervention programs are accessed and as I have already stated, we need to designate a single state agency — the State Education Department to provide for the funding and regulation of such programs and services.

On behalf of our Association, I thank both committees, members and staff for your continued interest and commitment to resolving these issues and for holding this hearing today. ■

Thomas Sobol New Education Commissioner

At a special meeting held March 24, 1987 the Board of Regents elected Thomas Sobol, Superintendent of Scarsdale Schools for the past 16 years, as President of the University of the State of New York and Commissioner of Education. Mr. Sobol will assume his new duties on July 1, 1987. Sobol succeeds Gordon M. Ambach, who resigned from the position last year, and becomes the 11th State Education Commissioner to serve since the position was created in 1904.

As Commissioner of Education, Sobol will serve as Chief Administrative Officer to the Board of Regents which has jurisdiction over the most comprehensive state educational system in the nation. The system encompasses every educational endeavor in the state

including public and non-public elementary and secondary education, vocational rehabilitation, colleges and universities, museums, libraries, historical societies and archives as well as responsibility for the licensing and professional discipline of 31 major professions.

As superintendent of schools in Scarsdale, one of the most highly regarded school systems in the nation, Sobol has achieved a national reputation as an outstanding administrator and educational leader.

In commenting on the appointment, Chancellor Martin C. Barell said, "The Regents feel fortunate in having been able to select a new Commissioner with the depth of experience that Tom Sobol possesses. He has a record of outstanding success and the ability to develop innovative ideas to solve persistent problems. We are confident he will bring this same enthusiasm and creativity to help us resolve statewide problems in education. He has clearly stated his commitment and dedication to the improvement of the educational situation in the inner city."

The NYSARC, Inc. extends congratulations to Mr. Sobol on his recent appointment. It is the hope and desire of the Association that during Mr. Sobol's tenure as Commissioner of Education that many of the issues that face our educational system for children who are disabled will be appropriately addressed. ■

NYS Comptroller tells State to Pay Organizations Faster

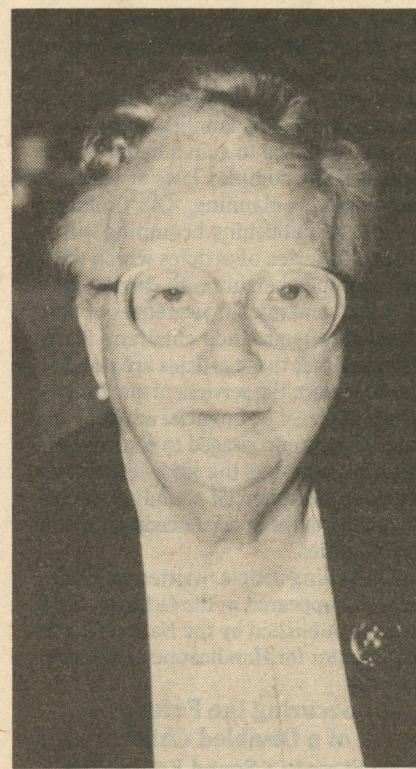
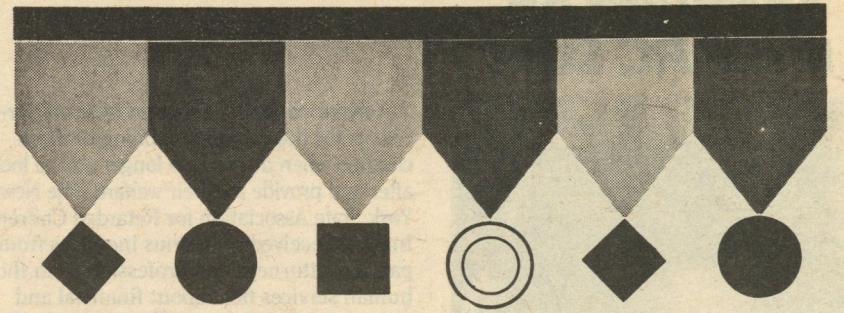
The Comptroller of the State of New York, Edward V. Regan said recently that state agencies must expedite payments to non-profit organizations which provide essential community services. His report found that delays occur because state agencies are slow in approving their contracts.

The Comptroller's report, sent to the Governor in October 1986, indicated that delays in processing contracts between state agencies and non-profit organizations cause significant cash-flow problems.

The Comptroller stated that "the contract award process itself is the primary cause of the problem. Our study determined that some major state agencies have not signed contracts with the non-profits until long after the contract period is under way. Therefore, non-profit organizations have been unable to submit invoices for payment because, by law, invoices cannot be paid unless there is an approved contract."

One of the agencies cited in the report was the Office of Mental Retardation and Developmental Disabilities. Of 27 OMRDD Community Residence and Family Support Service program contracts with non-profits processed between August 1985 and March 1986, three were not approved until the contract period was over. Additionally, processing time for the contracts averaged 105 days.

"We are talking about services that affect people's lives — millions of dollars of vital support services from thousands of voluntary non-profit agencies which the State itself is not in a position to supply," Comptroller Regan said. "Yet the State takes for granted that such services will continue to flow without benefit of either a contract or a reliable flow of cash to help finance them."



Gladys Wood, recipient of the Dr. King Award.



Henrietta Messier, recipient of the 1987 "Citizen of the Year Award," Down Syndrome Aim High.

Onondaga Chapter Board of Governor Receives Dr. King Award

On May 1, 1987, Gladys Wood, a long time member of this Association, was presented with the Dr. King Award for community service.

This award presented by the Liverpool Rotary Club, is named after Robert King who gave tremendously to the Liverpool community. Mrs. Wood is currently employed by the New York Conference of the United Church of Christ in public relations and communications. In 1979 she was named a woman of achievement in the area of religion by the Post Standard and Syracuse Federation of Women's Clubs.

In addition to serving as a current Board of Governor for our Onondaga chapter, Mrs. Wood has served as the chapter's vice-president and president, and states that "I am now on the Board of Governors for the State ARC. I cherish the hope that my efforts will result in a climate of hope and caring for retarded people so that they may live lives of fulfillment, joy and meaningful choices."

Gladys, you are one in a million. Our entire Association joins in as we congratulate you for this wonderful honor and we thank you for the years of hard work and dedication. We wish you continued good health as you and all of our other dedicated volunteers help make the world a better place for our citizens who are mentally retarded to live and work in. Congratulations! ■

Rensselaer, Board of Governor, Henrietta Messier Receives Citizen of the Year Award

Henrietta Messier, the Board of Governor representative for the Rensselaer chapter, was recently honored by the Down syndrome — Aim High Organization for her many years of hard work and devotion to bettering the lives of persons in our state who are mentally retarded/developmentally disabled.

On March 20, 1987 Henrietta was presented with the 3rd Annual Citizen of the Year Award at a special dinner held at the Ramada Renaissance Hotel in Saratoga Springs.

This award is presented each year to an individual who has demonstrated an outstanding commitment to the field of mental retardation/developmental disabilities and whom has been instrumental in helping to provide needed programs and services for these persons.

It would be impossible to recite the many accomplishments of Henrietta. Henrietta is one of those people who, no matter what the obstacle, she is there with some kind of solution.

Henrietta has been involved with our Association for many years, and we are all very thankful that she is a part of our organization. Congratulations to a very special person. ■

Spotlight on NYSARC Staff



In the next several issues of OCV, we will be spotlighting the staff of the State ARC Office. The first staff member is Erica F. Berman, Director of Guardianship and Special Projects.

Erica F. Berman

Ms. Erica F. Berman is the Director of Guardianship and Special Projects. She has been employed at NYSARC since July 18, 1982. Erica was previously employed by the Sullivan County Chapter as its Director of Quality Assurance from 1980 to 1982. Prior to that experience, Erica worked at the Sullivan County United Cerebral Palsy Association as an Educational Specialist.

Erica holds a Masters in Special Education from George Peabody College for Teachers of Vanderbilt University and a Bachelors Degree from the same University. She was born in Liberty, New York and was most active in community affairs in Sullivan county.

In her current capacity, Erica has direct oversight responsibilities of the State Association's Guardianship Program. This includes the on-going monitoring and evaluation of the Guardianship Program as well as addressing all issues pertaining to medical consents, wills and trusts. Her responsibility in the Guardianship area finds her serving as a resource to NYSARC chapters, State agencies and other organizations external to the Association in the area of guardianship.

Over the past two years, Erica has personally made visits to over thirty chapters and has provided direct consultation to almost every NYSARC chapter concerning the Guardianship Program.

In addition to her guardianship role, Erica also administers at the State Office level the Scholarships and Awards of the Association. She serves as the direct liaison with the Scholarship and Awards Committee assisting in all applications and procedures.

And, as if that is not enough, Erica has been assigned to the Association's Education Committee, the Ad Hoc Committee to Study Parent Outreach Services and Resolutions Committee.

Erica lives in Albany, New York and is one of the most respected staff members of our organization. She is always available to answer any questions regarding Guardianship, Wills or Trusts and our members are urged to contact Erica with any questions. Erica's sensitivity and devotion to the Association makes her an asset to NYSARC, Inc. ■

Securing the Financial Future of Persons with Disabilities

A major concern expressed by most parents is for the future well-being of their children when they are no longer able to look after and provide for their welfare. The New York State Association for Retarded Children, Inc. has received numerous inquiries from parents, attorneys and professionals in the human services field about financial and estate planning for individuals with disabilities and the impact wills and trusts have on the benefits received through governmental entitlement programs.

Taking into account the ever increasing concern expressed by families of persons with handicaps and to gain a better understanding of the complex laws affecting financial and tax planning, "Our Children's Voice" will be publishing beginning with this issue, a series of articles which will provide our membership with current information and generate an awareness of how one might safeguard their children's future. Please note that these articles are not designed to replace the services of an attorney in rendering legal or financial advice. Families are strongly encouraged to consult with an attorney who has the knowledge and expertise in the financial planning process as it pertains to the special needs of persons with disabilities.

The following article, written by Ellen Hermanson appeared in the October, 1984 newsletter published by the National Information Center for Handicapped Children and Youth.

Securing the Future of a Disabled Child

Five Steps to a Sound Estate Plan

At the top of the list of painful problems confronting parents of handicapped and disabled children is planning for the day when they won't be there to care for their sons and daughters.

No one enjoys estate planning, and most of us indulge the tendency to postpone this chore. Indeed, a shocking 70 percent of Americans die without a will! But it's critically important for parents of disabled children to overcome this instinct and safeguard their children's future. Without a carefully drawn plan, sudden death or injury to the parents can have unforeseen — and unhappy — results. Well-meaning friends and family who have to make hasty arrangements may mishandle important legal and personal issues. Or — and this is the deepest fear that haunts every parent of a disabled child — no one will be available to look after the child's interests according to the parents' wishes.

Many factors contribute to the inertia parents so often display, estate planners report. Often, parents fail to realize that they ought to make special provisions for their child; others believe that only the wealthy have to worry about estate planning (and can afford to pay for it); many expect that the government will provide for their child after they're gone. And, of course, parents may simply be overwhelmed by the need to provide solutions for immediate problems.

But at a time when government benefits are under review and attack, parents shouldn't rely on them to meet the child's lifetime needs. Social and economic changes suggest that eventually the alternatives available to disabled children may change as well. Parents can and should see to it

that they provide for continuity of support for their child's entire lifetime by designating someone to look after the child's interests and by setting up financial mechanisms to provide for future needs.

The hard facts are that hundreds of thousands of children and adults suffer some degree of impairment, either at birth or later in life. According to the March of Dimes, 250,000 children are born annually with birth defects. Many of these birth defects are slight, and the children will suffer little or no impairment when they grow up; others, of course, are so disabling that the children will never be able to care for themselves. And additional hundreds of thousands of people suffer injuries serious enough to incapacitate them and impair their abilities to earn a living or live by themselves. Medical advances have made it possible for many children, who once would have succumbed to a host of illnesses, to outlive their parents.

The need for estate planning is obvious.

Where to Get Help

Figuring out where to start and who to turn to for professional help can be a daunting prospect. Many well-respected estate planners lack experience in making arrangements for clients with handicapped children. But detailed, current knowledge of state and federal regulations is crucial to setting up a successful plan that can withstand any court challenges, should they occur. The range of considerations exceeds that for more conventional estate plans.

To help parents find appropriate advisers, local organizations such as the Association for Retarded Citizens (ARC), local chapters of United Cerebral Palsy, and other developmental disability organizations frequently can provide recommendations and guidelines.

"Seek out someone who's done this before," advises B. John Readey, III, a Kansas City lawyer who, with Chris Hinken of Christopher T. Hinken and Associates, has prepared many such plans.

Other experts agree. "Select a lawyer sensitive to your needs," urges Elaine Petersen, a future-planning specialist with Oregon's ARC program, called Guardianship and Advocacy Protective Services (GAPS). "You may want to benefit from tapping assets to pay for state-sponsored care. Proper wording protects the trust's assets by making it clear that the assets are not owned by the beneficiary. And assets are crucial in determining eligibility for programs such as SSI."

One example of a trust document is the Craven Trust, named for a family in Washington state. "The trust was created with the idea of preserving eligibility for such programs as Supplemental Security Income," says Tom O'Brien of the Foundation for the Handicapped in Seattle. "Anyone who has an estate that they want to pass over for a handicapped son or daughter is well-advised to protect the trust from invasion by the government."

Because of widely varying state laws, the trust document that works in one state may be disallowed in another. "Parents must use trusts with caution," notes Petersen. "There's never been a test case in Oregon, for example, but that doesn't mean one won't come up."

Hinken, too, expects eventual court challenges, but he stresses that a challenge doesn't mean the plan won't work.

Many organizations are preparing sample trusts for use by parents of handicapped children. The South Dakota Guardianship Program was told that the discretionary trust it developed could allow the beneficiary to have available the trust resource and still be eligible for federal entitlements. Of course, income from the trust to the handicapped person would have to be considered carefully so as not to jeopardize benefits. Accordingly, says Robert J. Kean, an attorney with the South Dakota Advocacy Project, this means that government benefits can't be denied or removed from beneficiaries of this particular trust on the basis of the resource it provides. "Parents can now provide funds to pay for a long list of items that Medicaid, for instance, doesn't cover," he says. "Items such as cosmetic surgery, and certain kinds of dental work."

That recent development underscores the importance of periodic review of all these arrangements and documents. "If there are legal or regulatory changes and older documents aren't brought up-to-date," says Kean, "the benefits might be put in jeopardy. Parents thought they were doing one thing, but the results could be very different."

Unless a family is wealthy, the most likely mechanism to guarantee funds will be life insurance. It can be especially helpful to those with disabled children, even if they have sizable assets. "If the proceeds are paid to a named beneficiary," Hinken says, "they pass outside of probate and immediately create the funds."

Perhaps even more importantly, if the proceeds of the policy are used to fund an irrevocable trust set up for the child's support, and the trustee is the named beneficiary, most states will not consider the child the owner. Consequently that insurance benefit won't threaten the child's eligibility for government benefits.

The amount of life insurance necessary will depend on the plans made to spend it and how much the family can currently afford to set aside.

Hinken suggests the parents normally look at a minimum of \$100,000 in life insurance to fund a trust. And he advises a team approach with a lawyer to guarantee that the financial plans are successfully integrated with the legal requirements.

Reflecting on what he considers the primary benefit of this intensive planning, Hinken says, "The best gift parents can leave their other children is a workable plan so they won't be financially responsible for their handicapped brother or sister, even if parents have to leave their entire estate to that one child."

And families who lavish time, thought, and care on estate planning reap an immediate benefit.

"For me, it was a tremendous relief to make these arrangements," Fred's mother says. "I know we've planned to take care of him in the way we want, and I know his care won't burden our other son. He will assume the moral and emotional responsibility, but he won't have to provide for his brother's care and take money away from his own family when the time comes." ■

NYSARC COMMITTEES

... AT WORK
... IN ACTION

Committee Chairperson, Joan Edwards Guest Speaker in Washington, D.C.

Joan Edwards, Chairperson of NYSARC's Prevention Committee and Coordinator for the Western New York Task Force on Prevention of Mental Retardation and Developmental Disabilities, Inc. was a guest speaker at the President's Committee on Mental Retardation Conference held in Washington D.C. on February 10-12, 1987.

The purpose of the conference was to stimulate commitment to a national effort to prevent mental retardation and related developmental disabilities.

The conference provided a forum for state representatives to discuss strategies that facilitate success in developing, implementing or expanding state/territorial plans for the prevention of MR/DD.

Joan enthusiastically presented our efforts to lessen the incidence of mental retardation and developmental disabilities. ■



NYSARC YOUTH Committee proudly displays the new YOUTH Organizational Kit developed by their Committee. Left to Right: Maythorne Winterkorn, Susan Lyons, George Oaks and Christina Johncox.



Recreators and volunteers from Monroe County YOUTH-ARC enjoy a sing-along, one of the four activities which make up their Saturday morning recreational program.



Participants in the Special Olympics workshop take time out to look at photo albums and medals won by Wendy Winterkorn, a very proud Special Olympian.

Planning for the NYSARC 1988 Annual Event Begins

Work is proceeding on the organization of the 1988 Valentine Rose Legacy of Love. That special event is coordinated by the NYSARC Public Information Committee. At a recent committee meeting Jan Gile, Administrative Assistant from the Schoharie County Chapter, made a presentation of the

product which will be used for the coming event. During the late summer, information packets will be sent by the Committee to all chapters which will include a variety of ways in which individual chapters can participate. ■



Attendees at the 1987 Convention will be receiving complimentary mementos consisting of a totebag and pen, which were designed and selected by a NYSARC Public Information subcommittee coordinated by Debra Kiskis from the Albany Chapter. The items highlight the convention's theme "NYSARC Advocacy - Strategies for Transition into the 90's" Pictured above are left to right: Cindy Case, Montgomery Chapter; Debra Kiskis, Albany County Chapter and Jack Decker, Monroe County Chapter.



Gene Allen, Director of Public Relations, Oneida County Chapter (second from left) reviews with members of the NYSARC Public Information Resource Group, material which is being put together for the Resource Bank which Gene is coordinating.



Members of the Ad Hoc Committee on Convention Program Planning meet to review and select those workshops which will be presented at the 1987 NYSARC Convention in Syracuse on October 15-18. Pictured above left to right are Barbara Rothenberg, Delaware; Gene Allen, Oneida; Tom Ellison, Sullivan; Dr. Lyle Lehman, Livingston-Wyoming; Richard Minogue, Clinton and Sandy Ku, Broome-Tioga. Also present but not shown was Mary Caniano from the Albany Chapter.

On the Road Again!

NYSARC Youth Committee members (youth organized and united to help the association for retarded children) are now ready to come to your community to provide technical assistance to those chapters who are interested in starting a YOUTH-ARC program. This assistance is also available to chapters wishing to revitalize their existing programs.

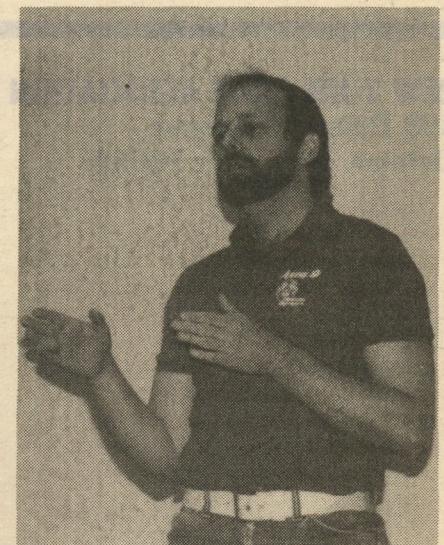
YOUTH-ARC is a group of young people 13 to 25 who have joined together to help persons who are mentally retarded/developmentally disabled. YOUTH groups work with their local ARC chapters to establish recreational/social programs for children and adults with disabilities.

YOUTH-ARC is a viable alternative to existing programs in the community. YOUTH-ARC was organized in the early 70's to provide recreational opportunities for mentally retarded children. It continues to be a vital part of several NYSARC chapters.

A 75 page organizational kit has been developed and is available to any interested chapters or persons who wish to form a YOUTH-ARC group. To obtain a copy please write or call the NYSARC State Office. ■



Dr. Robert Lehr, chairperson of the Education Committee and Dr. Luanna Meyer discuss with other committee members the current status and future direction of the least restrictive environment (LRE) issue.



Supplementary Recreation and Special Olympics Committee member Corlous T. Fisher, talks about how to train Special Olympians at a regional workshop recently in Syracuse.



NYSARC ADVOCACY

STRATEGIES FOR TRANSITION INTO THE 90's

NYSARC, Inc.
Annual Convention
October 15-18, 1987

1987

ASSOCIATION CALENDAR OF EVENTS

June

5 Youth Advisory Council Meeting
Delmar, N.Y.
5-6 Guardianship Committee Meeting
Delmar, N.Y.
19 Resolutions Committee Meeting
Delmar, N.Y.

July

8 Adult Services Committee Meeting
Delmar, N.Y.
9 Supplementary Recreation and
Special Olympics Committee
Meeting
Delmar, N.Y.
10 Executive Committee Meeting
Buffalo, N.Y.
17 Ad Hoc Committee on Family
Outreach
Committee Meeting
Delmar, N.Y.
31 Community Residential Services
Committee Meeting
Delmar, N.Y.

Aug.

6 Safety Group Meeting
Delmar, N.Y.
14 Insurance & Pension Meeting
Delmar, N.Y.
Legislative Committee Meeting
Delmar, N.Y.
21 Prevention Committee Meeting
Delmar, N.Y.
Sept.
18 Developmental Center Committee
Meeting
Delmar, N.Y.
18 Youth Regional Workshop
Oct.
15-18 Board of Governors' Meeting and
38th
Annual Convention,
Hotel Syracuse
New York

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.
393 Delaware Avenue
Delmar, New York 12054

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