

# OUR Children's Voice

## Retarded Children Can Be Helped

### State Association Reviews Medicaid Home and Community Quality Services Act

*NYSARC begins to discuss provisions of the bill with Key Legislators in Washington*

The "Medicaid Home and Community Quality Services Act of 1987" was introduced by Senator John Chafee on September 10, 1987. This is very similar to legislation which has been sponsored in the past by Senator John Chafee (Rhode Island) on the subject of the Reform of Medicaid Services for persons with developmental disabilities.

Senate Bill 1673 would greatly expand medicaid eligible community-based services while at the same time discouraging the use of institutionalization.

The Association is currently re-reviewing the bill as there have been a number of changes to the bill which the Association feels will benefit persons with mental retardation and developmental disabilities living in New York State.

In order to understand the bill and its provisions, NYSARC has invited Ms. Christy Ferguson of Senator Chafee's office to discuss the bill at the March 18-19, 1988 Presidents and Executive Directors meeting in Syracuse, New York. NYSARC's State Office staff have been discussing the provisions of the Chafee bill with the Senator's Office in Washington D.C. A full report will be given at the April 22, 1988 Board of Governors' meeting. ■



Senator John Chafee (R. Rhode Island) and NYSARC Executive Director, Marc N. Brandt discuss key provisions of the Chafee Bill in Washington D.C.

### Association's Attempts to Stop Co-Location at Rome D.C. is Denied by Court

*Judge dismisses NYSARC lawsuit attempting to enjoin the establishment of a prison at Rome D.C. until after the facility is lawfully closed. Construction continues - co-location takes place.*

On December 23, 1987 Judge John Connor of the Albany County Supreme Court dismissed the Association's lawsuit which attempted to enjoin the establishment of a prison at Rome D.C. until after that facility is lawfully closed. Along with the Association, five parents of adults living in Rome D.C. requested an immediate injunction to prevent the state from converting RDC into a medium security prison while persons with mental retardation continue to be housed on the grounds.

The Association's attorneys argued in court that the Commissioner of the Office of Mental Retardation and Developmental Disabilities had no legal authority to close Rome D.C. since the Mental Hygiene Law requires that RDC be maintained as a facility for the care and treatment of persons with mental retardation. The suit further charged that closure of Rome D.C. included a plan for the "co-location" of convicted criminals and persons with mental retardation on the Rome D.C. campus in anticipation of the complete conversion of "RDC" into a prison.

The suit also charged Commissioner Thomas A. Coughlin of the Department of Correctional Services and Commissioner Arthur Webb jointly formulated the plan to close Rome D.C. and to commence using the campus as a prison even before Rome D.C. residents have been relocated.

In his seven page response to the Association's suit, Judge Connor stated: "Although petitioners allege certain detrimental affects on OMRDD clients from the co-location of

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### Welfare League Chapter Appalled at Incinerator proposal for Letchworth Village D.C.

*NYSARC requests denial of permit to operate incinerator at Letchworth Village Developmental Center.*

In 1984 the Office of Mental Retardation and Developmental Disabilities began developing a plan to address the faulty incinerator on the grounds of Letchworth Village Developmental Center located in Thiells, New York. OMRDD released a request for proposal to seven firms and ultimately a firm by the name of Remtech was awarded the project.

The proposed incinerator would produce steam to provide heat and energy to the 200 buildings at Letchworth. In addition, however, the proposed incinerator would burn as much as 48 tons of infectious hospital waste each day — primarily syringes, bandages, tongue depressors, sheets, masks and gowns, rubber gloves, toothbrushes and plastic containers. Some of the waste would be pathological waste, including body parts and bacteria and virus-contaminated materials. This infectious hospital waste would be trucked from hospitals on a daily basis.

At its annual convention held in October, 1987 the Association strongly opposed the development of such a facility on the grounds of Letchworth or any other developmental center. The Delegate Assembly passed a resolution which was forwarded to the Commissioner of OMRDD which strongly opposed the incinerator.

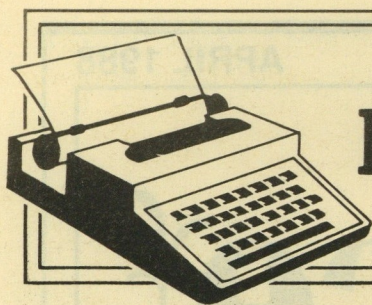
The New York State Department of Environmental Conservation (DEC) has issued a draft environmental impact statement concerning the proposed incinerator project. After a careful review NYSARC has found much fault with the proposal based not only on the Association's advocacy issues but for technical reasons.

The following are the comments submitted by the Association's attorneys concerning the Draft Environmental Impact Statement on behalf of NYSARC and the Welfare League Chapter.

Mr. Lawrence G. Biegel  
Senior Environmental Analyst

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## EDITORIALS

### The Staffing Crisis: A Fundamental Recognition

At OMRDD's budget hearing before the Legislature Fiscal Committees, Commissioner Arthur Y. Webb frankly and boldly admitted that he had made a "mistake" by neglecting to recommend that salary enhancement for Local Assistance employees be included in the Governor's FY 88-89 budget request. The Commissioner's open admission of this flaw in the Governor's budget in front of the fiscal committees took considerable courage since the Commissioner is officially obligated to defend the spending plan put forward by his boss. That the Commissioner took it upon himself to make this statement serves to underscore the need for the Legislature to rectify this budgetary flaw by adding funds to the FY 88-89 budget in order to enhance the salaries of Local Assistance employees. We applaud the Commissioner for his courageous statement.

The Commissioner's statement is also appreciated since it underscores our belief that the "staffing crisis" is for the most part a "salary crisis". Too often issues of recruitment and retention have been looked upon by state officials as problems of mysterious origin which can be understood only after long and painstaking analysis. After reading much that has been written and spoken on this subject, there appear to be many theories regarding the precise causes of the "staffing crisis". Labor markets are analyzed, the image of our field in the public eye is reflected upon and training and management techniques are cited as possible causes of this problem. The whole discourse begins to sound very academic, as if we were trying to track down the mysterious cause of a mysterious illness.

Nevertheless, those activities are of value. Whatever can be uncovered through such analysis that leads to resolution of our staffing problems is to be appreciated. However, we must, first and foremost, deal in fundamentals. And fundamentally we must recognize that the lack of adequate pay and the patchwork arrangement of good, bad, terrible and nonexistent fringe benefit packages offered to our employees are the overriding causes for our current difficulties. Since our Association strongly believes in the common sense notion that you get what you pay for, we cannot help but feel that the fundamentally inadequate wage and benefit scales available to pay our employees are at the root of the staffing crisis.

The Commissioner's public recognition that the failure of the Governor's budget to provide salary enhancements to Local Assistance workers was a mistake legitimizes our belief that we must attack this problem by looking at fundamentals. The Commissioner should be applauded for expressing this position at political risk to himself. Such action is the basis for showing real leadership on the issue of staffing. ■

### Local Assistance: The Lack of Consensus

For almost the last decade the cry for "Local Assistance Reform" has been persistent and widespread. Almost every provider has incorporated it into his or her foremost list of complaints. There is wide recognition that the current Local Assistance System is administratively backward and above all provides funding which is neither adequate or equitable. OMRDD, the Division of the Budget and the Legislature all agree that achieving "Local Assistance Reform" would mark a major step forward in the evolution of the entire state system of services to persons with developmental disabilities.

Yet despite the overwhelming consensus that "Local Assistance Reform" must take place, there is little consensus over how to achieve this goal. A key area of dispute is accountability and control. Simply stated: to what extent and in what manner do providers want to be held to tighter financial reporting requirements and explicit program standards? It appears that this sensitive issue is becoming increasingly critical. Key personnel from OMRDD, DOB and the Legislature refer ever more frequently to the inappropriateness of pouring more funding into a system that has achieved the reputation for being an unaccountable, financial blackhole. Yet, it is the need for more funding which in one form or another, is at the root of our concerns.

Thus the central problem for providers is how to enhance program accountability and control in return for a local assistance funding system that provides adequate funding in a stable and predictable manner. The need to resolve this dilemma has become more urgent as Local Assistance funding has become increasingly less adequate. Specifically, salary enhancements enacted last year for residential programs and recommended by the Governor in this years budget for day treatment programs have ignored the salary requirements of Local Assistance Staff. This has only served to make the salary needs of this group stand out like a sore thumb. Further, it is now four consecutive years that inflation for Local Assistance programs has been capped at 3%. Such woefully inadequate allowance for increasing costs has steadily added to the number of providers experiencing deficits in these programs and calling for reform.

Maybe some of these issues will be addressed in this years State Budget. We should know shortly after this article is published. Our Association has requested that both salary enhancements for local assistance staff and enhanced contract increases be enacted by the Legislature for FY 88-89. Perhaps the Legislature, in some form, will approve of our requests.

Yet, even if the Legislature takes such action it will not amount to the kind of permanent fix that most of us want. Winning increased contracts for FY 88-89 still leaves the Governor free to propose reduced contracts for FY 89-90. Given such occurrence,

we will once again be forced to respond to another local assistance crisis. Perhaps, we are embarking upon an annual event.

We hope this is not the case. However, from where this office sits, only a few miles from the state capital, it increasingly appears that Government — OMRDD, DOB and the Legislature — will be reluctant to provide a permanent solution to local assistance until providers and OMRDD can reach agreement on the key issues of "control and accountability". This won't be easy. The wide diversity of opinion amongst providers on these issues and our legitimate need to insure that any concessions we make will ultimately result in a substantially more adequate funding system will severely challenge the ability of all concerned parties to reach a real consensus.

Clearly, the issue of Local Assistance reform is starting to reach a critical juncture as the need for adequate funding has become more acute. What eventually transpires may hinge on our own abilities to work openly, honestly and productively, not only with OMRDD, but especially with each other in order to achieve a true consensus. ■

### Did You Know?

...that a parent is no longer the legal guardian of his or her child who is mentally retarded, 18 years of age or older unless that parent has been legally appointed by the Surrogate's Court??

...that an adult who is mentally retarded may not be able to obtain necessary medical and dental services requiring the "informed consent" of the person unless there is an appointed guardian??

...a guardian is not responsible for the acts or financial obligations of the person who is mentally retarded??

...if parents believe that their young or adult child is unable to make sound decisions in regard to personal care and/or financial matters and that he or she will require guidance and supervision throughout his or her lifetime, guardianship and standby guardianship can be established at anytime before or after the person is 18??

You can learn about these and other questions on guardianship, wills and trusts by contacting the New York State Association for Retarded Children, Inc., 393 Delaware Avenue, Delmar, New York 12054, (518) 439-8311. ■

*The family of Joseph T. Weingold wishes to express their sincere gratitude for the many expressions of sympathy received during their recent bereavement.*

*Let us all remember always what Jerry attempted to accomplish and let us follow in his footsteps.*

**Barbara and Jonathan Weingold**

### NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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the OMRDD facility and a correctional facility at the RDC campus, this court fails to find that the determination to reduce OMRDD services and to locate a correctional facility at the site, as contemplated by Phase I, lacks a rational basis."

The judge concluded by stating:

"In conclusion, this court finds that the petition must, in all respects, be dismissed. Accordingly, all preliminary and permanent injunctive relief is denied."

The Association has in the past and continues to vehemently oppose co-location 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.

NYSARC has stated on several occasions that 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 also creates a substantial detriment to the therapeutic atmosphere which is essential to adequate care and treatment. An environment which includes guards, barbed wire, security towers, and violent criminals does not nurture the sense of security essential to the well-being of the residents at Rome. NYSARC also believes that the extraordinary preparations which the state must take to ensure even a minimal level of protection for the residents of Rome Developmental Center will shift attention away from activities which must be devoted to their care and treatment.

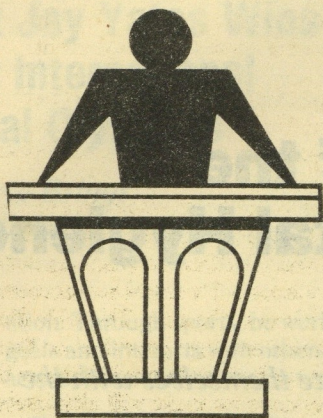
The suit did get wide coverage in the media, particularly in the central region of the state. This suit did draw attention to the issue and did raise the issue of poor planning on the part of OMRDD in regards to their closure plans.

Commenting on the decision to allow co-location at Rome Developmental Center, NYSARC, Inc. Executive Director Marc N. Brandt stated, "although we lost this round the fight to prohibit co-location as well as the humane and careful closures of developmental centers has just begun". ■

## Quote of the Quarter

"It is up to us to see that the staff who must constantly be present in day or residential programs for their care, comfort and training are lifelines to the kind of safe, enriched environment they deserve. This is the difference between the institutional life we took them from and the normalizing life we promised them in the community".

Mrs. Jane Gerstheimer  
Orange County ARC  
Speaking before the Legislative  
Hearing on Workforce Issues  
February 3, 1988



# The President Speaks

As President of our Association, I know that my feelings of disappointment and frustrations are felt by many concerning the co-location of Rome Developmental Center. While our chances of winning in court were slim I had still hoped that perhaps a court might see our point of view and prohibit co-location until all persons who are mentally retarded and developmentally disabled were appropriately placed in community residential settings.

Since the creation of our Association in 1949, we have been dedicated to providing services to persons with mental retardation and developmental disabilities and advocating for their rights — whether they reside in the community or in developmental centers. Our Association, in the past, has been a plaintiff in cases in which the rights and well-being of persons who are developmentally disabled were either threatened or violated.

Services to persons who are mentally retarded or developmentally disabled must be carefully planned. Unfortunately, the state's track record in this respect has been a model of inconsistency. Rome Developmental Center is but just one more example. In 1986, the state declared that Rome D.C. would have a permanent role to play in the care and treatment of persons who are mentally retarded. In 1987, the facility was targeted for closure. In addition, the state announced that Rome D.C. would be used as a prison. Neither NYSARC nor any other group representing the residents of Rome D.C. were consulted prior to this decision. Instead, we were told that such action was required by the critical shortage of prison space.

Our Association is cognizant of the need to ensure that sufficient prison space exists in order to remove dangerous individuals

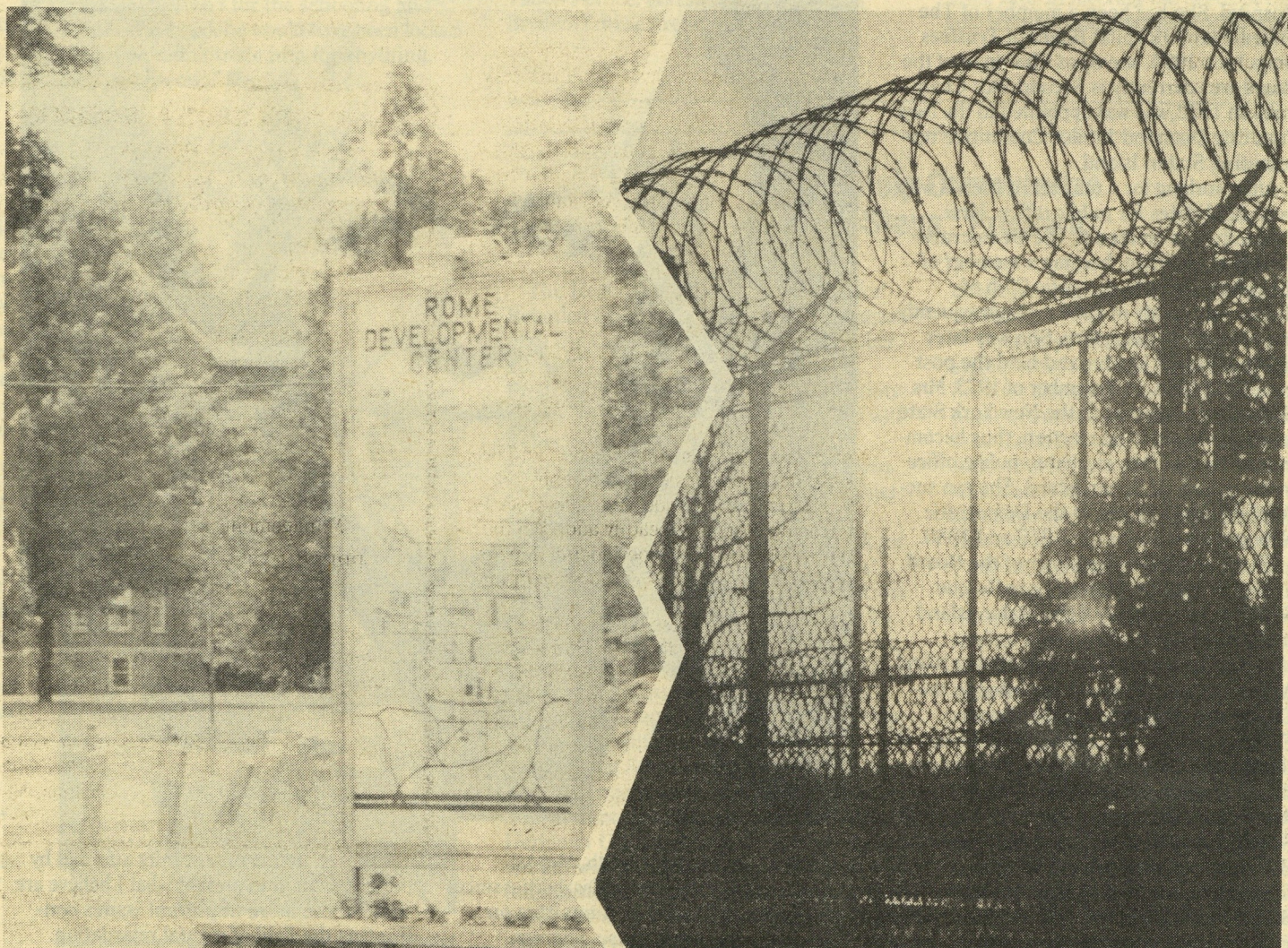
from society. We do not feel, however, that this should be done with callous disregard for persons with mental retardation. It is simply not believable that the long-standing need for prison space has suddenly become so critical that the legal prerequisites for closing Rome as a developmental center should be ignored and that the conversion of the facility into a prison be commenced even before the current residents are relocated into appropriate alternative settings.

It is the feeling of our Association that the co-location of residents of Rome Developmental Center with convicted criminals will have a terrible impact upon the public understanding of mental retardation, persons with mental retardation and their families. We have worked long and hard to erase the stigma associated with mental retardation. The co-location will only reintroduce and reinforce the negative image as Rome D.C. becomes a facility for convicted criminals and persons who are mentally retarded without any noticeable distinction between the two groups.

Our Association does not object to the policy of deinstitutionalization which is carried out lawfully and which focuses on the needs of the residents of developmental centers. We might have lost the battle at Rome D.C. but the state should be put on notice that our Association will continue to fight any further and future plans of co-locating developmental centers. Plans which disregard the needs and rights of persons who are mentally retarded or developmentally disabled which seek to subject them to conditions which no other group would tolerate will not be tolerated by our Association. ■

*David B. Lettman*

Rome Developmental Center



B.C. (Before Co-location)

D.C. (During Co-location)



# Special Feature: Meet the Chairpersons of the Legislative Committees on Mental Hygiene

*OCV thought it would be of great interest to our readers to better familiarize themselves with the Chairpersons of the Assembly and Senate Mental Hygiene Committees.*

*OCV has requested Assemblywoman Elizabeth A. Connelly, Chairperson of the Assembly Committee on Mental Health, Mental Retardation and Developmental Disabilities and Senator Nicholas A. Spano, Chairperson of the Senate Committee on Mental Hygiene to provide to our members and readers: A) a statement as to what they see as the most important issues currently confronting the field of mental retardation, and, B) any special goals or objectives that they feel their respective committees will be responding to during the 1988 legislative session pertaining to mental retardation.*

*OCV on behalf of the Association takes this opportunity to thank both Assemblywoman Connelly and Senator Spano for their time and efforts in responding to our request.*

## Assemblywoman Elizabeth A. Connelly

*58th Assembly District (Part of Richmond County — North Shore)*

*Chairperson, N.Y.S. Assembly Standing Committee on Mental Health, Mental Retardation and Developmental Disabilities.*

Assemblywoman Connelly was born in Brooklyn, N.Y. and raised in the Bronx. She was educated in the N.Y.C. Public School System. She is married to Robert V. Connelly and has four children — Robert V., Jr., Therese, Alice and Margaret.

Mrs. Connelly was a volunteer for the Staten Island Hospital 1961-1974, and was named Volunteer of the Year 1972 and 1973; managed the gift shop for the Auxiliary, proceeds of which were donated to the Hospital. She has been a member of The Staten Island Hospital Board of Trustees since June 1974, served as Chairman of the Board and currently is Second Vice Chairman. In 1973, she was appointed to the New York City Diamond Jubilee Committee representing Staten Island.

After working for a number of friends who were candidates for public office, Mrs. Connelly was elected to the Democratic County Committee, became a member of the North Shore Democratic Club of Richmond County in 1966 and subsequently was elected its Secretary. She was later elected District Leader and held the post from 1972-1974. In November of 1973, Mrs. Connelly was elected to the New York State Assembly in a special election, thus becoming the first woman elected to public office in the history of Staten Island. She ran successfully for Delegate to the Democratic National Conventions in 1976 and 1980.

She is an advisory member of the Board of Directors of the North Shore Rescue Squad #1; a member of the Staten Island Institute of Arts and Sciences and an Honorary Board member of the Staten Island Amputee Club. She was appointed to the Committee of 100 for Public Higher Education on Staten Island; is a member of the National Order of Women Legislators, the Staten Island Botanical Garden Association, the Staten Island Mental Health Society, Staten Island Council on the Arts, Business and Professional Women's Organization of Richmond County, the Staten Island Committee on Alcoholism, the Full Committee on Scouting for the Handicapped, Friends of Clove Lakes, Staten Island Hospital Auxiliary, the Conference House Association and Protectors of Pine

Oak Woods, is on the Professional Advisory Board of A Very Special Place, Inc., and is on the Board of the Seton Foundation for Learning.

From 1977 to 1986, Mrs. Connelly was Chairwoman of the New York State Assembly Standing Committee on Mental Health, Mental Retardation/Developmental Disabilities, Alcoholism and Substance Abuse. She currently chairs the new

Transportation and a member of the Committees on Health, Environmental Conservation, Rules, House Operations, Veterans Affairs and Correction. She was named by Governor Cuomo to the State's Task Forces on A.I.D.S., the Homeless and New Americans and the Special Inter-Agency Task Force on Troubled and Needy Children. She is also a member of the Assembly Subcommittee on Women Veterans.



Committee on Mental Health, Mental Retardation/Developmental Disabilities since there is now a Standing Committee on Alcoholism and Drug Abuse. She was Chairwoman of the Assembly Sub-Committee on Drunk Driving. She is senior member of the Assembly Standing Committee on

I appreciate the opportunity afforded by this publication to present what I believe are some of the more important issues confronting the field of mental retardation.

While the Assembly Committee on Mental Health, Mental Retardation and Developmental Disabilities is currently addressing

a number of items involving the mental retardation and developmental disabilities service delivery system there are two issues which I believe have particular quality of care impact. They are: The Office of Mental Retardation and Developmental Disabilities' plan to close a number of developmental centers and voluntary provider agency employee recruitment and retention programs.

## Developmental Center Closure

The Governor in his 1987-88 budget submission recommended the closure of seven developmental centers; Staten Island, Westchester, Bronx, Craig, Manhattan, Newark and Rome.

After extensive review of the Executive's plan and the solicitation of constituent reaction through public hearings and numerous meetings, I agreed to support the closure initiative.

My support, however, was not unconditional. I made it clear that I would continue to support the DC closings only if the clients and staff at the facilities are appropriately transitioned into the community. In addition I made very clear what I believe to be the elements of appropriate transitioning. They are:

a) The availability of sufficient and suitable community-based services prior to the movement of clients into the community.

b) Clients currently living at home who are awaiting services must not be adversely affected by the closings and appropriate funding must continue to be available to serve this population.

c) A maximum development of State operated community programs and utilization of developmental center employees in staffing those programs.

d) State participation and cooperation with the surrounding communities in the development of alternate use plans; and

e) Executive/Agency flexibility with respect to closing dates to insure an orderly closure process.

In the year since the closure announcement we have seen the completion of the Staten Island DC closure and the first phase of the Rome closure plan.

The first year closure experience has provided numerous evidence that the concerns I expressed at the initiation of this effort were well founded.

## SIDC

Even with the completed SIDC closure there remains a number of Executive/Agency commitments which have not yet been fulfilled. These were issues and commitments which address the very purpose or philosophy of the closures, and that is to provide a better way of life for the disabled.

## Rome

Commitments which were made to the Rome community have also not yet been fulfilled such as resources to improve accessibility of Rome community recreational and social facilities and the availability of sufficient medical services and equipment for medically frail clients now residing in the Walsh Building on the Rome DC campus.

## Community Clients

We are also receiving reports that the placement of DC clients into the community both as a result of closure and restructuring is having an adverse impact on the availability of services to clients currently living at home with families or other caregivers who are awaiting services.



## Staffing

Another problem being exacerbated by closure and restructuring is staffing availability and continuity. I am receiving constant reports that the staffing which is supposed to accompany clients into the community is not always available and that because of the uncertainty of many staff members regarding their future a number of them are taking other jobs, interrupting continuity of care and adversely affecting the quality of that care.

I want to point out that staffing must be improved at all D.C.'s not just those slated for closure. I will continue to press for adequate staffing throughout the state. The availability of adequate staff is too often a terrible problem.

While I still support the concept of community care in the least restrictive setting I am not confident, because of the way that closure has been implemented to this point, that developmental center closure can proceed as scheduled.

As I have stated all along on this matter I must be confident that DC closure will result in an improvement in quality of care before I can support it.

## Voluntary Program Staff Recruitment and Retention

Voluntary providers of service to mentally retarded and developmentally disabled persons are an integral part of New York State's MR/DD service delivery system. Currently voluntary providers service 20,000 clients in community-based programs and employ approximately 25,000 persons. Additionally, OMRDD plans to restructure its service system call for a steady increase in that participation.

Despite the essential nature of the voluntary sector's participation in service provision to persons with mental retardation and developmental disabilities, the increasing difficulty of voluntary programs such as those operated by the Association for Retarded Children, to recruit and retain staff threatens their ability to continue providing quality care.

The reasons contributing to the staff recruitment and retention crisis are numerous. They include the inability of providers to offer adequate salary and fringe benefit packages due to insufficient State reimbursement, the lack of career and educational advancement opportunities for voluntary program employees, increased workforce competition both within and outside of the mental hygiene service system and a reduced interest on the part of young people in choosing careers in the "helping professions".

The situation I describe is not new, we have seen it developing for some time and the voluntary sector has been most diligent in informing the Legislature of its plight. The State's response, however, has only minimally begun to address this important issue.

The 1987-88 State budget contained a total of \$11 million to enhance the salary's of direct care employees of voluntary Mental Health and MR/DD programs. This enhancement accomplished an average increase of \$1,825 for employees in the New York City region and \$1,625 for those employees throughout the rest of the State. While these increases provided much needed relief for direct care employees, workers in day treatment, local assistance and clinical services were left out.

The 1988-89 Executive budget recommendation contains \$1,634,000 to enhance the salaries of day treatment direct care and support staff salaries. While we welcome the Executive's initiative his recommendation fails to address a significant number of day

service employees specifically those funded through local assistance and direct contracts.

The Assembly Committee in an effort to address the salary needs of those voluntary employees who are not included in the Governor's budget request will recommend legislative approval of an additional \$9.8 million for employees of voluntary local assistance and direct contract programs.

Additionally in an effort to initiate long term reform of the process of reimbursing voluntary providers thereby improving their recruitment and retention capabilities, I am recommending that OMRDD be required to develop a new mechanism for annually adjusting rates, fees and contracts. It is the intent of this proposal to provide voluntary providers with inflationary increases which more accurately cost trends. I am also recommending that OMRDD address the wide variation of voluntary program fringe benefit packages, some of which are woefully inadequate, by proposing minimum fringe benefit levels.

It is by belief, support by the experience of the voluntary providers throughout the State that these proposals will go a long way in addressing their staffing concerns and insuring an MR/DD service delivery system which offers quality of care in the least restrictive setting.

Other priority issues for the Assembly Committee are:

## Family Support Services

1. Additional free-standing respite program
2. Case management to assist families to navigate the complex MR service delivery system.

## Insurance and Rent Increase Reimbursement

Many programs are experiencing drastic increases in rent and insurance costs. As there is no funding stream for these increased costs the programs are often forced to cover these increases with funds intended for services.

- a. recommend funding to reimburse agencies for these costs; and
- b. some mechanism to incorporate these costs into a regular funding stream; or
- c. the establishment of incentives for landlords and insurance companies to hold these costs such as tax incentives.

## Developmentally Disabled Offenders

Individuals with developmental disabilities have been found at virtually every stage of the criminal justice system. For example, recent estimates have indicated a significant increase in the percent of the New York State Prison population that is developmentally disabled. This rise does not include the numbers of persons with developmental disabilities who are being incarcerated in police lock-ups and jails, or those on probation or parole.

The Assembly Standing Committees on Correction and Mental Health, Mental Retardation and Developmental Disabilities recently held public hearings on the issue of developmentally disabled offenders. Our efforts were aimed at identifying and addressing the problems that place persons with developmental disabilities at a distinct disadvantage in the criminal justice system.

The Committees have since developed a series of legislative initiatives which include a number of bills and budget items.

The program which we will submit to the Legislature would:

- develop and implement a study to identify clearly the number of developmentally disabled persons and the levels of their disabilities in State and local correctional facilities;
- expand programs and services designed to address the particular needs of developmentally disabled inmates, including the establishment of three 50-bed Special Needs Units within the State's Department of Correctional Services;

— divert persons with developmental disabilities who are charged with misdemeanors and certain non-violent felony offenses to alternative programs;

— develop and disseminate training curricula for criminal justice practitioners;

— enhance the court's ability to obtain psychological and developmental evaluations of alleged offenders; and

— improve discharge planning for developmentally disabled inmates about to be released from prison. ■

## Senator Nicholas A. Spano

35th Senate District  
(Part of Westchester County)  
Chairman, NYS Senate  
Standing Committee on Mental Hygiene



Senator Nicholas A. Spano is serving his first term in the New York State Senate representing the 35th Senate District following eight years in the State Assembly. The 35th Senate District includes portions of the cities of Yonkers and Mount Vernon and the Towns of Greenburgh and Mt. Pleasant in Westchester County.

Senator Spano is a lifelong resident of Yonkers, where he was born. He received a B.A. in political science from Iona College in New Rochelle.

The oldest of 16 children, Senator Spano represents the second generation of his family to enter public service. His father,

Leonard Spano, is a member of the Westchester County Board of Legislators, where he is chairman of the Committee on Budget and Appropriations.

Nicholas Spano was first elected to the State Assembly in 1978 as one of its youngest members. In doing so, he defeated a five-term incumbent in a district that was overwhelmingly Democratic in enrollment. When he was elected to the State Senate in November 1986, he again overcame a significant Democratic enrollment advantage, emphasizing his record of working with all sides of the political spectrum within his district.



Chairman of the Senate Mental Hygiene Committee, Senator Spano also has been appointed to the Senate Committee on Labor, Alcoholism and Drug Abuse; Corporations, Authorities and Commission; Civil Service and Pensions; and Tourism, Recreation and Sports Development.

Senator Spano was the original sponsor of legislation adopted in 1986 to create Economic Development Zones to revitalize urban areas through the use of targeted tax incentives and economic development assistance.

Senator Spano has been active in local community and civic affairs, including Big Brothers/Big Sisters, Inc. of Yonkers; the United Slavonian American League (USAL); the League of Women Voters; Westchester Association of Retarded Children and Board of Directors, Yonkers General Hospital.

Senator Spano also has been active in the Yonkers Police Athletic League, the Queen's Daughters Day Care Center Advisory Board and College Careers, among others.

Senator Spano and his wife, the former Mary Troy, reside with their two children, Christina and Leonard in Yonkers, New York.

This session will be a challenging one in terms of the Office of Mental Retardation and Developmental Disabilities. There are a number of major on-going issues that the Legislature will be confronted with this year. Among them are the continuing closings of six developmental centers, staffing levels at these and all of the developmental centers, and workforce recruitment and retention in voluntary agencies.

These matters deserve immediate attention because they concern the well-being of the mentally retarded and developmentally disabled as well as the livelihood of thousands of mental hygiene care professionals.

In the time that I've served as the Senate Mental Hygiene Chairman, I've had the opportunity to meet with countless numbers of people who have legitimate needs and concerns regarding these and other areas of the system.

It is my intention to work towards ensuring that the quality of care for the state's mentally disabled is maintained in a manner that is both efficient and beneficial to the needs of the individual.

There are a number of pressing issues confronting the mental hygiene system. During the last session, we introduced a number of bills aimed at correcting many of the problems related to the quality of care for the mentally disabled. I will continue to pursue legislation in an attempt to ensure that appropriate care is provided.

Currently, there are many mentally retarded and developmentally disabled persons who are living in the communities with their families and other caretakers while waiting for placement in "appropriate residential settings."

The responsibility of providing shelter, supervision and care throughout the clients life usually falls on the family or caretaker. These provisions are usually quite expensive and in many instances are without financial assistance from the state.

#### Plan for Development

Vetoed by the governor was a bill that requires OMRDD to establish a plan for the development of residential and other services for mentally retarded and developmentally disabled individuals living at home and awaiting placement in programs operated by OMRDD. These clients should not include those people in aging-out or special-education beds, or beds supervised, certified or funded by any department of the state.

#### Protection for Clients

Another concern is the selection of candidates for employment within the system. Employees caring for residents in facilities licensed by OMRDD are responsible for the treatment of individuals who can neither defend themselves from abuse, and in some cases cannot even report it to the authorities.

One bill that passed in the Senate during the 1987 session would permit not-for-profit providers to check the backgrounds of candidates for criminal convictions when they will be engaged directly in the care and supervision of clients.

#### Speedy Approval of Rate Appeals

Another bill that passed in the Senate dealt with timely response to rate appeals. There is currently no guideline for submitting and approving rate appeals for voluntary operated community residential programs licensed by OMRDD. This results in unnecessary delays in processing rate appeals. This is costly to both the state and provider, it's time consuming and most often has negative effects on the quality of facility operations.

This bill requires the Commissioner of OMRDD and the Division of Budget to make a final determination for a fee rate or rate appeal within 90 days after receiving a completed application.

#### Capital Dollars for Land Costs

Another issue for consideration is reimbursement of land costs. Because suitable buildings and land are needed for community development, reimbursement of cost is justified.

I sponsored a bill that would reimburse voluntary providers for the costs of real property acquired for approved capital projects serving persons who are mentally retarded and developmentally disabled.

#### Recruitment and Retention of the Workforce

Finally, I'm quite concerned with the workforce in voluntary agencies. New York has consistently been a leader in moving the mentally retarded from institutions into the community. As a result, many private not-for-profit "voluntary agencies" have been contracted to provide services.

Unfortunately, these agencies which employ more than 54,000 people and are responsible for providing vital programs have encountered great difficulty in recruiting and retaining workers.

The process of constant recruiting and retraining has proven to sometimes have a negative impact on mentally retarded and developmentally disabled persons whose relationship with the health care worker becomes the center of his or her life.

The issue of salary enhancement is yet another barrier confronting the workforce. Health care professionals are overworked, overstressed and underpaid. The result is a high staff turnover rate.

It's been estimated that by 1986, the yearly staff turnover at some community residences was as much as 50 percent.

In efforts to prevent a possible crisis, money was allotted in the 1987-88 Mental Health Budget for salary increases. We are looking for other alternatives to aid in the prevention of high staff turnover rate.

On February 3, I held a joint public hearing in Albany with Assemblywoman Elizabeth A. Connelly on workforce recruitment and retention in voluntary agencies in hopes of deciphering just exactly what the legislature can do to address the problem.

#### Care at Developmental Centers

The Office of Mental Retardation and Developmental Disabilities plan to close six developmental centers in a growing concern... especially when considering the impact the closings will have on clients residing in the developmental centers and those living at home with their families as well as on employees and the community.

As mentioned before, New York has consistently been a leader in moving its mentally retarded and developmentally disabled from institutions into the community. To maintain an institution is considerably more costly than community alternatives.

It becomes increasingly apparent that the closing of developmental centers is necessary to aid in the funding of community programs.

By the year 1991, OMRDD has targeted to close six of its institutions with Staten Island Developmental Center already having been closed last year. The time-table has been set for Westchester, Craig, Bronx, Manhattan, Newark and Rome Developmental Centers.

I think that a community setting would better represent a superior living environment for the mentally disabled.

We will make every attempt to place clients in community programs that are based as closed to their families as possible. Placement will be determined based on need and accommodating the desires of clients and their families.

In addition, most clients will be afforded an earlier opportunity for community placement than otherwise would have occurred.

My primary concern with developmental center closings is making certain that the clients living at home don't suffer at the expense of the facility closings. There are many people who have awaited placement in appropriate residential settings at home with their families. They should be afforded the same opportunity of getting a community bed as those in the institutions have.

The Commissioner of OMRDD is required to submit on a quarterly basis information involving the closings. Also to be included will be information on the development of programs to address specialized services for special populations such as the medically frail.

I will closely monitor the information contained in these reports to make sure that the needs of the clients are being met and that the quality of care is maintained.

I also plan on looking into ensuring that there's adequate staffing levels at all of the developmental centers to ensure quality of care. The Senate Mental Health Committee held two hearings last fall and was able to gather some pertinent information on staffing levels. Coupled with helpful suggestions, we received input on just what the situations and problems are. We can now sort through recommendations and use information to develop new initiatives regarding the system. Now we are better able to go forward and examine developmental center staffing levels in hopes of guaranteeing adequate care.

The New York State Association for Retarded Children has done a commendable job in establishing some truly inspiring programs. Your enthusiasm and unlimited dedication has resulted in quality care for many needy and deserving clients. For these reasons, I would like to thank you for your time and assistance. Your contributions are appreciated.

I am currently in the process of establishing a State Wide Advisory Committee on Mental Health. The panel is intended to provide advocates representing families, Boards of Visitors and advocacy groups with a forum to express their concerns.

As always, I look forward to working with the Association for Retarded Children. Please do not hesitate to contact me if I can be of further assistance. ■

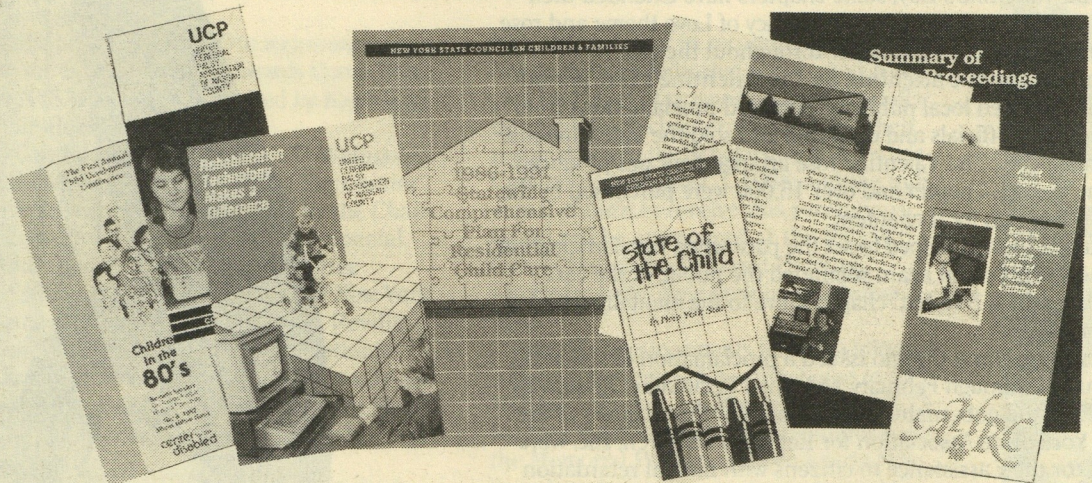


**NEWSLETTERS comma BROCHURES comma ANNUAL REPORTS comma FLYERS comma PRESENTATION MATERIALS comma SLIDES comma DISPLAYS comma CHARTS comma OVERHEAD TRANSPARENCIES comma MAGAZINES comma PROGRAMS comma INVITATIONS comma FOLDERS comma STATIONERY comma LETTERHEAD comma BUSINESS CARDS comma ENVELOPES comma POSTERS comma POINT 44 period**

***Partial client list:***

Albany County ARC  
Center for the Disabled  
Franklin County ARC  
Sullivan Diagnostic Treatment Center  
Suffolk County AHRC  
Nassau County UCP  
NYS Association for Retarded Children  
O.M.R.D.D.  
NYS Commission on Quality of Care  
NYS Council on Children and Family  
NYS Department of Health  
Health Systems Agency of NYS  
Northeastern Association of the Blind  
NYS Association of Rehabilitation Facilities  
NYS Head Injury Association  
Very Special Arts of New York City  
Illinois Department of Family and  
Children Services  
Massachusetts Office for Children  
NYS Governors Task Force  
on Domestic Violence

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**Point 44, Inc.**  
701 River Street  
Troy, New York 12180

**Contact:**  
**Darrell Berman**  
**(518) 272-7800**

## Senate and Assembly Hold Joint Hearings on Workforce Issues

*NYSARC joins with seven other voluntary organizations in providing the Legislature with a seven point budget proposal addressing the staffing crisis.*

On February 3, 1988 the Senate Standing Committee on Mental Hygiene and the Assembly Standing Committee on Mental Health, Mental Retardation and Developmental Disabilities held a joint public hearing in Albany, N.Y. concerning "workforce recruitment and retention in voluntary agencies".

NYSARC joined with seven other voluntary organizations in presenting testimony comprising virtually every private, not-for-profit agency providing services to persons with mental retardation and developmental disabilities. Groups participating with NYSARC were the N.Y. Association for the Learning Disabled, N.Y.S. Association of Community Residence Administrators, N.Y.S. Association of Rehabilitation Facilities, N.Y.S. Association of Day Treatment Providers, N.Y.S. Council of Catholic Charities Directors, United Cerebral Palsy Association of N.Y.S. and the Interagency Council of Mental Retardation and Developmental Disabilities Agencies.

Senator Nicholas Spano (Chairman of the Senate Mental Hygiene Committee) and Assemblywoman Elizabeth Connelly (Chairperson of the Assembly Committee on Mental Health, Mental Retardation and Developmental Disabilities) as well as respective members of their committees listen to testimony from providers, advocates, commis-

sioners, staff members and parents concerning issues regarding the staffing crisis.

The coalition of organizations representing agencies who provide services to persons who are mentally retarded and developmentally disabled presented to the Legislature a seven point proposal (see OCV article "Association Recommends Changes to 1988-89 N.Y.S. Executive Budget") aimed at enhancing employee wages and benefits as well as service-related education and training opportunities.

Following the legislative hearings a press conference was held. Both Senator Spano and Assemblywoman Connelly were present at the press conference.

The Executive Director of NYSARC, Inc. Marc N. Brandt, opened the press conference with a joint statement from the salary coalition. He stated to the press that:

"We have come before the Legislature today to tell the public about a critical problem threatening the care rendered to the mentally retarded and developmentally disabled citizens of New York State who are served by not-for-profit agencies such as ours. Simply stated, our ability to pay employees competitive wages and benefits has been steadily eroding over the past few years. As a result, we are losing our ability to recruit and retain adequate staff to care for the severely disabled persons to whom we pro-

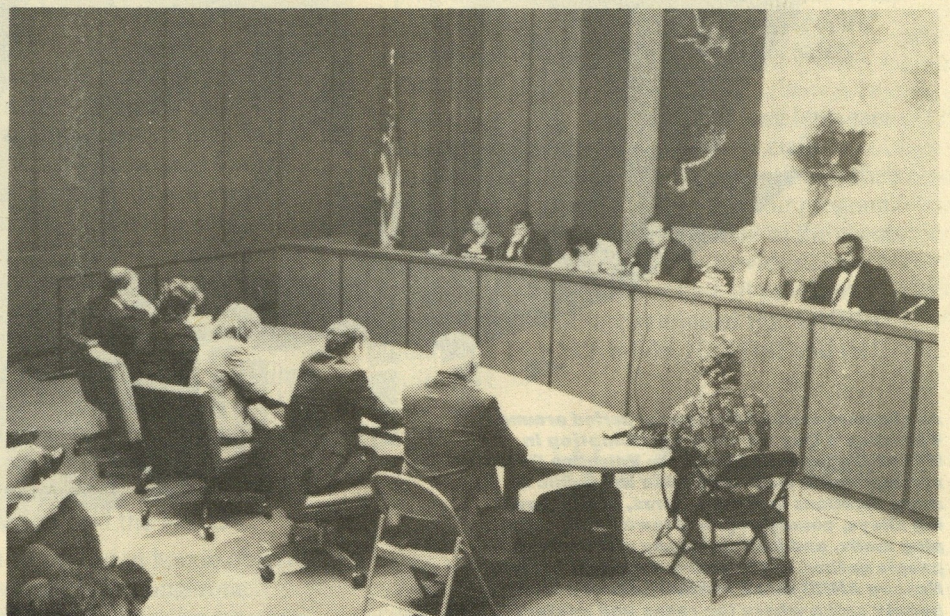
vide services. Staff turnover rates are now between 30% and 50%. On average, 75% of our staff are employed by our agencies for less than three years.

Right now there are some 200 not-for-profit agencies offering a broad range of day and residential services to some 50,000 persons with developmental services throughout New York State. These agencies employ some 25,000 persons and are the backbone of the state's own policy of providing community services to this severely disabled population. In order for this policy to succeed, we must be able to recruit and retain decent staff. Without such staff, the welfare of the severely dependent and highly vulnerable person for whom we care will be increasingly threatened.

Today, we have set forth a seven point proposal aimed at enhancing employee wages and benefits as well as service-related education and training opportunities. We are hopeful that the Legislature will adopt this proposal as part of the state's 1988-89 budget.

I would like to thank both Assemblywoman Elizabeth Connelly and Senator Nicholas Spano for holding today's joint hearings and giving us the opportunity to bring the staffing issue to the attention of the State Legislature. Today's hearings are essential if the public and the state are to realize the importance of addressing this critical issue."

It is hoped that the Legislature as well as the Governor will respond favorably to the salary coalitions proposals. ■





# Legacy of Love Marked by State

Many NYSARC chapters took part in this year's Legacy of Love public awareness effort.

Something very special happened in N.Y.S. during February from Niagara Falls in Niagara County through the entire state to Montauk Point in Suffolk County.

While special attention was given to the chapters to the period around Valentine's Day, some chapters have extended their participation and are using the Legacy of Love theme and rose arrangements as a fund-raiser throughout the year.

To focus public attention on the Valentine's Day period chapters placed local publicity, obtained proclamations from government officials and displayed and sold the Valentine rose arrangements. The Valentine rose arrangement was produced by the Cayuga Chapter and over 15,000 were purchased by the public through local chapters.

Matilda Cuomo helped to set the pace when her participation in the special event again reminded the public of the care and love which NYSARC chapters give to the mentally retarded year-round.

Governor Mario Cuomo issued a proclamation designating February 7 through February 14 Mental Retardation Awareness Week. In the gubernatorial proclamation the chapters of the New York State Association for Retarded Children, Inc. were cited for their assistance to citizens with mental retardation and their families. The governor emphasized that because of NYSARC's efforts thousands of individuals are leading fulfilling and productive lives. He cited NYSARC's efforts in public education and emphasized that the Legacy of Love public awareness campaign will add to the public's understanding of people with mental retardation. ■



**New York's First Lady, Matilda Cuomo, was presented with a Legacy of Love rose arrangement by Deborah who is in the Schenectady day treatment program.**



**As chapters marked the special period around Valentine's Day for their participation in NYSARC's Legacy of Love, the Valentine Rose arrangements were offered to the public in many locations including stores, banks, bowling alleys, county centers, town halls, shopping malls, and just about any place where people gather. In the photo, members of the Nassau AHRC make another sale at a local beauty salon where the roses and posters were displayed.**



(Continued from Page 1)

New York State Department  
of Environmental Conservation  
21 South Putt Corners Road  
New Paltz, New York 12561-1696

RE: Draft Environmental Impact  
Statement Proposed Letchworth  
Village Hospital Waste  
Disposal System, DEC 13422-25-3

Dear Mr. Biegel:

On behalf of our clients, the New York State Association for Retarded Children, Inc. ("NYSARC") and the Welfare League, we submit the following preliminary comments to indicate the nature and extent of their concerns regarding the proposed hospital waste disposal system at Letchworth Village Developmental Center ("LVDC").

NYSARC is a statewide not-for-profit organization dedicated to protecting mentally retarded individuals in the state and insuring that there are appropriate and adequately funded programs and treatment facilities available for this special population. NYSARC has chapters in all counties in this state and at ten developmental centers. The chapter affiliated with LVDC is known as the Welfare League.

NYSARC and the Welfare League are extremely distressed by New York State's Office of Mental Retardation and Developmental Disabilities' ("OMRDD") or "Applicant") current proposal to allow an inexperienced private contractor to construct and operate a hospital waste incinerator on the LVDC premises. Particularly inappropriate is OMRDD's proposal to cart in hospital waste from surrounding areas, necessitating a different sort of incinerator than would otherwise be appropriate for LVDC. It is evident from the Draft Environmental Impact Statement ("DEIS") that OMRDD's concern is solid and infectious waste management from a statewide perspective. First and foremost, however, OMRDD should be protecting the mentally retarded. Instead, OMRDD is prepared to expose them to unknown risks in a misguided effort to save perhaps a few dollars in fuel costs. This abuse of discretion by the Applicant, coupled with the comments on the DEIS stated below, demonstrates that OMRDD's application for a permit for the proposed hospital waste incinerator at LVDC should be denied.

I. No Satisfactory Analysis Has Been Done of The Effects of the Effluents which will be Produced by the Project on LVDC's Special Population

Specific analysis of the local population is clearly required by the State Environmental Quality Review Act ("SEQRA"). Section 8-0109 (2) requires that the Environmental Impact Statement deal with the specific significant environmental impacts which can be reasonably anticipated.

See also 8-0109(2)(i).

The DEIS states, at page 41, that the current residential client population of Letchworth Village is composed of more than one thousand mentally retarded adults. The DEIS further notes that the "patients' educational abilities are limited to elementary grade level."

The DEIS does not make any further attempt to analyze the project's effect on this population, with its obviously special characteristics.

For example, no mention is made of the remarked and well-known increase in physical disabilities associated with this special population. OMRDD's Own Developmental Disability Information Survey, dated February 5, 1988, finds that, among other things, (i) 25% of the LVDC residents suffer from epilepsy; (ii) 24% suffer from neurological impairment; (iii) 57% have behavioral disorders, and (iv) 30% suffer from seizure disorders. In addition, a full 58% of the LVDC population regularly requires some sort of medication.

The DEIS fails to address whether these medical conditions, including the side effects of medication, alter the conclusions drawn by the DEIS. Instead the comparison is made of the effects of the effluents of this plant with the guideline rates, obviously established based on a "normal" population. Thus, no satisfactory analysis has been made of the effects of the effluent to be produced by the proposed project on LVDC's medically sensitive population, and, for that reason alone, the requested permit should be denied.

II. Letchworth Village's Population Will Be Exposed to the Effluent 24 Hours a Day, Six Days a Week

Unlike the "normal" populations studied and upon which the guidelines for emissions standards have been drawn, the affected population here is not mobile. They are the "normal" population, which either works by the incinerator but leaves to go home to other, cleaner air, or lives by the incinerator but leaves daily to go to work some place else. Because they would be in extremely close proximity to the proposed incinerator 24 hours a day, six days a week — every moment the proposed incinerator is working — any adverse effects of the "normal" population must be multiplied. This has not been taken into consideration by Applicant, and the DEIS provides no satisfactory analysis of this heightened risk factor.

III. The Provisions for Responses in Emergency Situations are Inadequate

Eighty-two percent of the LVDC population are severely or profoundly mentally retarded. Should an emergency situation, such as a fire, an explosion, a spill, or a transportation accident, occur, no procedure has been developed to manage this special population, which would have no awareness of the potential dangers posed by proximity to infectious waste. Indeed, OMRDD seems to have wholly ignored this problem.

The LVDC population is, for the most part, not able to be trained in emergency procedures and they require constant supervision. Often, they freely traverse the campus and may easily be exposed to dangerous and hazardous conditions. A guard at the entrance to the facility, the safety factor proposed in the DEIS, will not adequately protect the LVDC population in case of fire or other emergency. Clearly, the security precautions described at para. 5.10 of the DEIS are inadequate.

IV. The Steam Sterilization (Autoclaving) Technique Alternative Was Not Adequately Considered by OMRDD

At pages 136-37 of the DEIS, the authors dismiss the steam sterilization alternative as not viable "for disposing of large waste steam generated within the county that will be handled at the Project." However, no analysis is done which would reflect its viability for disposing of the small amount of hospital waste produced at Letchworth Village.

The disregard of this alternative is simply another manifestation of the Applicant's callous disregard of the interests of the special population at Letchworth Village, interests OMRDD is obligated by law to protect. Indeed, OMRDD seems to view the mentally retarded as an easy mark upon which to implement untested technologies.

V. Remtech, the Operator, Has No Experience in Running These Incinerators

All the projections contained in the DEIS assume that the plant will be operated efficiently. (e.g., "Because an incinerator is most efficient when operated at a continuous temperature..." (p.111)) However, Remtech, the operator chosen by OMRDD, appears to have no prior experience in operating a facility of this nature. Accordingly, the prospect of running the plant as efficiently as stated is greatly diminished and the risk to the community commensurately greater.

Moreover, even the DEIS recognizes that the training program provided by the Manufacturer (IWI), is inadequate. It is planned that this training will be augmented by "a training and certification program being developed by Northeast States for Coordinating Air Use Management and the American Society of Mechanical Engineers." In addition, a DEC-sponsored combustion institute is being established for such training programs at Cornell University. (DEIS at 11). However, since appropriate training programs do not currently exist, the future implementation of these proposed programs is purely speculative. At a minimum, no permit should be granted until these training programs are established and shown to be adequate.

In addition, the DEIS provides no satisfactory analysis of the effects on any population in the event the plant is not run at peak efficiency. This probability must also be considered and analyzed.

VI. No Penalties are Provided for the Operator Should the Facility Not Be in Compliance with All Federal, State and Local Health and Safety Codes, Rules and Regulations

The DEIS notes that the operator is contractually obligated to monitor its compliance with applicable rules and regulations (DEIS at 62). However, a review of the contract between Remtech's assignor and OMRDD, dated March 28, 1985, reveals that there are no penalties provided should Remtech, the inexperienced operator, fail to comply with any rule or regulation. Moreover, as noted in the DEIS, the state currently has no enforceable regulations, and the federal government has no standards for hospital waste disposal. Thus, the pur-

ported contractual protection provides no comfort at the present time. No permit should be granted until penalties to assure operation at the most efficient levels have been established.

VII. No Studies Have Been Provided Which Demonstrate the Safety of the Recombinant Chemicals Produced by this Project

The analysis provided in the DEIS traces particular chemicals going into the incinerator and analyzes these chemicals' presence in the effluent. No analysis is presented of the effect that combining these chemicals and burning them has on the emissions. And once again, no analysis is made of the effect of this recombinant effluent on the special population of LVDC. See Points I-II supra.

VIII. Any Determination of this Application Should Be Stayed Until Appropriate Regulations Are Adopted by DEC

As of the date hereof, no enforceable regulations exist which would require compliance with performance standards and best available control technology (see p. 59 of DEIS). As the current DEIS evaluates the proposed project based solely on "proposed guidelines", further evaluation should await enactment of the final regulations and, therefore, no permit be granted until it can be shown that the proposed incinerator would meet those standards.

In sum, SEQRA clearly requires the DEC to take steps to establish the safety of this specific project on the most specifically affected population — LVDC residents. This simply has not been done. The Applicant has not produced a single study of the effect of this project on a mentally retarded population living in such close proximity for the entire 24 hours, 6 days per week this incinerator will operate. Exacerbating this glaring deficiency is OMRDD's failure to select a contractor who has a record of safe and efficient operation and the absence of any enforceable and meaningful standards for its operation.

Based upon the foregoing, NYSARC and the Welfare League request that the Applicant's request for a permit be denied. Should DEC consider any other conclusion, NYSARC and the Welfare League hereby request that both a public hearing on the DEIS and an adjudicatory hearing on Applicant's request for a permit be held, and that they be provided an opportunity to participate fully.

Robinson, Silverman, Pearce,  
Aronsohn and Berman

By: James M. Altman

**The Welfare League Chapter as well as NYSARC will be following the course of events regarding this proposal. The Welfare League is extremely concerned for the welfare and rights of the residents living in Letchworth Village D.C.**



# GUEST COMMENTARY

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

## Recent Cases of Legislation Concerning the Role of Guardians, Conservators, Committees and Courts in Life-Sustaining and Other Significant Medical Decisions

by:  
Paul Stavis, Counsel  
State of N.Y. Commission  
on Quality of Care for the  
Mentally Disabled

(The following article is reprinted with permission by the author, Paul Stavis. The article appeared in the June-July 1987 Quality of Care Newsletter. The role of the guardian is of extreme importance to our Association and Mr. Stavis' comments should prove interesting for our members.)

When and how can a person being kept alive by the heroic measures of modern medical technology be disconnected to allow nature to take its course, and who is to make that decision? Indeed, what measures might be considered both heroic, yet also so fundamental to basic human care (such as air, water and food), that they may be refused by no one else but the patient. These questions have been increasingly handed to courts to resolve on a case-by-case basis. And, as this article is being written, the State Assembly and Senate have indicated their intent by passing the comprehensive "Do Not Resuscitate" bill (S413/A678-A) and sending it to the Governor.

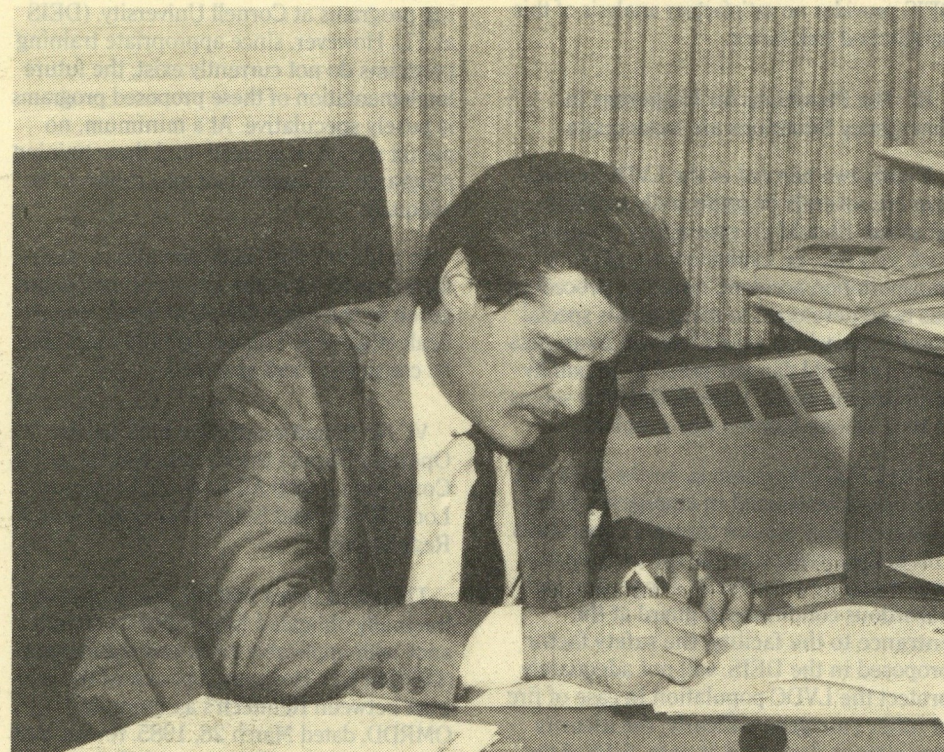
Recently, New York's Appellate Division (the middle level appeals court) added another landmark judicial precedent which permitted a conservator (the patient's wife) to order and legally authorize the treating hospital to remove a feeding tube from her 33-year-old husband who was existing in a chronic vegetative state with no hope of recovery. See, *Delio v. Westchester County Medical Center*, N.Y. Law Journal, June 4, 1987. The *Delio* decision and others which have been discussed previously in this column, such as *Storar*, *Eichner*, *Conroy*, et al., all deal with the difficulty of deciding important matters of life and death for patients unable to decide for themselves—legally termed "incompetent" to make medical decisions. This type of incompetency affects comatose patients, mentally disabled persons and young children, and requires that medical decisions for them be made by another.

### Legal Principle

The emerging principle of law that has arisen from these recent cases is that as far as life-sustaining medical decisions are concerned, a competent person can refuse virtually any significant medical treatment; a person who has become incompetent to make medical decisions but who has recently made clear and convincing expressions of his desires regarding life-sustaining treatment may have those decisions implemented by an authorized legal surrogate or by a court of law or both; and, a persistently or

lifelong incompetent person who has no known competent expressions of his desires regarding life-sustaining treatment may not have such a decision made for the first time by another person, even a legally appointed surrogate, e.g., a guardian, conservator or committee without the enactment of some specific laws from the Legislature.

Beginning with the *Eichner* decision by the highest court in New York State, 52 NY 2d 363 (1981), the principle was established that life-sustaining treatment may be ordered terminated by the patient's committee who has been duly appointed by a court, if there is clear and convincing evidence that such were the patient's instructions or wishes to committee, family, friends or others. The Court of Appeals stated its reasoning by



acknowledging that: "The basic right of a patient to control the course of his medical treatment has been recognized by the Legislature in the Public Health Law." Next, it stated that under the New York law: "There is no statute which prohibits a patient from declining necessary medical treatment or a doctor from honoring the patient's decision... even if the treatment is necessary to preserve the patient's life... Thus a doctor cannot be held to have violated his legal or professional responsibilities when he honors

the right of a competent patient to decline medical treatment." 52 NY 2d at pages 376-377.

### Catch-22

It is important to note the position of the opposition to termination of life-sustaining treatment, which was asserted by the district attorney in the *Eichner* case, who contended that: "whatever right the patient may have is entirely personal and may not be exercised by any third party once the patient becomes incompetent". Of course, in a sense this position is a Catch-22. Consider a case where a competent patient decides not to have life-sustaining treatment, which is concededly his or her right. However, as soon as the patient lapses into a coma or otherwise becomes incompetent immediately before death — maybe only a few minutes after his competent declaration — then a conservator, guardian, committee, treating physician could not, under the DA's position, ever refuse life-sustaining treatment. The Court of Appeals rejected this position, and held that: "where it is claimed that a person, now incompetent, left instructions to terminate life-sustaining procedures where there is no hope of recovery...", then medical treatment may be terminated upon the order of another person who is or has been legally authorized to act as the committee, conservator or guardian of the person. But there is an important caveat, to wit: the desires of the patient must be or have been clearly made known and be of such a nature to convince a reasonable person, such as the surrogate decision-maker, the treating physician and probably the treating institution as well. If all concur, then the patient's wish may be honored. If one of these parties has doubts and is not convinced, or does not want to run the risk of liability or future litigation in this regard, then a court may be petitioned to decide in advance whether

which was decided by the Court of Appeals at the same time as the *Eichner* case, the patient was incompetent throughout his life due to mental retardation, and his surrogate decision maker was his mother who was also his judicially appointed guardian and committee. She at first consented to blood transfusions, then she refused the transfusions. The Court of Appeals did not question either her authority as mother or surrogate to make medical decisions for her son and conceded that she was acting in what she truly believed were the best interests of her son, who suffered considerable pain and discomfort from the life-sustaining blood transfusions at issue. However, at the request of the patient's primary caretaker, the director of the State Developmental Center, the Court gave him the surrogate power to consent to blood transfusion treatments for the patient because the Court could find no clear and convincing evidence of the patient's desires and believed, under the facts of the *Storar*'s case and without legislative guidance, that denial of the transfusions would be comparable to the denial of his fundamental needs even for a brief interval of months; it held this treatment to be in the patient's best interests.

### Role of the Courts

Judge Fuchsberg, in his dissenting opinion describes the role of the courts in such life-sustaining treatment decisions:

I do not question the power of courts to decide such questions. In open cases, when there is disagreement among those in whom resides the practical and primary responsibility to make such agonizing moral choices, when the disputants reach an impasse, the judiciary, the arm of our society trained to decide controversies between persons or between persons and the State, cannot shirk its obligation.

For example, the *Delio* case was commended because the treating facility would not accede to the wife's request that it remove the feeding tube from a 33-year-old man in a permanent vegetative condition. His wife petitioned the Court to be appointed conservator for her husband with express power to order removal of the feeding tube. Despite the fact that the trial court could find abundant evidence that was clear and convincing that by the patient's previous expressions and actions he would want the tube removed, the Court felt that it had not statutory authority to appoint a conservator to do this. However, the Appellate Court reversed and established the conservatorship of the wife with express authority to order the facility to stop the tube's use or transfer the patient to a compliant facility. Thus again, a case is brought to court because a concerned party such as a spouse, family member, friend, medical professional, institution or caretaker, disputes a prospective course of treatment. The Court then decides who is the best surrogate decision-maker, or whose proposed decision for the patient is in his or her best interests. And it is important to note that in those instances where treatment is ordered to cease, that order is implemented through a surrogate decision maker such as a guardian, conservator or committee of the person. See, also *Workman's Circle Home v. Fink*, NYLJ 5/19/87 at pg. 14.

Guardians, conservators and committees of the person are inherently empowered to preserve the welfare of that person (called the "ward"), which often includes direct

clear and convincing evidence exists that the patient would desire a cessation of life-sustaining care of if it would be in that patient's best interest to do so. Indeed, in all of these cases on the appropriateness of cessation of such treatment, it was commenced because one of these principal parties had doubts about the facts and applicable law regarding the patient's care or of their own responsibilities and liabilities under the law.

By way of contrast, in the *Storar* case,



authority to take action to preserve a patient/ward's physical and mental health. Importantly, the appointing court must believe that such surrogates will act as a fiduciary, i.e. in the best interests of the ward. As put by one court:

Fiduciaries such as trustees, administrators...or guardians of wards of the Court are generally expected to conduct themselves in a manner above reproach. They are entrusted with an obligation to conduct the affairs of others, who in many instances are unable to do it for themselves...This standard has been applied with uncompromising rigidity by the Courts.

#### In Mtr. of Zaccaro NYLJ 8/31/84

Decision by courts in other state jurisdictions have stated that persons who were never competent or who have not made clear expressions previously regarding life-prolonging treatment have the same right to terminate treatment as competent persons, based upon the value of human dignity. Compare, *Storar* discussed above with *Superintendent of Belchertown State School v. Saikewicz*, 370 NE 2d 417 (1977); *Matter of Quinlan*, 355 A 2d 647 (1975); and *Matter of Spring*, 405 NE 2d 115 (1980). In *Saikewicz*, the Massachusetts Supreme Judicial Court stated: "...the prevailing ethical practice seems to be to recognize that the dying are more often in need of comfort than treatment...To protect the incompetent person within its power, the state must recognize the dignity and worth of such a person and afford to that person the same panoply of rights and choices it recognizes in competent persons".

#### A Case Study of Aggressive Care in the Absence of Court Order or Surrogate

The Commission's report, *In the Matter of Joseph Kirsch*, demonstrates the consequences which sometimes occur when no legally authorized surrogate decision maker is readily available to consent to the prompt provision of appropriate medical care, to refuse medical treatment that might be futile, as well as to assure the completion of periodic or necessary examinations. In the case of Joseph Kirsch (a pseudonym), the option of aggressive medical treatment (chosen for the patient by his residential facility when no legally authorized surrogate was available, nor court order sought) illustrates the concern that such treatment may at times result only in the prolongation of a painful death. The facility, at times, may be compelled to avoid the choice of palliative, conservative treatment to discourage any criticism that it failed to provide the appropriate medical treatment that a family member would have provided or the individual, if competent, would have chosen. In Mr. Kirsch's case, the aggressive medical treatment approach mandated a double amputation of his legs to provide skin grafts for severe skin ulcers and a colostomy to avoid infection of the wounds. Timely consent for less drastic treatment at an earlier stage was not obtained through court authorization and that once the patient's condition severely regressed, a more conservative approach was apparently not seriously considered. Mr. Kirsch died after the colostomy and before the amputations could take place. If Mr. Kirsch had a proper surrogate to participate in his medical decision making, the course of his treatment might not have been as chaotic as it was.

#### Related Legislative Proposal

The Commission has introduced a legislative initiative (Senate 6090, Assembly 7994) to clarify the existing New York State common law (court decisions) that judicially appointed surrogate decision makers have the authority to consent to health and medical services. The bill would make other due process changes and also expand the guardianship statute, Surrogate's Court Procedure Act Article 17-A, to authorize the appointment of guardians for persons who have a developmental disability and for whom such an appointment would be in the guardianee's (the ward's) best interest as determined by the Court. In addition, the judge must make a finding that the proposed guardianee is unable to manage his or her personal affairs prior to appointment a guardian of the person for the mentally retarded or developmentally disabled person.

Thus, while a third person, such as a guardian, under the Commissioner's proposal as well as common law, see, *Storar* as well as N.Y.S. Public Health Law Section 2504(4), may give medical consent for another in many instances as the court in *Matter of Spring* 405 NE 2d 115 (Sup. Jud. Ct. Mass. 1980) stated: "these private decisions must be made responsibly, subject to judicial scrutiny if good faith or due care is brought into question in subsequent litigation." Guardians, conservators and committees, as judicially appointed surrogate decision makers, are fiduciaries and, as such, must conduct themselves in a manner above reproach. In addition, the proposed medical treatment for wards of these fiduciaries are presented by medical professionals who are held to the ethical standards of their profession enforced by professional misconduct and licensing proceedings. The alternative and risks of the treatment must be explained to the legally authorized decision maker for the professional to receive valid informed consent on behalf of the ward.

Section 1756 of the Commission's legislative proposal, the first proposed major revision to the 17-A guardianship article of law, provides for the appointment of a guardian ad litem, an attorney to assist the ward and to review the guardianship order when the judge determines that the interests of the guardian are adverse to the ward or that the interests of justice require a review of the appointment. This, and other aspects of the legislative proposal are intended to enhance the due process protections afforded the ward under current law.

The appointment of a surrogate decision maker, an advocate to review critical decisions being made or which should be made on behalf of the ward, can promote the provision of timely and appropriate care and treatment as well as assistance in other aspects of life. As stated in N.Y. Mental Hygiene Law, Article 80 (the surrogate decision-making committees demonstration project to provide consent for patients without judicially authorized surrogates or family members), the provision of timely access to health care for mentally disabled persons is an important objective for New York State and resort to court authorization has, in some cases, resulted in undue delay in the provision of necessary care, needlessly jeopardizing the health of the mentally disabled.

The provision of medical consent by judicially appointed surrogates is thousands of years old, dating to ancient Greece and Rome. Such persons under contemporary law are under continual jurisdiction of the Courts to behave in a fiduciary capacity and the medical procedures at issue are also subject to scrutiny by the ethical standards

of the medical professionals and treating or residential facility staff. This traditionally recognized mechanism to promote timely and appropriate care while protecting a patient's right to determine the course of his own treatment or to have the treatment determined so as to serve his best interest, is a tried and true system that has stood the test of time.

#### Conclusion

As has happened so frequently since the famous *Brown v. Board of Education* case in 1954, the judiciary has had to tackle tough societal questions first, and the Legislature has followed later with statutes on how these issues would be resolved. Desegregation, rights of the mentally disabled, family rights such as family planning, custody of children, etc., and now the so-called "right to die" were primarily addressed in litigation and thereafter by statute, as is now happening with the nation's first do-not-resuscitate law.

While the matter of informed consent is a fundamental human right recognized in, and protected by, the U.S. and New York Constitutions, as well as in law, regulations, and by the courts, it is certainly as important that a patient with a major medical illness receive prompt and appropriate treatment to preserve his rights to life, liberty and well-being. Guardianship has been utilized in one form or another for over two thousand years in Western civilization as a means to ensure that, for those patients who cannot give informed consent and determine their own best interests, then the next best person be recognized as having the authority to do so as a surrogate decision maker. In the absence of guardianship, the patient is relegated to the court process for obtaining medical authority, which usually means significant delays in gaining amelioration of illness, and, as seen in many instances by the Commission, this delay and the lack of alternative surrogate decision

making (see, e.g., Surrogate Decision-Making Program, N.Y. Mental Hygiene Law, Article 80) have caused the illness to become an emergency.

Thus, having a stable guardian, particularly a close family member, can be a distinct asset to a mentally disabled person having such needs. ■

## Equipment Loan Fund for the Disabled

The New York State Department of Social Services has instituted a new program which provides low-interest loans (currently 8%) to eligible New York State residents with disabilities to enable them to purchase essential equipment so that they may overcome barriers in daily living or conventional functioning following rehabilitation. The program offers loans from \$500 to \$2,000 for the purchase of essential equipment such as prostheses, ramps, wheelchairs, van lifts, communication devices for the hearing impaired and devices which allow individuals who are visually impaired to pick-out printed materials. Application forms and additional information are available from New York State Department of Social Services, Equipment Loan Fund, P.O. Box 10, One Commerce Plaza, Albany, New York 12260. ■

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# Assembly Committees on Correction and Mental Retardation Develop Recommendations Concerning the D.D. Offender

*Press conference held on January 20, 1988, brings forward several recommendations addressing the issue.*

In December, 1987, the Assembly Standing Committees on Correction and Mental Health, Mental Retardation and Developmental Disabilities held joint public hearings on the issue of persons with mental retardation and developmental disabilities who are involved or at risk of becoming involved with the criminal justice system. The particular focus of the committees was to examine the legal and service delivery systems, as well as other practical considerations, in order to identify why offenders with developmental disabilities are at a substantial disadvantage in the courts and in the community. It's these problems which have resulted in an increase in the number of persons with developmental disabilities being incarcerated in New York's overcrowded jails and prisons.

As a result of the hearings, as well as a series of meetings with key administration officials in both the criminal justice and developmental disabilities service system, a number of problems were identified that negatively impact on offenders with developmental disabilities. These problems result from a general lack of understanding by criminal justice and human service practitioners regarding the problems that these offenders encounter in the criminal justice system. Further, almost no legal avenues or programs exist in either system or in the community to allow courts to divert such persons from jail or prison. Thus, incarceration is often the only placement available for developmentally disabled persons who are arrested.

On January 20, 1988, a press conference was held in Albany, N.Y. The Chairman of the Assembly Committee on Correction, Assemblyman Daniel Feldman, the Chairperson of the Assembly Committee on Mental Health, Mental Retardation and Developmental Disabilities, Assemblywoman Elizabeth Connelly, and the Executive Director of NYSARC, Inc. Marc N. Brandt, answered questions from the press concerning the issue of the D.D. offender.

The two standing committees at the press conference presented a number of recommendations to begin to address the issue. The recommendations presented were the following:

— The enhancement of programs and services designed to address the particular needs of State prison inmates with developmental disabilities, including the establish-

ment of three 50-bed Special Needs Units, intensive case management services and vocational, occupational and special education programs within the Department of Correctional Services;

— legislation to provide for the diversion of persons with developmental disabilities who are charged with misdemeanors and certain non-violent felony offenses to alternative programs;

— the development and dissemination of training curriculums for criminal justice practitioners;

— improving the court's ability to obtain psychological and developmental histories and evaluations of alleged offenders;

— improving discharge planning for inmates with developmental disabilities about to be released from prison;

— the development and implementation of a research study to clearly identify the number of persons with developmental disabilities in New York's State and local correctional facilities.

It is the belief of the Association and the two standing committees in the Assembly that incarceration of offenders with developmental disabilities is often counterproductive to the principles of either justice or rehabilitation. Placing persons with developmental disabilities in jail or prison is often destructive to the individual and disruptive to the correctional facility. Where possible, alternatives to incarceration and other diversion programs should be established which keep such offenders who are found mentally incapacitated or who do not present a threat to community safety from jail or prison. For those offenders whom incarceration is necessary, a continuum of programs must be available.

At the October 1987 Annual NYSARC Convention the Board of Governors approved the formation of an Ad Hoc Committee to Review and Study the Issues Pertaining to Persons who are Mentally Retarded and Developmentally Disabled at Risk or Within the Criminal Justice System. When the committee meets it will be reviewing the recommendations of the Assembly Committees on Correction and Mental Health, Mental Retardation and Developmental Disabilities. ■

# Association Recommends Changes to 1988-89 N.Y.S. Executive Budget

*NYSARC, Inc. calls for additional funds for enhancement of salaries and local assistance funding; higher client care staffing ratios; restoration of COPREP and the establishment of an 800 hotline number to assist in the referral of persons with developmental disabilities who come into contact with the criminal justice system.*

On January 6, 1988 Governor Mario Cuomo delivered to the Legislature his annual State-of-the-State message. The following week the Governor's budget request was delivered to the Legislature.

This year the Governor's State-of-the-State message was entitled the "Decade of the Child" and emphasized the "frightening" statistics concerning the extent to which children in New York State live in poverty, are inadequately nourished and under educated. In keeping with this theme the Governor's message emphasized the need for the state to put forward programs dealing with childhood health and education. Special emphasis was given to the "Plight of the New York City Public Schools", "Early Childhood Education and Child Care" and "Targeted State Aid" aimed at the "at risk student".

The Governor's message also addressed services to persons who are mentally retarded and developmentally disabled. The State-of-the-State message had specifically mentioned the workforce issue, contained salary enhancements for day treatment direct care and support staff, recognized the importance of services to home-based clients and stated that there would be accelerated community development particularly in New York City. The Governor's message also contained remarks concerning individuals who are developmentally disabled who are at risk or within the criminal justice system.

After a careful review and analysis of the proposed budget, the Executive Committee of the Board of Governors adopted the following recommendations for the fiscal year 1988-89 State Budget.

## I. Office of Mental Retardation and Developmental Disabilities

**A. Staffing Crisis** Not-for-profit agencies serving persons with developmental disabilities have been experiencing severe problems recruiting and retaining adequate staff. Low salary scales, sub-standard fringe benefit rates and limited opportunities for employee advancement and training are largely to blame.

### Recommended Budget Action:

1. *Appropriate \$9,800,000* to enhance salaries effective April 1, 1988 for direct care and support workers in Local Assistance and other community services directly contracted by OMRDD including family support and supported work.

2. *Appropriate \$1,664,000* as requested by the Governor in the OMRDD budget to enhance salaries for direct care and support staff working in Day Treatment Programs effective April 1, 1988.

3. *Enact Budget Language* requiring OMRDD, in conjunction with service providers, to propose minimum basic fringe benefit levels and fringe benefit enhancements to be implemented in FY 1989-90.

4. *Enact Budget Language* requiring OMRDD to develop a new mechanism for annually adjusting rates, fees and contracts so that our agencies can receive inflationary increases that keep our salaries competitive.

Language also requires OMRDD to revise existing salary screens to recognize competitive labor costs.

5. *Appropriate \$1,000,000* to establish a loan forgiveness/tuition assistance program that would be awarded to individual agencies to employees in return for a specific work obligation.

6. *Appropriate \$1,000,000* to develop and implement a flexible program to provide for various training needs.

7. *Appropriate \$3,100,000* to enhance salaries effective January 1, 1989 for all direct care and support staff by an additional \$1,000 per employee to bring all of these salaries up to competitive levels.

**B. Local Assistance Funding** Aid to Localities formula funded programs including Local Services, Chapter 620, Unified Services and Direct Contract Funded Sheltered Workshops have been limited to 3% increases in State Aid Contracts for the past four years. These increases have not kept pace with inflation associated with operating programs such as sheltered workshops, clinics, day training and recreation. As a result many chapters are incurring operating deficits which restrict necessary expansion as well as routine maintenance of plant and equipment. These programs are the backbone of community day services to persons with developmental disabilities and must receive sufficient reimbursement for the cost of providing services.

### Recommended Budget Action:

1. *Appropriate \$2,500,000* in additional funding to enable formula funded programs to receive a 6% contract increase for FY 1988-89. This amount is aimed at compensating current contract levels for inadequate prior year inflationary increases and paying for anticipated levels of inflation expected during FY 88-89.

2. *Appropriate \$1,000,000* in additional funding for the Voluntary Day Maintenance Program in the Aid to Localities Budget in order to enable formula funded programs to adequately address routine maintenance concerns which have often been neglected due to the general shortage of state aid.

### C. Developmental Center Staffing

The Governor deleted language requiring minimum staffing levels from his FY 88-89 budget request. This language should be restored by the Legislature to safeguard minimum developmental center staffing requirements.

### Recommended Budget Action:

1. *Enact Budget Language* restoring minimum developmental center staffing requirements. This action should include increasing the client care ratio from 1.235 to 1.350 to reflect the need for intensified staffing in recognition of the increase in average client disability levels since this ratio was first proposed in 1984.

2. *Appropriate \$2,500,000* to support the higher client care staffing ratio recommended in #1 above.



**Marc N. Brandt, Assemblywoman Elizabeth Connelly and Assemblyman Daniel Feldman answer questions at January 20th press conference.**



## Consolidated Fiscal Reporting

A new Consolidated Fiscal Reporting System (CFRS) has been developed by the N.Y.S. Department of Mental Hygiene (DMH). The goal of this system is to standardize the content and the reporting periods of the various documents required to be filed by providers of services under the three agencies which are governed by DMH. These agencies are: The Office of Mental Health (OMH); the Office of Mental Retardation and Developmental Disabilities (OMRDD); and the Division of Alcoholism and Alcohol Abuse (DAAA).

The Consolidated Fiscal Report (CFR) together with the Year End Expenditure Report (YEER) are the two essential components of the new CFRS. The CFR, as its name implies, is a consolidation, into a single report, of all the fiscal and statistical information required to be filed with DMH annually. Providers will no longer file separate documents for the various programs they offer. The new report will include information relative to all programs, including workshops, day training, education, fund-raising, etc.

The CFR is designed in such a fashion that its information will complement the information contained in the YEER. These two documents will now be completed in conjunction with each other. Both will use the accrual method of accounting. A required attachment to the CFR filing will be a copy of the provider's certified financial statements.

Providers of services under OMRDD will find that the new report significantly reduces the amount of detailed information required to be reported. All supporting detailed information must be retained by the provider and made available at the time of an audit. The provider is required to certify that all supporting documentation is in their custody.

As indicated above, the CFR is part of a unit together with the YEER and the provider's certified financial statements. What does this mean to a provider and

what adjustments must a provider make? A provider must realize that DMH will now receive a report reflecting the entire picture of the Agency's operations. With the CFR, the YEER and the certified financial statements, DMH will have the capability to compare the three reports for consistency of the reported information and the use of expense allocation methods. Providers must increase their efforts to monitor expenditures and plan spending well in advance to maximize revenues in all the programs offered. This function becomes a year-round task rather than a year-end or base-year task. More careful identification and classification of expenditures, particularly administration costs, is essential.

The draft CFR proposes to standardize the methods used for the allocation of administration costs. The use of these methods is mandated unless alternative methods are requested and justified by the provider and subsequently approved by each of three DMH agencies that fund that provider's programs.

The certified financial statements required to be attached to the CFR must reflect the same twelve month period as the CFR itself. This may impact on providers offering additional programs governed by other state departments like the State Education Department which also requires financial statements with their report. If the reporting periods for the different departments do not coincide, the provider may have to incur the cost of two or more twelve month audits within a single year.

Although initial filings of the CFR will not begin until 1989, providers should begin making any necessary changes now as the initial reporting period for upstate providers is January 1, 1988 through December 31, 1988 and for downstate providers July 1, 1988 through June 30, 1989. ■

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## Membership Survey on Guardianship

*In an effort to assist NYSARC in planning for the future guardianship needs of citizens in New York State who are mentally retarded and their families, we would like your assistance in obtaining the following information:*

1. Your County of Residence

2. What is your relationship to the individual who is mentally retarded?

*(mother, father, brother, sister, cousin, other)*

3. If family member, please indicate family composition:

**PARENTS**

Mother

Father

**SIBLINGS**

Male \_\_\_\_\_ Female \_\_\_\_\_

Male \_\_\_\_\_ Female \_\_\_\_\_

Male \_\_\_\_\_ Female \_\_\_\_\_

Male \_\_\_\_\_ Female \_\_\_\_\_

Male \_\_\_\_\_ Female \_\_\_\_\_

Male \_\_\_\_\_ Female \_\_\_\_\_

Male \_\_\_\_\_ Female \_\_\_\_\_

Male \_\_\_\_\_ Female \_\_\_\_\_

Male \_\_\_\_\_ Female \_\_\_\_\_

4. Is there currently a guardian for the person who is mentally retarded:

\_\_\_\_ YES

Relationship \_\_\_\_\_

5. Is there an interest in obtaining guardianship within the next five years?

\_\_\_\_ YES

6. Would you be interested in obtaining information on a method for funding a guardianship program for the lifetime of the person who is mentally retarded?

\_\_\_\_ YES

7. Do you wish to have the New York State Association for Retarded Children, Inc. act as standby guardian for your son or daughter in the future?

\_\_\_\_ YES

8. Would you like more information on guardianship, wills or trusts?

\_\_\_\_ YES

9. OPTIONAL – Please indicate name and address below:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

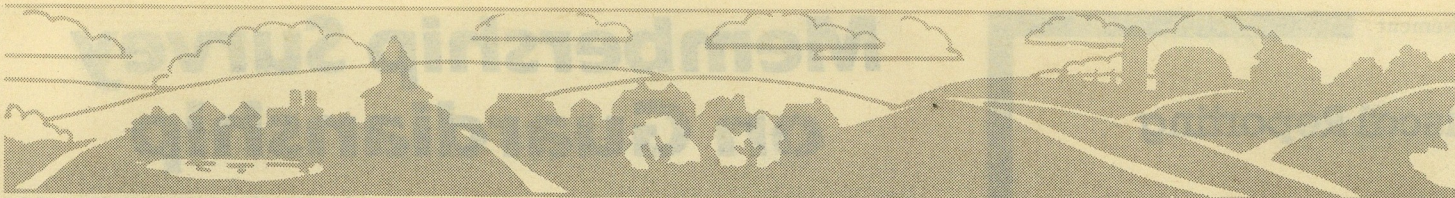
For further information on guardianship, wills and trusts, you may contact the New York State Association for Retarded Children, Inc. at the following address:

NYSARC, Inc.  
393 Delaware Avenue  
Delmar, New York 12054  
(518) 439-8311

**PLEASE RETURN THE SURVEY TO NYSARC, INC. BY APRIL 30, 1988.**

**Thank you for your assistance.**





# CHAPTER

## FULTON

### Photography Club Work Displayed by Arts Council

The Photography Club of the Fulton County Chapter recently completed its first-ever photo exhibit at the Fulton County Arts Council Gallery. The close relationship that is being developed with the Arts Council indicates that the photo exhibit, in which numerous color photos of Fulton County subjects were shown, will be the first of many opportunities for the Fulton County Chapter to explore the arts.

Fulton County Arts Council Board Member Mrs. Lisa Mehigan has been instructing a dance class for the chapter's recreation group since last November and a Spring recital is planned.

Jeremy Walsh, who instructed the Photography Club members on the principals of photography, has helped Recreation Director Nancy Murphy interest the group in both painting in acrylics and simple ceramics. Some of the members hope to show their works at the Fulton County Arts Show in May of this year.

On February 29th, the "Rainbow Theatre Company", another project of the recreation department staff and volunteers demonstrated their creative talents at a dinner theatre production of children's stories in pantomime.

"We strive for a holistic approach to our activity program," said Ms. Murphy, "one that can reach all our clients through exposure to everything from sports to fine arts." ■



Some works of the Fulton County Chapter's Photography Club, on display at the Fulton County Arts Council Gallery, are examined by Fulton County Arts Council Instructor, Jeremy Walsh, and members of the Photography Club, Rose McConley and Paula Mercadante.

## ALLEGANY

### ARC Helps Clients to Move Toward Independent Living

PWI Allegany Chapter's sheltered workshop has recently helped four clients move into apartments.

What will make the difference is that through a state grant, ARC will be able to provide the four people with some support services as they make the transition from living at home, with their families, to living on their own.

Those who will occupy the apartments are doing so because they feel, and the ARC staff agrees, that they are able to make the transition from living at home to independent living, with the help that will be provided by the support staff, headed by Project Manager Sharon Flanigan.

"They are doing so by choice," Mrs. Flanigan says, of the people who are participating in the program. The staff did evaluate the applicants to determine if they were ready to make the move toward independent living.

The residents of each apartment "know each other" through work, but the agency matched them as roommates, based upon personality screening it conducted, Ms. Winans explains.

THE ARC RECEIVED a grant from the state Office of Mental Retardation and Developmental Disabilities (OMRDD) amounting to \$7,900 per apartment to cover start-up costs.

That grant, Ms. Winans explains, covers the staff necessary for the program. It also picks up the cost of leasing the apartments for two months in advance, to get them set up for the program, and provides funds for the purchase of some of the "housekeeping" items the apartment residents will need.

Furniture came from the state warehouse, ARC Executive Director Paul Carpenedo explains, noting the state "buys in bulk" major appliances and furniture, and then agencies, such as ARC, shop at the warehouse to select what they need for their particular programs.

THE SUPPORT STAFF, which consists of Mrs. Flanigan and a part-time worker, will be available to spend up to three hours a day working with each client. ■

## BENEVOLENT SOCIETY

### Willowbrook Chapter to Host 38th Annual Luncheon!!!

The Benevolent Society's 38th Annual Luncheon will be held at the New York Hilton and Towers at Rockefeller Center, at 53rd Street and Avenue of the Americas on May 14, 1988, at 12:00 noon.

Anne and Mannie Barsky, this year's co-hosts, sends out a clarion call to all our members and friends to join together and help make Luncheon Time 1988 as successful as our Anniversary Luncheons have been in the past. Join with us for a delicious lunch, some fine entertainment and help keep our organization in the forefront of those working to make this a better world, better for those who can't always help themselves.

We are honored to have as our most honored guests, Senator Nicholas (Nick) A. Spano, Chairman of the New York State Mental Hygiene Committee who can be justly proud of his accomplishments in his sponsorship of legislation to benefit and protect the developmentally disabled population and the long-time member of the Benevolent Society, Irwin Bier, who retired to Florida after holding almost every office and assignment in BSRC. He did not sit in the proverbial 'rocking chair' or play golf. He did not rest on his laurels but continued to work vigorously in Florida's Broward County where his efforts have been rewarded with many services and facilities for the benefit of the persons who are mentally retarded. And to help bring it all together, we have with us once again that lovely TV newscaster of the National Broadcasting Co.

NEWSROOM, Jane Hanson who has very graciously consented to be the Luncheon Mistress of Ceremonies.

Anne and Mannie Barsky, co-chairpersons of this year's Luncheon offer the following information:

- Call Genevieve and Jim Camen for information on the Luncheon for our Staten Island friends. The Camen's can also be contacted for ads in our Souvenir Journal, at (718) 698-3999.
- Call Miriam Rosenbaum, our Rafflebook Chairperson, for more rafflebooks at (718) 377-0849.
- You will receive a *free* ticket to our 38th Annual Luncheon for every \$40.00 worth of raffles or journal ads. The more money you bring in the more *free* tickets to the Luncheon. ■

## MONROE

### Monroe County ARCers Win Special Olympic Honors

Two clients of the Monroe County ARC won medals at the New York State Special Olympic Winter Games held at the Concord Resort, February 21-23. Competing against 700 participants, Monroe's David Braun won a gold medal in the 100-meter cross country competition and a bronze in the 1-kilometer race.

In ladies events, Molly Brennan captured a 2nd place silver medal in the 100-meter along with a 4th place award in the 1-kilometer.

Monroe ARC Recreation Therapist Marie DeRosa was one of several Special Olympic coordinators who accompanied 21 area athletes to the games. ■

## DELAWARE

### 20th Annual Membership Drive

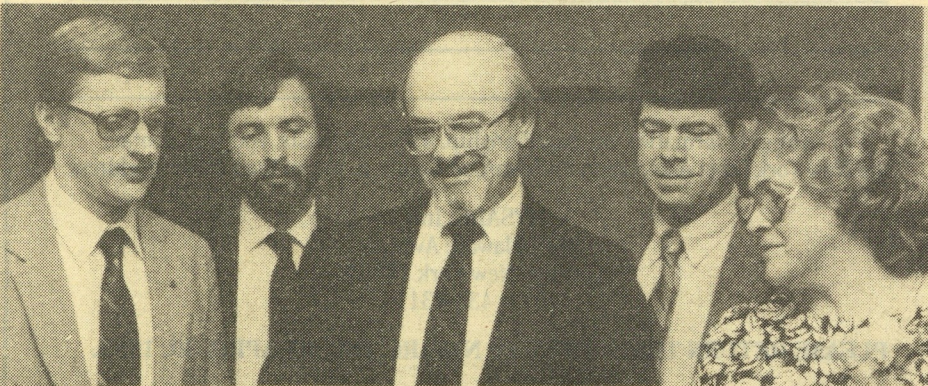


Senator Charles D. Cook, Honorary Membership Drive Chairman, in the love with the children at the Early Intervention Center (Stec)

The Delaware County Chapter, New York State Association for Retarded Children, Inc. proudly began its 20th Annual Membership Drive on February 8, 1988, to coincide with "Mental Retardation Awareness Week" as proclaimed by New York State Governor Mario Cuomo and the ARC Awareness Week with the "Legacy of Love" theme celebration sponsored by the State ARC. The theme of the Delaware County Chapter's drive is "Cast a Vote for Great Feelings...and Get Many Happy Returns." The Chapter utilized a new method in approaching members with the aim of reaching as many potential members as possible.

Mrs. Luella Rogers, membership Committee Chairperson, was pleased to report that New York State Senator Charles D. Cook, a longtime friend and member of the Chapter, led the way in the drive as Honorary Membership Chairman. "Senator Cook has always been a good friend to the children for as long as I can remember" said Mrs. Rogers, "and when I asked him to be Honorary Chairman this year, he immediately accepted. We wanted to try a different approach this year in order to reach as many people as possible in Delaware County with our message, and I hope the Senator realizes how important his involvement is to the success of the Membership Drive."

"In the past we have mailed to our current members urging them to renew. We also asked our friends and staff for names of people who would be interested in joining



Paul Carpenedo (left), Executive Director of the Allegany County Association for Retarded Children (ARC), Friday presented a certificate of appreciation to Fred Zazycki, Director of the state-operated J.N. Adams Developmental Center, for the assistance he and his staff provided to help ARC set up its first support apartments. On hand for the presentation were (from left) Mr. Carpenedo; Richard Mahaney, Program Specialist for the developmental center; Mr. Zazycki; Robert Wood, Assistant Deputy Director for the developmental center, and Sharon Flanigan, project manager for the local program. (Picture provided by Olean Times Herald)



## DELAWARE

### Membership Drive Begins



Senator Cook, Chairman for the Delaware County Chapter, shares on Center at the Hamden facility. (Photo credit: Matt)

and wrote them a letter inviting them to become members. The letters went out over Senator Cook's signature. Although we were successful in this approach" added Mrs. Rogers "we did not feel we were reaching enough people with our message."

To overcome the disadvantage, the Chapter decided to develop a quality brochure and mail it to every household in Delaware County - over 22,000 homes. A quality fold out piece with a tear-away return envelope was designed. Senator Cook appears in the brochure surrounded by children from the Early Intervention Center (EIC). His message, taking on the theme on the exterior of the brochure (Cast a Vote for Great Feelings... and Get Many Happy Returns) is "Join our Legacy of Love...and get the good feelings that come from caring." He also urges current members to renew for 1988.

In addition to the countywide mailing, local radio stations have broadcast public service announcements recorded by Senator Cook about the voice of the membership in helping, the Legacy of Love, and Mental Retardation Awareness Week. Press releases along similar lines have been issued and published.

So far the response has been excellent. About half of the responses received have been new memberships. Everyone at the Delaware County Chapter hopes the positive response continues and the 1988 membership Campaign is the best ever. ■

## CHAUTAUQUA

### Employees honored for years of service, dedication, and commitment.

Each year The Resource Center honors the staff members who have served the Agency for five years, ten years, fifteen years, or more. A total of 600 staff and Board Members were honored at this year's service awards. Fifty-eight percent of those eligible for five year awards were the employees of The Intermediate Care Facility which opened its doors in 1982.

Mr. Samuel E. Restivo, Interim Executive Director for The Resource Center gave the opening remarks in which he thanked all those attending for their outstanding loyalty, dedication, and compassion. Speaking of the current transition in administration and the rapid growth of the Center, Mr. Restivo noted that although the Agency had experienced some difficulties, The Resource Center employees have risen to the occasion with an unending commitment toward meeting the Center's goals. "Whether you be an aide, a nurse, an MSW, or a Board Member, each and every one of you have played an equally important role in helping our individuals who are mentally retarded and developmentally disabled, grow in spirit and in skills," said Director Restivo.

Mr. Michael Felice, Vice President of The Resource Center's Board of Directors echoed Mr. Restivo's remarks and added: "You are the best people I know, clearly I consider myself lucky to be here with you today. These awards are simply to say thank you for everything - for the job you are doing

and for staying with us."

The three top honorees receiving awards for dedicated services were all distinguished members of The Resource Center's Board of Directors. They were Mr. Wilbur Dennison, 20 years; Mr. Joseph Trusso, Jr., 20 years; and Mr. Elmer Muench, 15 years. ■



Guests of honor (back row left to right), Michael Felice, Vice President of Directors; Award Recipients, Wilbur Dennison - 20 years; Elmer Muench - 15 years; (front row left to right) Delores Olson - 22 years; Freda Eddy - 23 years; Mary Andrews - 23 years; Joseph Trusso, Jr. - 20 years (missing from photo)

## PUTNAM

### Essay Contest Winners to have Broadcasting Lesson

Through the cooperation of Roy Sova, Executive Vice-President of WMJV-FM, Route 292, Patterson, the essay contest winners from a recent event sponsored by the Putnam Association for Retarded Citizens will be given a broadcasting experience at the station, where they will read their essays over the air.

Recently, a comprehensive essay contest was promoted to commemorate the "Legacy of Love Awareness Week," which was designated by proclamation statewide and locally by County Executive Peter Alexanderson.

According to Stuart Greif, Executive Director of the Association, "Participation in this program was a very important link in our attempt to educate the community and communicate to them the loving care our chapter makes possible for all persons who are mentally retarded, young or old."

The children who received commendations from County Executive Alexanderson and Executive Director Stuart Greif, were lauded at a reception, had a tour of the Sheltered Workshop where they learned how individuals who are mentally retarded can become extremely productive and worthwhile community citizens, and the culmination, a broadcasting learning experience.

The contest subject, "What Caring Means to Me," included information about who the participant cares about and is concerned about in the community.

According to Greif, "The Association has a longstanding commitment to champion the rights of persons who are mentally retarded and today has an innovative and comprehensive educational, developmental and rehabilitative program." ■

## NASSAU

NYSARC Chapters mark the holidays in many special ways. There were parties, dinners, and even visits by Santa Claus.

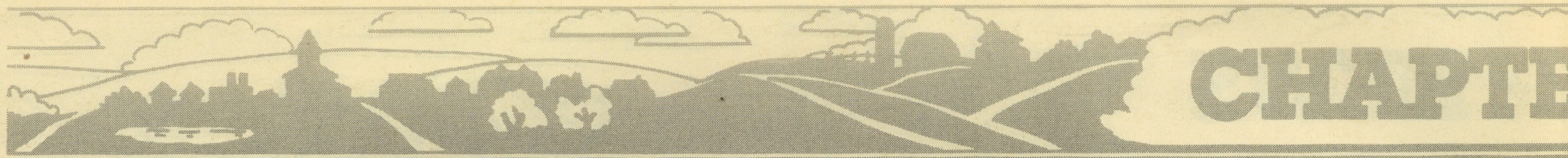
At the Nassau AHRC's Vocational Training Center clients who are in the food service program prepared a dinner with all the trimmings.

Nassau, which has two vocational training centers and sheltered workshops, also conducts an active job placement program in the community with food service being one of the many skills for which the clients are trained. ■



Nassau AHRC's Food Service Program





## ROCKLAND

### Rockland Chapter Celebrates "Legacy of Love"

The Rockland ARC kicked off its celebration of the Legacy of Love Awareness Week at a reception at its Pearl River Community Residence on February 9th. Rockland County Executive John Grant proclaimed the week for the county, stating that "the county will reaffirm its commitment to the less fortunate and will continue to be a growing positive influence upon the treatment needs of mentally retarded and developmentally disabled people through cooperative and collective efforts."

Clarkstown Town Legislator, Alex Gromack, representing county legislative Chairman Ed Gorman, was also present at the reception and made a legislative proclamation of the week, citing the importance of providing appropriate service to persons with special needs and praising the work that the Rockland ARC has done to meet those needs in the county.

The highlight of the evening, was the presence of members of the school community from the Clarkstown School District. In an effort to involve the community further in the celebration and to encourage young people to think about others in their communities, the ARC sponsored an essay contest at two elementary schools. The children were asked to describe people in the community for whom they care for and to describe how they can show that caring. The winners from each school were recognized at the reception by Mr. Grant and Mr. Gromack with certificates of excellence. ARC Executive Director Karyl Caplan read excerpts from some of their compositions and presented them with gift certificates from a local bookstore.

In her essay, Melissa Needle, a fifth grader, refers to disabled people when she says, "It doesn't matter how they talk, it just matters how they feel inside." Lisa Hecht wrote, "Individuals should help people with a disability. If you give disabled people the same respect you give other people, their spirits will rise." In her composition, entitled, *The Greatest Gift of All*, Jamie Rosen writes about a loving, caring friend of hers who happens to have Down syndrome and expresses how

she has received the gift of love and caring from her disabled friend..." Other students wrote of assisting with Special Olympics, wanting to work with persons with disabilities when they grow up, and the need to show on-going love and caring for others. It was heartwarming for those at the reception to hear children's expressions of concern for persons with disabilities.

The chapter thanked both of the participating schools with plaques commending them for their initiative in teaching children to respect differences and in promoting awareness and community acceptance of persons with developmental disabilities.

In addition to the winners and their families, the reception was attended by families whose children are receiving services from ARC programs, members of the Board of Directors and friends, many of whom are active in community affairs.

In addition to the all out chapter effort to sell the "Legacy of Love" roses, this reception literally brought the Association and the community together in a celebration of love and caring. ■



**Left to Right:**  
County Executive John Grant, Leah Altmayer,  
3rd grade student at Link Elementary School,  
RARC Executive Director Karyl Caplan.

## ONONDAGA

### Volunteer Program Expansion

During the last year, the Monarch Training Program (MTP), the day treatment division of the Onondaga ARC, has expanded its community volunteer program in which MTP II participants do volunteer work for the Salvation Army, the American Lung Association of Central New York, and other non-profit groups.

Participants, under the supervision of MTP II staff, have worked on bulk mailings for a variety of agencies and have done lawn mowing and other groundskeeping tasks for Vera House, a temporary shelter for women in crisis. In January of 1988, MTP

II initiated a new project in which a couple of participants volunteer once a week for a day care program run by the Salvation Army.

The volunteer projects have given participants an opportunity to utilize previously learned skills in a realistic setting, to perform a community service and to interact with people in the community.

MTP II staff have worked in concert with the Volunteer Center, a Syracuse organization which matches agencies in need of volunteers with people who want to volunteer. ■

## CHEMUNG

### Chemung County Workers Presented with Eagle Scout Awards

Three worker/trainees at the Chemung County Association for Retarded Citizens, Inc., received widespread media coverage for their achievement when they were presented with their Eagle Scout Awards in a joint ceremony. They are Edgar Paine, Phillip "Pete" Estelle and James Butler.

The Eagle Scouts are members of Troop #154 for disabled Scouts. They join Al Barnstead who was the first from the troop to earn the Eagle Award. He earned his award in January, 1983.

In addition, troop leader Durland Bennett was cited as "The best of the best" in a newspaper editorial citing his service to the troop.

As part of the Eagle Award requirements, each of the Scouts performed a service pro-

ject. Edgar planted 150 trees for a local Lions Club pond project, Pete painted 14 picnic tables and benches at a local park and James planted flags at tombstones in an Athens, PA. cemetery and catalogued the stones for the local historical society.

Congratulations were received from President Reagan. The Scouts later joined Eagle Award winners and Girl Scout Silver and Gold Award winners from throughout the country at a recognition dinner held Feb. 13th. The annual tribute was presented by the Big Flats American Legion.

Earning their Eagle Awards are Chemung Chapter's Troop 154 Scouts (from left) Edgar Paine, Phillip Estelle and James Butler. ■



**Earning their Eagle Awards are Chemung Chapter's Troop 154 Scouts (from left) Edgar Paine, Phillip Estelle and James Butler.**

## NIAGARA

### Welcome Home!

The Intermediate Care Facility became a new home to twelve people on November 23rd, just in time for a Thanksgiving homecoming.

The Niagara County Association for Retarded Children Intermediate Care Facility, located at 3076 Saunders Settlement Road, Sanborn, New York, provides a clinically supervised living arrangement in a home-like setting for developmentally disabled adults who need additional supports and services to be maintained in a non-institutional, community living situation. The I.C.F. program consists of highly structured programs, which are developed by specialists in the field of Developmental Disabilities, to promote skill development toward the least restrictive residential accommodation within the individual's capabilities. "The I.C.F. strives to be a component of the total community, integrating services with existing resources to facilitate a total continuum of programming for the individual resident," stated Kurt Zuk, Director of the Residential Services Division. ■



**Welcome Home! Niagara County Chapter I.C.F.**



## WAYNE

### Foster Grandparent Program Provides Caring Volunteers

Wayne County ARC — Roosevelt Center Preschool, Newark, N.Y. is one of the many special stations in Wayne County providing opportunity for Foster Grandparents to become a caring, loving influence in a child's life. Seven grandparents volunteer to work in classrooms four hours a day, five days a week with disabled children who range in age from two to five years.

"Being a Foster Grandparent gives me lots of enjoyment", says Pearl Cole, a long-time Foster Grandparent at Roosevelt Center Preschool. "I look forward to getting up in the morning and going to school to help the children. All they want is extra love", smiles Pearl as she points to her lapel pin which says: "Love is Ageless".

The grandparents, men and women sixty years of age or over, receive formal training as part of the Foster Grandparent Program orientation so that they are equipped to meet the needs of each exceptional child assigned to them. They are prepared to do a lot of talking, listening, playing, singing, walking, or just plain cuddling in a rocking chair.

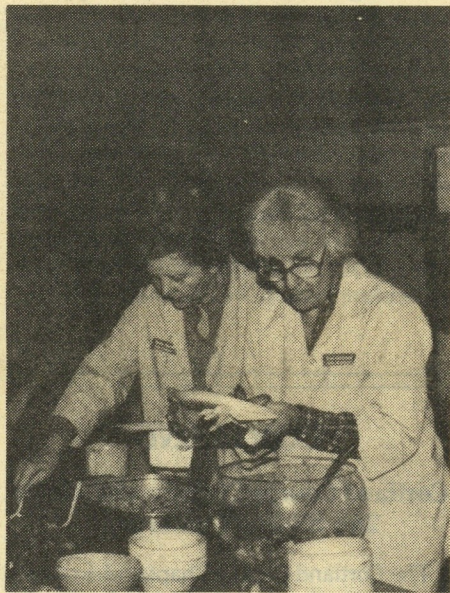
Normad Russell, a first-year grandparent, enjoys "just being needed". Each grandparent works under the supervision of a classroom teacher. Carrie Kashuba, Norma Russell's supervising teacher speaks highly of her and says, "Days she's not here we really miss her."

In return for their service, Foster Grandparents receive a modest tax-free stipend, transportation allowance, accident insurance, annual physical examination, free nutritious meals on the job site, assistance in non-job related problems, paid vacations, sick time, personal leave and legal holidays.

The Foster Grandparent Program has been very successful at Roosevelt Center. The senior citizens gain satisfaction from

being needed and making others happy. The school program benefits also from the loving care and extra attention given to the children. Roosevelt Center Preschool at present is happy to include into its family circle the following Foster Grandparents: Pearl Cole, Norma Russell, Margaret Humphries, Adeline Langlois, Emma Pound, Anna Frank, and Rose Colarocco.

The Foster Grandparent Program is always looking for loving senior citizens who would be interested in joining the program. It is an opportunity to gain satisfaction from being needed and making others happy. Those interested should contact the Foster Grandparent Program by calling (315) 946-5646. ■



Two of Roosevelt Center's Foster Grandparents.

## JEFFERSON

### JRC To Join Chapters Across the State in Legacy of Love

The Jefferson Rehabilitation Center is joining sixty-five (65) chapters of the New York State Association for Retarded Children, Inc. February 8-14th in NYSARC's Awareness Week — "Legacy of Love".

The State Organization was established in 1949 when New York City parents responded to a blind ad in the Times to form a group of parents of mentally retarded children in need of education and support services. Similar events were repeated in counties across the state, with our local agency, the JRC, being established in 1954 for eight children. Today, the State Organization and its chapters continue to serve 23,000 mentally retarded and developmentally disabled individuals in a variety of ways. JRC locally provides day treatment, sheltered workshop, community residence, and preschool programs for over 420 children and adults.

The State Organization and local chapters continue to meet the challenges provided by state and local governments as they advocate for the rights and needs of those they serve. Part of this process will be making the public aware of the extent of mental retardation and our ability to prevent almost

half of the incidence of occurrence. Currently, statistics demonstrate that 3% of the children born each year in this country are added to the already 60 million individuals identified as being mentally retarded. By the year 2000, it's estimated that one million of our children will be born with or become mentally retarded. Current knowledge allows us to prevent 30-50% of the incidences of mental retardation by educating the public regarding genetic counseling, prevention of lead poisoning, and RH hemolytic diseases, preschool immunization, the absence of the use of alcohol, illegal drugs and medicines during pregnancy, early prenatal care and more. At the very least, early intervention and programs provided locally and across the state may help reduce the consequences of mental retardation.

Governor Cuomo will be declaring February 8-14th as NYSARC's Awareness Week. Locally, Mayor T. Urling Walker will do the same with a formal proclamation for the City of Watertown.

The JRC is proud to be a part of this state-wide effort to educate and share, indeed, in this "Legacy of Love". ■

## ONEIDA

### ARC Gala Huge Success — Thanks to Volunteers

The Oneida Chapter celebrated Christmas a little early; at the Second Annual ARC Gala, hosted by Frank and Joanna Basile, at Alfredo's Resturante. Over 250 people helped the ARC celebrate at an evening filled with fine food, music and dancing, designed to enthrall even the most sophisticated among us. One guest was heard to comment, "I feel as though I've stepped into an episode of Lifestyles of the Rich and Famous."

And what a night it was! The guests were treated to delightful sounds of music all evening, with a selection of songs reminiscent of the big-band era as well as contemporary pieces that invited you to get up and dance.

But let's back up a little. What is this all about? Why go to all this trouble and expense? Is it worth it? The person to talk to is the Chairman of the event Frank J. Basile, and so we did.

"The ARC is an amazing organization, and I was surprised to learn that many people knew very little about the agency and the people they serve, or had a different perception as to what it's all about" said Basile. "So my wife and I, decided we would like to do something for the ARC to heighten people's awareness." He continued.

"One of the best ways to get to a large group of people and talk to them on an informal basis is to throw a party. But you need to grab their attention first. There are many Galas going on in this area and we wanted the ARC's to be a night people would remember for a long time," said Basile. "I think we have accomplished that. This year's

attendance was up from last year and people were contacting us to find out how they could help."

"But a Gala is nothing more than a night out, without a reason. Each year we choose a theme revolving around the services provided by the ARC. This year we picked the ARC clients in sports as our message." He said.

"Our special honored guest was John Lindsey. John has been involved with the ARC for over 11 years now. He is active in every sports program offered by the ARC, playing on both the Baseball and Basketball teams as well as Special Olympics. This year he was the representative for Oneida County at the International Special Olympics, held at Notre Dame University, in Indiana," Basile said. "He gave us a first hand account of what it's like to be involved in what was the largest amateur sporting event to ever be held on a college campus, and how it felt to win a bronze medal, as well as the training that preceded the Games."

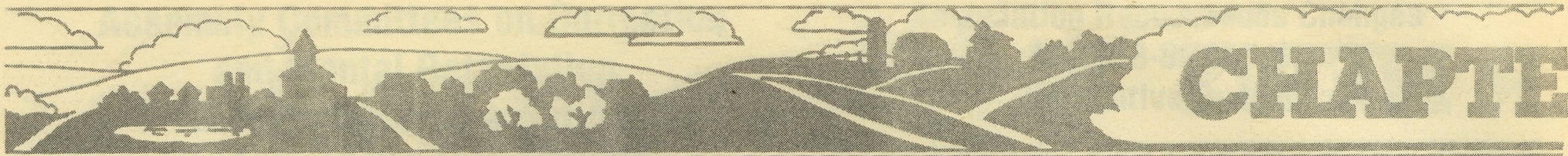
The invocation for the evening was given by Linda Greco, another ARC client. Linda is actively involved in local Special Olympics and is a member of the ARC Raiders Cheerleading Squad, according to Basile.

"These two individuals represent what the ARC is all about. They are the reason for holding an event of this nature," said Basile. "Is it worth all the time and effort? You bet it is! One look on the faces of John and Linda says it all. We're already planning for next year and we're looking forward to it, he concluded. ■



Oneida County's International Special Olympics representative, John Lindsey, keynote speaker at the second annual Gala.





## COMMUNITY LEAGUE

### Marketplace Jerusalem

Life at Wassaic is a constant challenge. We are continuously searching for new ways to bring meaning and add depth to the lives of our citizens who are mentally retarded. When the Rev. Zora M. Ficarra, Protestant Chaplain, came up with the novel idea of having a festival that recreates the ancient Jerusalem marketplace, I jumped at the notion. This was something different! The Catholic Chaplain the Rev. Sylvan Conover, agreed. Approval from the Administration was swift to follow and an idea was born: Marketplace Jerusalem!

The basic idea was to set up the Hilltop Gym with a dozen or so tables built with cloth canopies to simulate the vendors' stalls of the old marketplace. Each stall would feature different kinds of wares, crafts, goods or foods. Clients would be issued tickets with "Shekels" (Hebrew dollars) printed on them, and they could walk through the marketplace from stall to stall and "bargain" and "buy" things in exchange for their tickets.

With assistance from her committee, Rev. Ficarra contacted local church and civic groups for donations and volunteers. I helped with my contacts in the Jewish community. The Wassaic Community League supported our effort with generous financial support. Work Control helped make the booths, the Print Shop printed me the "shekels" (with a little Hebrew tutoring from me), and merchandise began flowing in. Pictures and posters of Jerusalem came from El Al Airlines and the Israel Tourist Office. The festival was beginning to shape up. The only unknown factor was — would it work? How would staff and clients respond?

On Wednesday morning, December 2nd, "Marketplace Jerusalem" opened for the first of two days. Decorated booths with various colored canopies featured exotic Middle Eastern fruits and grains, various scents and spices, baubles, bangles and beads. There was a stall with basketry and weaving, and another with sweets and pastries. Our only twentieth century anachronism was having one booth with Christmas holiday items and one booth with Chanukah holiday items.

The residents began to enter the "alleyways" of the "shuk" or "souk" marketplace) amid the stalls, donkeys and sheep of paper mache. The smell of felafel, humous, latkes, and fresh pita bread wafted through the air amid the distant sounds of Middle Eastern music.

They loved it! They made their way from booth to booth "haggled" over their bargains (in true marketplace tradition) and filled their bags with goods and goodies. They observed the "vendors" in their flowing robes and ancient garb. They stopped by the marketplace's own "scribe" and had their names written on a scroll. They tasted the cakes, candies, juices and exotic foods and came back for more.

The Marketplace Jerusalem Festival was truly a wonderful experience for bringing together staff and residents in a congenial and stimulating non-sectarian atmosphere. It was so good, in fact, that I've heard some gentiles repeating that old Jewish refrain, "Next Year in Jerusalem!" ■

## CLINTON

### Family Support Respite Home

The Clinton County Chapter of the Association for Retarded Children has received a grant from OMRDD to open a Free Standing Respite Home. This will be the first of its kind in the North Country and is located in Plattsburgh. This program will serve developmentally disabled persons and their families from a five (5) county area including: Clinton, Essex, Franklin, Jefferson and St. Lawrence.

Family Support Services will now expand, as it is presently operating to include this Respite Home. This home will accommodate three beds and one crib, and is available to persons of all ages and all developmental disabilities living at home with their families.

Room and board, twenty-four hour supervision and daily attention to health and self-care needs are offered. Families may use this program for a variety of reasons; a planned vacation, overnight respite care, relief for a few hours during the day or evening, or during an emergency or crisis situation which the family may experience. Many families have never had the opportunity to be away from the constant care sometimes made necessary by the disability of the family member.

It is the goal of the Family Support Services Program to assist families who have a developmentally disabled family member living at home. The relief provided will help the family remain strong and minimize the possibility of institutionalization of the developmentally disabled family member.

Families who have chosen to keep their developmentally disabled family member at home may experience considerable stress in trying to provide the care needed by the person. With the Respite Home and the specialized home-based services currently being offered by Family Support, it is our hope that each family can now function at its optimum. ■

## DUTCHESS

### Dutchess Chapter Plans Annual Journal/Dinner Dance

While plans are incomplete, the Annual Humanitarian Award Journal/Dinner Dance sponsored by the Association for Retarded Citizens, Dutchess County, (ARC, DC) has been scheduled.

The date is Saturday, May 14, and the place is Tom's Holiday Inn in Fishkill. The awardee will be announced in the next few weeks.

The event is one of ARC, DC's major annual fund-raising events. The money raised is used to further the programming offered to the mentally retarded and developmentally disabled clients served by ARC, DC. All clients served are from Dutchess County.

The awardee is a person who has shown a concern for the handicapped in the county and has done much to ensure that opportunities exist for the handicapped to have a better life. ■

## ULSTER

### Ulster Hires Director of Training and Education

In a move to coordinate and improve its In-service Training Program, the Ulster Association for Retarded Citizens has named C. Elizabeth Blower, B.S., M.P.S. to a new position as Director of Training and Education. Ms. Blower has been Residential Training Coordinator for the twelve residences operated by the UARC. In the expansion of responsibilities and restructuring of the department, Ms. Blower will provide training on an agency-side basis for its 550 employees. Working with Ms. Blower are Don Rogers, Dawn Kellogg and Mary Van Gorden.

The move to an agency-wide program will help eliminate duplication of training and provide a network that will allow training to be provided in a more timely fashion.

"Serving the needs of the handicapped population requires varied degrees of specialization," notes Ms. Blower. "There must be an emphasis on the specific requirements of each individual. While some of our clients are quite capable of caring for themselves, many of our direct care workers must deal with people with profound handicaps who may require assistance to stand, move from place to place, eat, keep themselves clean." The courses Ms. Blower will offer in the curriculum include health and hygiene,

client counseling, lifting and transferring, daily living skills, medication administration (under the supervision of a Registered Nurse), fire safety, crisis intervention and prevention or incidents., "I am very excited by the challenge of developing an agency-wide comprehensive training program for our staff. A well-trained staff will most certainly enhance the quality of life for our clients." ■



**C. Elizabeth Blower**  
Director of Training and Education  
Ulster ARC

## CORTLAND

### Cortland County Chapter ARC Holds 2nd Sibling Conference

The Cortland County Chapter (Advocacy, Recreation, Community Living Services), sponsored its Second Sibling Conference at the Cortland Holiday Inn. The focus of the conference was the "forgotten child" — the brothers and sisters of people with developmental disabilities. Nine families were represented.

Morning workshops included a parents' discussion group led by ARC Board Member Donna Funk who is also a special education teacher and sister of a person with disabilities; an adult and teen sibling discussion group about the videotape, "Protect, Defend and Love Forever" led by Dr. Ed Haddad, State Sibling Network Coordinator; and a young siblings' discussion and activity group led by Susan Griffin, Director of the Cortland YWCA Coalition for Children.

Family members with disabilities were entertained with many different games, activities, and crafts by an excellent support staff of Cortland State University students and ARC providers. Afternoon activities included a luncheon, role playing and discussion, and a pool party.

Sibling Kevin Pratt enjoyed the conference. "I kind of liked the skits," he said, "and the swimming too."

"I liked the eating!" quipped his sister Kris, who was disabled in a severe accident at age 1.

The conference will be followed up by several smaller workshops and family fun days in the months to come. ■

## WELFARE LEAGUE

### Welfare League Holds 48th Annual Luncheon

Welfare League, Letchworth Village Chapter, held its 48th Annual Luncheon on November 21, 1987. Relatives and friends of the Letchworth Village residents filled the ballroom at the New York Hilton and enjoyed a performance of magic produced by the Recreation Department.

Rich Lamb, well known reporter for CBS, was Master of Ceremonies and in appreciation of his interest in residents and his willingness to endorse our efforts on their behalf, Martha Plato, Luncheon Chairperson, presented him with a plaque that honored him for his interest in our work.

The Director of Letchworth Village, Albert P. Robidoux, was presented with the Welfare League Annual Award by David Kapsack, President.

Rose Horwitz was presented an award for her numerous activities as a member and for her many years of successfully chairing the Annual Luncheon, that provided funds for our many projects.

Frances Reville received an award for her years of dedication and advocacy — not only for Letchworth Village residents but for all the mentally retarded.

The afternoon ended on a happy note with many guests carrying home prizes. ■



## COLUMBIA

### COARC Purchases Auditory Trainer

The Claverack Lion & Lioness Clubs recently made it possible for COARC to purchase an Auditory Trainer through their generous donations.

This important piece of equipment makes it possible to assess an individual's need for a hearing aid and assess other auditory problems. The Auditory Trainer works to block out background noise so a single voice is heard clearly.

The first time Tina used the trainer, she said, "This would help me concentrate and do more work!"

"So many have responded to working with the trainer, we use it constantly!", Melonie comments.

Many thanks to people like the Claverack Lion & Lioness Club members for opening another door towards improving the quality of life for physically and mentally challenged individuals. ■



Photo L to R: Melonie Mueller, Speech and Language Pathologist, Tina of Promenade Hill Day Treatment Center and Ken Smith, Maintenance Supervisor and member of the Lion's Club.

## SARATOGA

### Alpha Industries Develops Unique Product Line

According to the U.S. Bureau of Labor statistics, manufacturing jobs are down nearly 100,000 in New York State in the past three years. This 7.5% decrease for the state contrasts a 0.3% national dip. New York's decline was the largest among 50 states. Factory jobs in the Albany, Schenectady and Troy area declined by 7,000. The decline in the State's non-metropolitan counties totaled 14,000 jobs.

With the decrease in manufacturing in New York State and increased competition among sheltered workshops for sub-contract work, ARC's are faced with a difficult challenge. But Alpha Industries is meeting this challenge head-on by engaging prime manufacturing, under the name "The Saratoga Horseworks". The Saratoga Horseworks marks a milestone for Alpha Industries as the firm for the first time is manufacturing its own product line of equine and equestrian soft goods rather than just depending on contract work from other manufacturers. The project required innovative and creative planning, as well as the support of the board and administration.

Less than a year ago, the Saratoga Horseworks was merely a concept. But this

month, the company's various products—coolers, horseshoes, flysheets, bandages, blankets, lead shanks—will be marketed to distributors and retail tack stores. Within two years we hope to gain national recognition as manufacturers of top-of-the-line equine products.

Michael Libertucci, Product Development Engineer and experienced horseman, has developed all our products including the superior wrap bandage. The superior wrap is unique in that it is specially designed to counter slippage.

Start-up and adjustments costs are expected to be minimal. All of the needed equipment is already on-site. In addition, the 151 clients involved will generally be performing tasks — sewing, assembly and packaging at which they are already skilled.

Although entering a new era, we are not diving in blindly. While formulating plans for the Saratoga Horseworks, Alpha Industries consults with key local business leaders who share their expertise in marketing, new product development, agriculture, public relations, the intricacies of the equine industry as well as the legal implications of our venture. ■

## WARREN/WASHINGTON

### Chapter Expansion Adds New Apartments, ICF and Family Support

Over the past several months there have been some exciting developments at the Warren-Washington ARC.

First of all the Supportive Living Program (SLP) has significantly expanded by adding five new apartments serving a total of nine new clients. Two apartments, a one-bedroom and a two-bedroom, are scheduled to open by March 31st. This will bring the total individuals served in the apartment program to twenty-four at thirteen scattered sites in the Glens Falls area.

New apartments mean new opportunities for a number of individuals. Eight clients living in the agency's community residences have or will be moving to this more independent, less restrictive alternative. Their movement paves the way for two Intermediate Care residents to move to a Community Residence joining six individuals from the community, who have been on the Chapter's waiting list for some time, who will finally achieve community residence placement.

In addition, construction of the agency's ten person ICF program in Warrensburg is near completion and will be ready to open on March 31st. This home will serve young adults including four clients from the Chapter's children's ICF, two individuals from the community and four clients from Wilton Developmental Center. The movement of the young adults from the children's ICF creates an opportunity for other children currently waiting placement.

The Warren-Washington ARC's Family Support Program is also expanding. At the end of February the Chapter will open a Respite Center which will be a base for all family support activities including: a planned afternoon and evening respite "drop-off" and recreational program, homemaker services and a twenty-four hour weekend respite for up to four individuals. The goal of the Respite Center is to provide support for families who are the primary care givers for developmentally disabled children and adults who live at home. ■

## ERIE

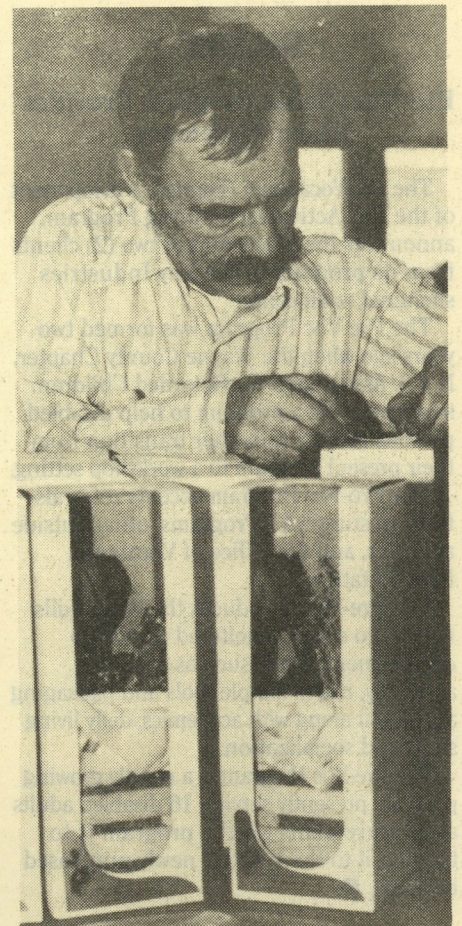
### H.E.P. Sets trend in Children's Programs

The Erie County Association for Retarded Children has implemented a new approach to educating children with developmental disabilities. This past fall, young school-aged children in ARC's Heritage Education Program began attending a multidisciplinary class in conjunction with their Special Education classes held at the Maryvale Primary School in Cheektowaga.

The class, which meets once a week combines art and music therapy with adaptive physical education activities in an effort to stimulate the child's sensory and cognitive development, as well as motor skills. The children participating range in age from six to nine and have a wide divergence of abilities. While mental retardation is the primary handicapping condition of most of the children served, physically handicapped, autistic, emotionally disturbed children and children with health impairments may also participate.

The program follows the trend toward teamwork, where teachers and therapists work together as a unit to provide the best possible opportunities for the child. The multidisciplinary concept is meeting with tremendous success in Erie County. ■

## ONEIDA



A worker from the Oneida County Chapter places an identification label onto the box of the product which was sold during the "Legacy of Love" event.

## STEBEN

### Jean Kosty Honored by Steuben ARC

Steuben Association for Retarded Citizens (ARC) of Bath has instituted an Employee Recognition Program to recognize outstanding service to the agency. Jean Kosty, Executive Secretary at Steuben Services' Vocational Division was nominated by her supervisor and selected by a committee of agency staff for her commitment, conscientiousness and dedication to the agency.

A ten-year employee, Kosty of Avoca is secretary to the Director of Program Operations, Training Center Director, Sales Coordinator, and Placement Specialist. She has witnessed the growth of the agency as she has managed and coordinated the daily flow of paperwork involved in keeping everything moving ahead.



# CHAPTER NEWS

## BROOME-TIOGA

### ARC Workshop Opens a Micrographic Service Bureau

The Broome-Tioga ARC — Country Valley Industries Marketing Department is pleased to announce a new "High Tech" service to our customers and the community — a Micrographic Service Bureau.

Micrographics is a process by which documents and files are transferred to 16 millimeter film. All files can be coded to allow for easy retrieval and records placed on film can be reviewed by an operator using a viewing screen called a Micrographic Reader. A micrographic records system will give businesses, organizations and individuals the ability to maintain permanent records in a more efficient manner by saving the space usually required for numerous storage boxes and file cabinets.

The Bell & Howell Company, located in Albany, New York, will be providing technical assistance and training to ARC staff and client-employees to help in the establishment of this program. Bell and Howell has been the pioneer in this field and have assisted many workshops across the country, including eight (8) others in New York State in establishing this service and work programs. The new micrographics service will train and utilize workshop client-employees to prepare documents for filming, to operate cameras, and to do material handling. This operation is an excellent opportunity for the ARC to provide its workers with a more sophisticated level of work.

## WAYNE

### Pre-Vocational Program Provides Client Placement

The Pre-Vocational Program, a component of the Day Activities Training Program, announces the placement of two (2) clients from its program to the Key Industries sheltered work center.

The Pre-Voc Program was formed two years ago when the Wayne County Chapter, N.Y.S. Association for Retarded Children saw a need for a program to help disabled persons make a smoother transition from their present program to a workshop setting.

The Pre-Voc Program accepts referrals from existing DAT Programs, other outside agencies, and the Office of Vocational Rehabilitation.

The Pre-Voc introduces the basic skills needed to enter a sheltered workshop environment. Skills such as collating, assembly, use of simple tools and packaging are taught along with academics, daily living skills and socialization.

The Pre-Voc Program is a rapidly growing program presently serving 16 disabled adults and future plans for the program is to transfer it to the WARC's newly purchased building. ■

## YATES

### Family Support Services Enhanced

Yates County is a participant in a four-county (Wayne, Seneca, Ontario and Yates) program for respite services. Approval has been received for 1988. The grant has been split equally among the four counties, giving the Yates Chapter approximately forty hours per month to provide respite.

The respite service is intended to provide individuals and families with a break from the day-to-day care of a developmentally disabled family member. The parent(s) or primary caregiver can use this time to conduct personal business, pursue a leisure activity, go shopping, and so on. There are no age restrictions, but the person must have a developmental disability (mental retardation, cerebral palsy, autism, epilepsy, or neurological impairment).

In addition, the Home Care Service is being expanded. With an increase in the grant combined with an increase in the rate, we are able to offer four additional direct service hours per week for a weekly total of twenty-four hours.

## ORLEANS

### Holley Hawk Spell-A-Thon Raises Over \$7,300 for Camp Rainbow

Last month Holley Primary and Intermediate School student, grades 2-6, raised over \$7,300 to benefit the Orleans Association for Retarded Citizens' Camp Rainbow.

Prior to the Holley Hawk Spell-A-Thon, the students who wanted to participate were given a list of 100 spelling words, approved by the New York State Board of Regents for their perspective grade levels, and were asked to study them. The Spell-A-Thon participants then solicited for people to sponsor them a specified amount of money, on a per word basis, for every word they could spell correctly on the 100 word test which was given over a three day period.

"The kids in Holley Primary and Intermediate Schools did all they could to cover the eastern end of Orleans County, and the people there gave very generously to Camp Rainbow," said De Carlo, who added that Orleans ARC's programs do serve the entire County.

The best spellers and money raisers were rewarded for their good deeds with various Holley hawk apparel, including T-shirts, sweatshirts, sweatpants, etc. The individual student who raised the most money was Paul Hicks, a sixth grader who will be going to lunch with Principal John Heise. Paul brought in over \$160. The class that raised the most money was Mrs. Nayman's third grade class.

Orleans ARC would like to extend its gratitude to the teachers and students at Holley Primary and Intermediate Schools who made the event possible. We would like to send an extra special thanks to Principal John Heise for initiating the Spell-A-Thon and seeing it through, and to Mrs. Sheeler for all her help.

According to Principal Heise, the Holley Hawk Spell-A-Thon went over well with the kids. "It was a fun way for the kids to learn a lot of new spelling words and something about community service," remarked Mr. Heise. ■

## NASSAU



*In addition to Governor Cuomo's proclamation, towns and counties throughout the state marked by special proclamation the Valentine's Day period as a special time to recognize the chapters of the New York State Association for Retarded Children, Inc. and to remind the public of the care and love which goes on year-round for the mentally retarded. Joseph Mondello, Presiding Supervisor of the Town of Hempstead, received the Legacy of Love rose from volunteers of the Nassau AHRC and in turn presented the group with a proclamation from the Town of Hempstead marking that township's participation in Legacy of Love. ■*

## LIVINGSTON-WYOMING

### Graphics Equipment Supported by Gannett Grant

The Livingston-Wyoming Association for Retarded Citizens was recently awarded two private foundation grants to purchase graphics equipment for Hilltop Industries, the ARC's vocational training program for adults with disabilities. A grant from the Gannett Foundation was received in the amount of \$5,000, and one from the Fred & Floy Willmott Foundation was for \$3,000. This is the first time the ARC has been successful in obtaining grants from private foundations.

According to Ron Hallinen, Executive Director of the ARC, the grants will make it possible to acquire needed equipment that is not provided for in the ARC's operating budget. According to Hallinen, "the ARC must turn to private contributions from individuals and foundations to meet many of its capitalization and equipment replacement needs. The federal, state and county government funds we receive provide fairly well for the day-to-day operations, but capitalization monies have always been scarce."

The grant awards were part of an overall campaign aimed at private foundations to update and modernize the graphics equipment used to train adults with handicapping conditions at Hilltop Industries. The ARC operates a full offset printing department at its 18 Main Street, Mt. Morris, facility as one of three training programs offered. Hilltop bids competitively for printing work from local business concerns and from individuals and uses this paid work to train the handicapped workers. Some of the workers then go out to placement in outside printing firms. According to Howard Anderson, Director of Production for Hilltop, the grant monies received will help to purchase state-of-the-art prepress and bindery equipment which will expand Hilltop's capabilities, provide additional training slots for handicapped workers and increase the potential for placement of Hilltop's clients in competitive jobs.



## NYSARC Scholarships and Recognition Awards made available

Applications have now been made available to NYSARC chapters and state universities to encourage statewide participation in the 1988 Scholarship and Awards Program offered by the New York State Association for Retarded Children, Inc.

These scholarships were originally established to recognize students and employees of the Association for their meritorious academic and/or professional achievements in the field of mental retardation and to encourage the pursuit of educational and personal growth in Special Education, or related fields.

The scholarship competitions include the *Joseph T. Weingold Scholarship*, *Jonathan Weingold Scholarship*, the *James F. Reville and Arthur Pense Memorial Scholarships*. Most of these scholarships are granted on an annual basis with the exception of the Arthur Pense Memorial which is offered biannually in the amount of \$1,000 to an employee in a developmental center located in New York State. The Joseph T. Weingold and James Reville Scholarships are awarded

in the amount of \$2,000 to recipients chosen by the Scholarship and Awards Committee of NYSARC, which is chaired by Kay Nogaj from Rochester, New York.

Candidates for the Joseph T. Weingold Scholarship who are entering their junior year in college are nominated by the Chairpersons of the Departments of Special Education in undergraduate degree programs throughout the State of New York. Announcement of the James F. Reville Scholarship is sent to the Association's chapters and is offered to students who are enrolled full-time in any year of their college training in a field related to mental retardation.

Deadlines for receiving nominations for all the scholarships have been indicated in this issue of OCV and announcements of the selected recipients will be made at the Spring Board of Governors' meeting on April 22, 1988.

Nominations for the NYSARC Volunteer Award were announced on February 9, 1988, and it is being offered again to a volunteer

NYSARC member in recognition of his or her continued dedicated service and advocacy on behalf of persons who are mentally retarded. Each chapter must submit their nominations to the Scholarship and Awards Committee by August 3, 1988, and the individual chosen to receive this prestigious award will be announced at the NYSARC Convention at the Concord Hotel in Kiamesha Lake, New York on November 4, 1988.

Formal announcements for two additional recognition events will be distributed to the NYSARC chapters on March 1 and April 15 inviting them to nominate candidates for the Memorial Plaque and Employer of the Year Award respectively. Announcements of the individuals receiving these honors will also be made at the Fall Convention.

Anyone wishing to obtain additional information on these scholarships and recognition awards can contact Erica Berman at the NYSARC Office at 393 Delaware Avenue, Delmar, NY 12054, telephone number (518) 439-8311. ■

## The Hazardous Materials Communication Standard

As of May 23, 1988, all non-manufacturing employers of ten or more persons must comply with the federal government regulations requiring employers to transmit information on the hazards of chemicals to their employees by means of labels on containers, material safety data sheets and training programs. The regulation found in 29 CFR 1910.1200 is administered by OSHA and supercedes all state Right-To-Know laws.

Basically, all employees routinely exposed to hazardous chemicals under normal operating conditions or in a foreseeable emergency are covered. Only certain substances are exempted and some of these are covered under other federal and state regulations. The exempted substances are:

1. Hazardous Waste
2. Tobacco or tobacco products
3. Articles which will not emit hazardous substances when operated on.
4. Food, drugs, cosmetics or alcoholic beverages packaged for consumers or for personal consumption.
5. Consumer or hazardous substances (e.g. cleaning agents) used in the same manner, frequency and duration as does a normal consumer.
6. Solid drugs, e.g. tablets, capsules and pills.

Situations may arise where consumer type hazardous cleaning agents are used in excess of normal consumer usage, or a chapter may want to consider even remote health hazards in the development of its hazardous material communication program.

All employers are required to:

1. Have surveyed the workplace(s) and complete a list(s) or inventory of chemicals. The list has to be available to employees and should be developed and posted by department or work site.
2. Material Safety Data Sheets (MSDS) are to be obtained from the manufacturer or supplier. The MSDS file must also be available to employees on request.
3. Labels on incoming and in-house containers must be accurate and descriptive of the contents, hazards, and precautions to be taken. The labels should be cross referenced to the MSDS and chemical listing. This will expedite retrieval of the correct MSDS if it is needed in an emergency. The internal labeling system should be easily understood by both clients and staff. Many commercial systems use excellent graphics which are easily understood.
4. Develop an information and training program for employees. Employees, which may include chapter clients, must be informed of operations where exposures occur, the locations of the written Hazard Communication program, the list of dangerous substances and the MSDS's.

The employee must be trained in how to observe and detect the presence of the dangerous substances, the hazards, and protective measures to be used when exposed.

5. Finally, the employer must have a written program which includes all of the above information and describes how a Hazardous Substances Communication Program is to be delivered to employees. Many standard written programs are available. The NYSARC Safety Group Management Committee distributed one during the first quarter of 1988. All of the programs must be tailored to the specific needs of each employer. This tailoring to specific needs and operations is an axiom of safety management.

Service providers in the health and long term care industries are encouraged to be especially scrupulous in design and implementation to their Hazardous Substances Communication program. This should be directed to the benefit of the clients working and living under the provider's care umbrella. NYSARC chapters and all providers licensed by OMRDD are reminded that OMRDD regulations 14 NYCRR 686.10(5)(iii) and (iv) require this.

**We Can Help You!**

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**D. Client Back-up Services** Increasingly chapters have been noting the absence of back-up services from DDSOs for persons resettled from D.C.s who are experiencing crisis episodes. The need for services such as behavior management, respite and counseling is essential if many of the very difficult individuals now being deinstitutionalized are to be satisfactorily integrated into community-based settings.

**Recommended Budget Action:**

1. *Enact Budget Language* addressing the lack of appropriate back-up services for persons resettled from developmental centers. Specifically, we recommend that language be adopted as part of the FY 88-89 budget requiring the Commissioner to evaluate the need for back-up services for voluntary providers and the adequacy of existing back-up services.

**E. Life Safety Code Improvements** During FY 88-89 Community Residences will be required by OMRDD to comply with Chapter 21 life safety code requirements. Such compliance will require a variety of capital improvements aimed at insuring facility fire safety. Funding for making these improvements has been requested in the Capital Projects Budget (see page 355). However, the utilization of these funds would be greatly facilitated if they could be accessed by voluntary providers through the Aid to Localities Budget.

**Recommended Budget Language:**

1. *Enact Budget Language* authorizing the transfer of funds out of the OMRDD Capital Projects Budget and into the OMRDD Aid to Localities Budget, Voluntary Community Residence Maintenance Program, to facilitate Chapter 21 Life Safety Code Improvements to Community Residences. Budget language should read:

Notwithstanding any other inconsistent provision of the law, funds from the following amount may be transferred to the general fund - aid to localities account of the Office of Mental Retardation and Developmental Disabilities to facilitate the purposes of this appropriation.

**II. State Education Department**

**A. Career Opportunity Professional Recruitment Education Program (COPREP) the Career Opportunities Professional Recruitment Education Program provides for the on-site training of Occupational Therapy Assistants (OTAs) and Physical Therapy Assistants (PTAs). This program, which was enacted in FY 87-88 budget, currently applies only to state operated programs. Authorizing not-for-profit agencies such as NYSARC to participate in COPREP would help to ameliorate the critical shortage of impacting our programs.**

**Recommended Budget Action:**

1. *Appropriate \$1,130,000* to restore COPREP as funded in the FY 87-88 State

Budget. The Governor deleted these funds from his FY 88-89 request.

2. *Appropriate \$1,000,000* in additional funds to enable not-for-profit agencies serving persons with developmental disabilities to participate in COPREP.

**B. Preschool Education** Under current law if a child turns five prior to December 1st, he or she is no longer eligible for preschool programming beginning on July 1st of that year. Rather, such children must attend summer school programming approved by the local CSE. However, it is very likely that since these children are new to the public school system, neither the school district nor the CSE has had the opportunity to become fully acquainted with such children and their individual needs. This fact serves to impede appropriate summer school placements.

**Recommended Budget Action:**

1. *Enact Budget Language* authorizing children who turn five (5) prior to December 1, 1988 to remain in their preschool placement.

**III. Department of Health**

**A. State Health Services Corps** Chapter 583 of the Laws of 1987 enables persons seeking advanced degrees in clinical professions to qualify for "Health Corps" scholarships in return for a specific work obligation in not-for-profit agencies serving developmentally disabled persons. However, the Governor only requested funding for 50 such scholarships in his FY 88-89 Budget.

**Recommended Budget Action:**

1. *Appropriate an additional \$500,000* to fund 50 additional "Health Corps" scholarships dedicated to persons making employment commitments in voluntary programs.

**IV. Developmental Disabilities Planning Council**

**A. Developmentally Disabled Offenders** Developmentally Disabled offenders have special needs which often require access to unique services. An 800 Hotline number would help coordinate provision of such services.

**Recommended Budget Action:**

1. *Enact Budget Language* requiring the establishment of an 800 Hotline number to assist in the referral of persons with developmental disabilities who come into contact with the Criminal Justice System to appropriate services.

2. *Appropriate \$75,000* for the development and implementation of an 800 Hotline number.

The next issue of OCV will report on the final adopted New York State Budget for April 1, 1988 - March 31, 1989. ■

## Westchester Honors Barbara Gibbs Levitz

The 18th Annual Ball of the Westchester Association for Retarded Citizens, scheduled for April 23, will honor Barbara Gibbs Levitz, a woman with a staggering list of accomplishments in the service of children who are retarded. It can truly be said that there is no parent with a child born in Westchester with Down syndrome in the past fifteen years who has not benefited from the pioneering accomplishments of this dynamo of a woman.

Mrs. Levitz has three teenage children, one of whom has Down syndrome, and she has used her energies and her considerable talents unsparingly to advocate for all developmentally disabled children from the moment of birth. She pioneered in establishing support groups for parents, and referral and outreach services. She founded WARC's Parent Assistance Committee on Down syndrome; initiated the concept of a Parent Education Network; established and supervises the Gibbs Memorial Collection in the Peekskill, New York, Public Library, a valuable resource for material on developmental disabilities. Barbara Levitz was a force behind WARC's Early Intervention Program serving children from birth to two years, and she runs a Hot Line out of her home which serves as an information, referral and resource center on disabilities.



**Barbara Gibbs Levitz**

As a member of WARC's Board of Directors, she has been First Vice President, a member of the Executive Committee, Education and Nominating Committees, and is presently on NYSARC's Board of Governors. She is a frequent guest on radio and television, lectures extensively and has contributed to books and articles on disability.

The ball honoring Barbara Levitz is WARC's major annual fund-raising event, and will again bring hundreds of members, family and friends of Westchester's citizens who are retarded to the Rye Town Hilton in Rye Brook, New York, to dine, dance and socialize as they honor this extraordinary woman. ■

## PREVENTION NEWS

**Government Approves New Vaccine**

A new vaccine expected to protect more children against a serious bacterial infection that strikes 20,000 youngsters a year and is the leading cause of acquired mental retardation received government approval recently. The Food and Drug Administration approved the vaccine, which protects against *Haemophilus B influenza bacteria*, for use in children ages 18 months to 5 years. The previously available vaccine is effective in youngsters at least 2 years old. However, about half the cases of disease caused by the bacteria occur in children under 18 months of age. The makers of the vaccine, CDC Life Sciences, Inc. of Canada and its U.S. subsidiary, Connaught Laboratories of Swiftwater, PA, plan to apply for permission to test the drug in children as young as 2 months of age. The bacteria usually causes bacterial meningitis, a sometimes-fatal inflammation of the membranes covering the brain and spinal cord that is the most common cause of acquired mental retardation.

**AIDS MAY CAUSE RETARDATION**

AIDS may become the largest infectious cause of mental retardation and brain damage in children within the next five years, says a report by two New York pediatricians.

The report, published as part of a series of articles called *Prevention Update*, estimates that the number of Americans under age 13 with symptoms of HIV infection could reach as high as 20,000 by 1991. In 1987 there were approximately 563 cases of pediatric AIDS and an estimated 1,600 cases of AIDS-related complex (ARC)

*Prevention Update* is published by the Maternal and Child Health Consortium Project and the National Coalition on Prevention of Mental Retardation.

The report, "AIDS and Developmental Disabilities," says congenital HIV infection usually causes developmental delays and learning disabilities. The delays are greater

in children with AIDS and often precede significant mental retardation.

Physicians who see children who are developmentally delayed and whose mothers are intravenous drug addicts should consider the possibility that the children are infected by the HIV virus, say the authors of the report, Dr. Gary Diamond and Dr. Herbert Cohen. Both physicians work with The Rose F. Kennedy Center University Affiliated Facility, Children's Evaluation and Rehabilitation Center of the Albert Einstein College of Medicine in Bronx, N.Y.

Most children with HIV infection acquire the disease before birth. Usually the mother becomes infected from contaminated needles used to administer intravenous drugs or from sexual contact with another infected individual. A smaller number of cases are related to blood transfusions.

**LAWSUIT ON BEHALF OF FETAL ALCOHOL SYNDROME CHILDREN FILED**

The first lawsuit in history on behalf of Fetal Alcohol Syndrome children were brought against the alcoholic beverage industry. The suits charge the industry with failure to warn that alcoholic beverages cause birth defects. Three actions have been filed in the United States District Court in the State of Washington on behalf of four children who allegedly sustained birth defects as the result of their mothers' alcohol ingestion during pregnancy. The children named in the suit suffer from a number of conditions associated with FAS, including mental retardation; behavioral, developmental and growth abnormalities; cleft lip and palate; and heart and limb defects. Named in the suit were James B. Beam Distilling Co.; Heileman Brewing Co; Beublein, Inc.; Potter Distilleries, Inc.; Anheuser-Busch, Inc.; California Cooler Co.; and Stroh Brewery Co. The National Council on Alcoholism, which was instrumental in bringing the charges, is calling for mandated labels warning of the risks associated with alcohol during pregnancy. ■



## OMRDD BUREAU OF REVENUE MANAGEMENT OFFERS ASSISTANCE

The following article was submitted to OCV by the Revenue Management Division of OMRDD.

The Bureau of Revenue Management is a branch of the New York State Office of Mental Retardation and Developmental Disabilities that has expertise in the areas of client benefits and finance management which it is willing to offer to all community members.

For the past half century, our bureau's primary goal was to see that New York State was paid for the care of its residents. However, as the state's objectives have changed to moving clients out of state operated residences into varied forms of community settings, so have our bureaus. The agents in the local field offices have very detailed, up-to-date and realistic knowledge about how to obtain and keep benefits for a disabled person, and how finances should be managed. They are available to advise a disabled person, parents, social worker, agency or anyone else who needs help on how to work through the system to get the benefits and assistance one might be entitled to receive.

We can, for instance, advise on how to apply for and obtain: Social Security for the disabled adult child of a retired or deceased worker; Supplemental Security Income (SSI); Food Stamps; Medicaid; Medicare and many other potential benefits. We can show you how to obtain and keep these benefits. There are a host of regulations surrounding each of these programs and if these regulations are not adhered to, benefits can be lost and huge overpayments can result.

In addition to the above entitlement programs, we can advise on how to set up and manage burial funds, conservatorships, trust funds and other legal entities. We are here to help!

If you have any questions or need advice on a specific case, please call or write the Revenue Management Office in your area.

If you or someone you know is mentally retarded or developmentally disabled...

### WE CAN HELP YOU!

GET BENEFITS TO WHICH YOU ARE ENTITLED  
APPLY FOR MEDICAID AND SSI  
LEARN ABOUT SOCIAL SECURITY AND MEDICARE  
FIND OUT ABOUT THE FOOD STAMP PROGRAM  
UNDERSTAND VETERANS ADMINISTRATION  
AND RAILROAD RETIREMENT BENEFITS  
PREPARE FOR A FAIR HEARING WHEN BENEFITS ARE DENIED  
ESTABLISH RECORDKEEPING  
SOLVE CLAIMING PROBLEMS  
OBTAIN FORMS FOR APPLYING FOR BENEFITS  
GET THE FACTS ON CONSERVATORS, COMMITTEES AND GUARDIANS

### CALL YOUR LOCAL REVENUE AND REIMBURSEMENT OFFICE

Office	Senior Agent
Albany: 100 Watervliet Ave. Albany, NY 12206	Peter Keegan (518) 457-0460
<b>Counties Served:</b> Albany, Fulton, Columbia, Greene, Hamilton, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren, Washington	
Binghamton: 2 Court St., 4th Floor Binghamton, NY 13901	Richard Wierman (607) 724-0364

#### Counties Served:

Broome, Tioga, Tompkins, Chenango, Otsego, Delaware, Oswego, Onondaga, Cortland, Madison, Cayuga

#### Bronx:

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Room 5081  
Bronx, NY 10461  
Lucinda Blackwell  
(212) 430-0371

#### Counties Served

Bronx, Westchester

#### Brooklyn:

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Room 1522  
New York, NY 10011  
Shimon Reit  
(212) 587-2328

#### Counties Served:

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Rockland P.C.  
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#### Newark:

Newark D.C.  
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Philip Dodd  
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#### Poughkeepsie:

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#### Rome:

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#### West Seneca:

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## ARC Celebrates the "Day of the Big Guy"



With the Rochester skyline as a backdrop, Executive Director Jim Mroczek's friends and staff bought a billboard to celebrate his 15 years with the Monroe County ARC.

On January 15, 1988, early in the morning, I opened the back door of ARC by the Monarc office and was greeted by the wonderful aroma of scrambled eggs and Polish sausage and the sound of rollicking Polish music (it was really German). I tried to work on this issue of Monarc for a few minutes but the pervasive odors wafting under my door sent me into the conference room next door where Bob Walsh and Gary Scialdone were cooking a Polish breakfast in honor of Jim Mroczek's 15th anniversary with the Association for Retarded Citizens. Coffee, orange juice, pierogies, fried potatoes and Polish coffee cakes and breads were also being served. The atmosphere was charged with excitement.

When Jim first arrived at the office he was greeted by an office without doors (red and white crepe paper streamers replaced them), red and white balloons floating in the air and bouquets of flowers everywhere.

Clients, staff and friends sported buttons that showed a heart-shaped face and said, "We love the Big Guy".

During the day vans arrived and departed bearing clients to share in the celebration. These happy clients joined Jim in his office for pieces of anniversary cake.

About 2:40 in the afternoon, a band composed of staff members Marilyn Hawk and Penny Cloonan (flutes), Jack Watts (clarinet), Kim Hartquist (tuba), Peter Cutulle (trumpet), and Owen Young (percussion instrument), saluted Jim playing, "When the Saints Come Marching In," and "Hail to the Chief."

At one point during the day Jim was whisked away to view a billboard at the corner of Mt. Hope and South Avenues which said —

### Congratulations!

### Jim Mroczek

### 15 Years of Service

### Association for Retarded Citizens

The staff planned and executed this spectacular under the leadership of Nancy Indivino, Personnel Director.

May the Board of Directors, Parents, Volunteers and Friends add their best wishes and thanks to Jim for his 15 years of wise and energetic leadership.

With the Rochester skyline as a backdrop, Executive Director Jim Mroczek's friends and staff bought a billboard to celebrate his 15 years with the Monroe County ARC. ■

## OVR Receives Federal Grant for Supported Employment

The New York State Education Department, Office of Vocational Rehabilitation has received \$1.3 million from the Title VIC of the Federal Rehabilitation Act to fund Supported Employment services in New York State. The funds will be used to establish Model Programs which will assist severely disabled persons to work competitively through the on-going availability of job site trainers. One hundred four proposals have been received in response to a formal Request for Proposals. These are now being reviewed and awards will be issued in February to programs across the State, which

has been organized into five Technical Assistance Regions.

Supported Employment is based on the principle that successful job training occurs on the job. In practice this means that people in Supported Employment can immediately begin earning money and reduce their dependence on public services. Supported Employment is a type of employment outcome intended for persons having a severe disability and who require on-going assistance in order to acquire and maintain meaningful community based employment. ■



# Jane Gerstheimer Represents NYSARC at Workforce Hearing

The President of the NYSARC, Inc., David B. Lettman, requested Mrs. Jane Gerstheimer to represent the Association, through the eyes of a parent, at the February 3, 1988, Senate and Assembly Hearing on Workforce Recruitment and Retention in Voluntary Agencies. Mrs. Gerstheimer is on the Board of Directors of the Orange County Chapter of NYSARC and serves on the Association's Board of Governors.

The following was the testimony presented by Mrs. Gerstheimer:

"My name is Jane Gerstheimer. I am from Orange County and the parent of a 39 year old son (Paul) with Developmental Disabilities who currently resides in a community residence and goes to a day treatment program run by the Orange County Association for the Help of Retarded Citizens. I also have two daughters who are professionals in the field.

My volunteer and advocacy activities date back 35 years to Nassau County, when Paul was at home, through 18 years at the Letchworth Developmental Center before he was placed in the community. He was first placed in Sullivan County and then moved to Orange County to be nearer where we live. I've served on the Board of Orange County AHRC for several years as well as on the New York State Association's Board of Governors. My experience over these years of supporting Paul and advocating for those like him, as well as meeting with parents in other counties across the State, has given me a broad perspective of what constitutes quality care for persons with Developmental Disabilities. I am speaking today as a parent concerned for my son and all the others who are dependent upon the community-based service system.

I want to thank both Assemblywoman Connelly and Senator Spano for allowing me

to testify today. You have both been exceptionally strong and consistent in the support you have given our programs regarding the issue before us today-the staffing crisis in the field of Developmental Disabilities.

Over the years I have seen a wide range of programs, from a sheltered workshop Paul attended in West Nyack when he was still at Letchworth, to visiting those run by agencies in most of the Mid-Hudson area. Some were excellent and stand out far above others, but regardless of program quality, the thing that was always most important was the quality of staff employed, their dedication to and knowledge of the clients they served. This was always the critical common denominator upon which the excellence of the program, or lack thereof, depended. The progress the clients made in the program was also very dependent upon the interest and support of staff.

This holds true for all types of organizations — profit or not-for-profit, but is especially important in the human services field where the people who work with our clients are so important to the human beings they serve. We are absolutely dependent upon the quality of staff to client interaction as the overriding means of promoting quality of care.

Our overwhelming dependence on good staff is underscored by the extreme vulnerability of the population entrusted to their care. We need exceptionally sensitive and understanding people to work with this population. Most Developmentally Disabled persons are not capable of protecting themselves from physical and emotional abuse, mistreatment or neglect. It is up to us to see that the staff who must constantly be present in day or residential programs for their care, comfort and training are lifelines to the kind of safe, enriched environment they

deserve. These staff must not only be trusted to avoid subjecting clients to negative behavior, but more important, to extend to them the kind of nurturing care which they must have to achieve their goals and to be happy. This is the difference between the institutional life we took them from and the normalizing life we promised them in the community.

It is with this in mind that I am especially disturbed by the implications of the present staffing crisis. Staff turnover approaches 200% annually in some programs and some agencies can't even afford to require that staff speak English. Standards have had to be lowered regarding education, training and just plain ability to cope with our population needs and the paperwork required. In fact, you sometimes have to wonder who is more capable in the program-the new untrained staff or the higher-functioning client who knows the ropes because he lives there or goes to program there.

Very often there are no professionals or trained people as supervisors in the first line of management to train new staff because they don't stay long enough to progress to the next step. This is discouraging for a new employee and they soon leave because they do not feel they're appreciated or getting the right direction and support from those supervising them. Professional staff are also very much lacking in most of the programs because the voluntary sector cannot compete salary-wise.

When a good employee leaves our clients are the losers. It is like losing a member of their family — the only family some of them know. They feel rejected and fearful of getting acquainted with yet another person who will be intimately involved with every phase of their daily living. Will he be nice to me — will he understand what I need? Our clients are expected to readjust constantly.

In Orange County we have very low unemployment. At this point even fast food chains are paying more per hour and giving better benefit packages for better hours and more pleasant working conditions. How can the voluntary agencies compete? Orange County has also become a very expensive county in which to live or rent. Our young people have to look elsewhere for jobs that pay enough so they can afford to live in the county or move elsewhere. Thus, it is not surprising that many not-for-profit agencies can't hold their employees for more than a few months, let alone finding a way to convince these employees to make a career for themselves in the field. Many caring people would prefer to work with our population but can't afford to.

In our area we have another unique problem in coping with the staffing crisis. There are twice as many State-operated group homes as there are voluntary. The State salary scale starts at approximately \$15,000 a year with an excellent health care package. This salary goes up another \$1,500 the first year. By comparison, the voluntary agency is only able to pay approximately \$11,500 for the same position with a 3% to 5% raise the first year-and the health care package is not as good. Again, how can they compete?

Consequently, fewer staff positions are filled in the voluntary sector to the point where it even becomes difficult to get the clients to the excellent supplemental recreation programs the Orange County AHRC runs in Orange County. Often, there are more State clients present than from the voluntary agencies. Often there is only one staff member on duty with ten clients be-

cause there is no relief staff available and the regular positions are not filled on that shift. There are many times when staff have worked 33 hours straight, some of them going from one house to another to fill another shift there. This does not promote quality care — how can they provide more than the most basic care under these circumstances? The dedicated employee also becomes a candidate for burnout and ends up leaving. The Residential Committee of the State Association has developed an excellent set of criteria for monitoring the quality of life in our group homes. However, this cannot be effectively used until the basic staffing problem is solved. Meanwhile our clients are again the losers!

The voluntary sector is expected to develop more programs to serve the unmet needs in the community — How can they possibly do this in good conscience when they can't staff existing programs?

We do appreciate the work the Commissioner and others have done in analyzing the staffing crisis, but there is nothing mys-



**Mrs. Jane Gerstheimer representing the parent point of view at recent Public Hearing on Work Force Issues.**

terious about what happens when you can't afford to pay employees decent wages and offer them decent fringe benefit packages. Granted, salary is not the only motivator, but it does make a statement about the importance of your position. Whatever other solutions that can be developed to help us deal with this issue are appreciated. I do believe that efforts aimed at enhancing agency management, employee training and the constructive ideas contained in the Commissioners report on this topic would be helpful. But first, we must recognize that the lack of adequate pay and benefits hampers efforts in just being able to recruit good staff. Then, we need to put in place other incentives to get them to stay.

For this reason, I strongly endorse the recommendations set forth in the 88-89 executive budget calling for salary enhancements for workers in the Day Treatment Program. I also want to express my appreciation for the action taken last year by the Legislature to enhance salaries for our residential staff. Both of these actions represent a good start toward resolving a very difficult issue. But there is much more that we need to do. It is in this spirit that I support the recommendations being presented to you today. They attack the staffing crisis on a fundamental level. They look at salaries, fringe benefits and some of the other issues such as training.

As a parent and advocate for those who are unable to speak for themselves, and are so dependent upon caring people for their welfare, I appeal to you to look favorably on these recommendations. Upon this hinges the success of our community-based program as an alternative to institutional care. Thank you." ■



**Senator Nicholas Spano and Assemblywoman Elizabeth A. Connelly following the remarks being made by Mrs. Jane Gerstheimer**



## Youth—ARC Client Jay Yates Wins Bronze Medal at International Summer Special Olympics

### Special Athlete Brings Back the Bronze

**Editorial Note:** In 1974, Jay Yates was six years old, he joined Monroe County ARC's Youth—ARCSaturdayRecreationalProgram as a recreator. I was then advisor to the group and came to know Jay well. Jay learned to swim in the Sigl Center pool and, as you'll see in the following article from Directions (the Schlegel newsletter), he earned a Bronze Medal in the swimming event at last summer's International Summer Special Olympics. We are extremely proud of Jay's success and happy that, sixteen years after joining the Youth — ARC program, he is still a member.

Skill, courage, sharing and joy. Jay Yates believes that a good athlete must have them all. And the champion swimmer and diver has proof that he's a good athlete.

The 20-year-old son of Sherry Yates, the occupational health nurse at Schlegel Rochester Division, won a bronze medal at the Seventh International Summer Special Olympics, held July 31 through August 8.

The Special Olympics is an athletic competition like any other. There are events in a wide range of sports, including track and field, gymnastics, swimming and diving, and baseball. The difference is, these games are for the mentally and physically handicapped. Jay has Down Syndrome, a chromosomal abnormality that causes mental retardation.

Jay lived up to the Special Olympics motto of skills, courage, sharing and joy when he joined three swimmers from his home state in the 100 meter freestyle relay to earn the third-place honors. The team trained together only once.

A special education student at Edison Technical School, Jay was the only participating athlete from the Rochester area. He was one of more than 80 competitors from New York State. The games attracted nearly 4,700 athletes and coaches from 72 nations. Most of the competition was at Notre Dame University in South Bend, Indiana. Jay was selected to represent New York based on his excellence at a statewide diving competition. He also hoped to capture a medal for diving at the international games, but a foul-up regarding the rules limited half of the divers, including Jay, to exhibition only.

The Special Olympics' credo is: "Let me win. But if I can not win, let me be brave in the attempt." If the athletes don't win, they know that it's not the end of the world; they're still loved. Every competitor gets a hug, enthusiastic applause and a ribbon after each event.

Their greatest victory is the chance to compete and to share in what is every athlete's first event — overcoming fear. Was Jay nervous during the relay, with thousands watching? "Not much, I've done it before," he answers.

A cool competitor.

To Sherry, the greatest benefit is not in winning races. "Swimming helps his coordin-

ation. Through sports, he works toward goals and interacts with others. That's an accomplishment."

The South Bend Police Department chose Jay as its representative for all the athletes in a closing parade. As an honorary policeman, he took home a uniform, cap and insignia.

Sherry went to South Bend to watch Jay compete. While she was there, she met several celebrities, including Eunice Kennedy Shriver, founder and chairperson of the Special Olympics.

Prior to the trip, Jay vowed publicly to bring home a medal. Sherry feels Jay's determination was doubly rewarded by the newspaper and television coverage he received.

Jay's summation: "It was great!" He packs the word "great" from end to end to put dynamite in his delivery.

Meanwhile, Sherry folds her hands firmly with forefingers pressed hard against her lips, as if this is the pressure point that blocks the tears. "With Jay, I feel so much pride. When he was six months old, the doctors told me to put him in an institution because he wouldn't develop."

She loses the struggle and turns away to conclude. "Things have changed a lot in 20 years. If it weren't for the schooling and people who cared, he would have been locked away. I wouldn't trade him for anything. He's just special." ■

Reprinted from DIRECTIONS,  
Schlegel Corporation Publication  
September/October, 1987



**International Special Olympics Bronze Medal Winner, Jay Yates from Monroe County proudly shakes the hands of fellow safety officers of which he was made an "honorary" member.**

## Day Treatment Ground-Breaking Ceremony

The Broome-Tioga ARC held a formal ground-breaking ceremony on November 23rd to initiate the construction of a new building for the ARC Day Treatment Program.

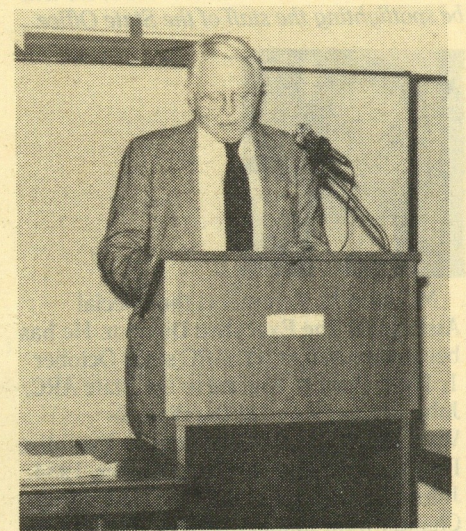
Nearly 100 individuals attended the event, including parents, clients, staff, Board Members, members of the Alhambra, and representatives of other agencies who have been involved with the development of this project.

Robert W. Shrader, ARC Board President, and Matthew Guokas, Executive Director



**Richard Thamasett, Director of Broome Developmental Services, Ruth Frawley, Broome-Tioga ARC Board of Directors and Broome County Executive, Carl Young preparing to lift the first shovel of dirt for formal ground-breaking for the new Broome-Tioga ARC Day Treatment Building.**

welcomed guests to the ceremony. Guest speakers included New York State Senator Warren Anderson, Broome County Executive Carl Young, Director of Broome Developmental Services, Richard Thamasett, Stephanie Davis representing Assemblyman Tallon's office, and James Bryden from Bryden-Trozze Architects.



**New York State Senator Warren Anderson was a Guest Speaker at the Ground-Breaking Ceremony for Broome-Tioga ARC's new Day Treatment Facility.**

Ruth Frawley, ARC Day Treatment Committee Chairperson, Carl Young and Richard Thamasett led the group in "digging out" the first few shovels of dirt.

The new 10,000 square foot building, scheduled for completion by July, 1988, will be located adjacent to the ARC Main Facility on Upper Front Street. It will have a total capacity to serve 75 people, allowing for an expansion of services to an additional 35 severely mentally retarded and developmentally disabled adults.

The Day Treatment Building Project is a joint effort between ARC, Broome County and the New York State Office of Mental Retardation and Developmental Disabilities and is representative of the commitment and interest of local and state governments to assist ARC in meeting the needs of the mentally retarded and developmentally disabled. ■

## Grants Help Computerize "First Steps" Program

The Herkimer County Association for Retarded Children is the recipient of a grant from the Gannett Foundation. On October 20, 1987, Jane Alexander-Paternoster, Program Director of the ARC's Community/Family Services Program, was presented with a check for \$4,100 from the Gannett Foundation. At a luncheon held at Twin Ponds, Eugene C. Dorsey, President, Chief Executive Officer, and a Trustee of the Gannett Foundation, presented a check for the computerization of the "First Steps" Program. The Gannett Foundation grant will allow the Herkimer County Association for Retarded Children to establish a computer networking and clearinghouse system for increasing the quality and quantity of services for children and families with developmental disabilities.

The "First Steps" computer project will store information on accessible services available, both within and outside of the Herkimer County region. This networking system will improve the coordination of interagency service provision, allowing the public one source for instant access to correct and full servicing of consumer needs. Overall, coordination of services will increase, consumers will experience less frustration, and information useful to persons with

developmental disabilities will be more available.

"First Steps" is an information and referral system which utilizes standardized guidelines for identifying at-risk infants, a single point of entry, and a case-conferencing system. Criteria for at-risk infants includes socio-economic, health, and maternal factors which alert the medical community and service providers to the possibility of an at-risk infant/family. When the "First Steps" Program is contacted, the Coordinator's role is to assess the situation and to facilitate the appropriate services through cross-agency referral agreements. Interagency case conferencing allows for the coordination of appropriate needs and the development of a service treatment plan for the infant/child.

The "First Steps" computerization project will achieve the following outcomes: (1) the dissemination of information which will increase the referral process for high-risk and developmentally delayed babies; (2) will enlarge the coalition of service providers that communicate and cooperate with each other; and (3) will enhance the access of parents and physicians to serve providers through a single point of entry help-line and computerized follow-up of children referred to the project. ■



## Spotlight on NYSARC Staff

*In the next several issues of OCV, we will be spotlighting the staff of the State Office.*



Mr. John M. Kemmer is the Special Assistant to the Executive Director. He has been employed at NYSARC since October 1, 1984. Prior to coming to the State ARC, John was employed at the Warren-Washington County Chapter as its Executive Director from May, 1980 to October, 1984. John also worked at the Clinton County Chapter from January, 1978 to May, 1980 as the Work Activities Program Director. He began his employment at the Clinton County Chapter in June, 1977 as a Sheltered Workshop Supervisor and later as a Primary Instructor for Special Programs.

John holds a degree in Psychology from the State University College at Plattsburgh, Plattsburgh, New York. John also received the Associates of Arts and Sciences Degree from the State University Agricultural and Technical College in Cobleskill, New York in Nursery Management. (A degree which John finds extremely helpful in his current position).

John first came to the State ARC office as Field Operations Manager. His position enabled him to visit many chapters and programs providing technical assistance and current information regarding regulations and funding mechanisms.

In his current capacity John has the responsibility of reviewing and evaluating the impact of proposed Federal and State Regulations on programs and services which our Association is involved with. He also assists in the monitoring of Legislation and assists the Executive Director in assuring that the goals and objectives set forth by the Association are being met.

John represents the Executive Director on numerous State and Governmental Committees. He has most recently been involved in the OMRDD Residence Task Force on Survey and Certification as well as the State Education Department's Advisory Task Force on Preschool Programs and Fiscal Guidelines and Standards.

John lives in Saratoga, New York with his wife Donna. John has been with the Association for almost four years. We are indeed fortunate to have an individual with his sensitivity and dedication. ■

## Madison Chapter Receives State Grant

State Senator Nancy Lorraine Hoffman D/I (Onondaga, Madison, and Oneida Counties) recently announced a \$45,000 state grant for the Madison County Association for Retarded Citizens. The monies will be used to purchase food processing equipment.

Ray Lewandowski, Executive Director of the Madison County ARC says, "With the Senator's help we were able to make this dream come true. We've created an environment which blends compassion with meaningful work experience. Our clients are now functioning as whole people."

Lewandowski adds that the new equipment has increased their food processing capacity

way beyond original projections. The plan called for an increase of 4.5 jobs for the handicapped and 2.5 non-handicapped positions. Now, the food processing unit employs approximately 50 combined handicapped and non-handicapped workers, an overall increase of 30 people, including a newly created second shift. The ARC sheltered workshop food processing units annual sales were originally projected at \$200,000, however, the actual annual sales have increased to \$600,000. At the same time, volume has increased from 16,000 lbs. per week beyond the projected 32,000 lbs. to nearly 100,000 lbs. of vegetables per week.

"I'm pleased that through this state grant there will be many economic and social benefits for the ARC," says Senator Hoffman. "There will be more work for the ARC sheltered workshop, increased employment in the community and a steady year round market for local farmers." Hoffman adds that food processing sales have gone from 100% in state to 70% out of state without a decrease in NYS sales.

The Madison County Association for Retarded Citizens is entering its 20th year of operation. ■

## Steuben Chapter Institute's Employee Recognition Program

The Steuben Chapter has instituted an Employee Recognition Program to recognize outstanding service to the agency. Mary M. Chiodo, Sales Coordinator of Steuben Services' Vocational Division was nominated by her supervisor and selected by a committee of agency staff for having secured a New York State contract of almost \$18,000 to manufacture trail markers for State Parks.

The trail markers will be made on site by clients of Steuben Services' Vocational Training Center. Additional State contracts totaling about \$90,000 have been awarded to Steuben Services during the past year. Because of the recent expansion of the ARC Training Center facilities, the agency is now able to handle work of this quality and quantity. ■

## Grant Funds Community Dance Recital for Preschoolers with Special Needs

The Livingston-Wyoming Association for Retarded Citizens is the recipient of a \$1,500 grant from the Genesee Valley Council on the Arts. The grant was given to fund the artistic and administrative fees for a Community Dance Recital for preschoolers with special needs. Public funds for this project were made available by the NYS Council on the Arts under the aegis of the decentralization program, and awarded locally by the Genesee Valley Council on the Arts Decentralization Program.

According to Annemarie Neubecker, the Director of the ARC Children's Services Program, which is the direct recipient of the funds, the project will be getting underway in the next few weeks with the recital to be presented sometime in May. Susan Ware of Genesee Valley Council on the Arts will be working with Ms. Neubecker and the children to put together the dance recital. Approximately 10-15 of the 100 preschoolers served by Children's Services will be involved in the presentation.

## Special Education Student Writes Poem

The following poem was written by a student in the Special Education Program in order to help students at Clarkstown North

better understand the students in the Special Education Department.

### *Do You Really Understand...?*

Why do people tease me?  
Do they really understand who I am?  
Do you really understand that when you tease me, it makes tears drip down my face?  
Do you really understand that you are wasting your time teasing me?  
Do you really understand what it's like to be teased?  
Do you really understand that I am not weird or strange?  
Do you really know what it's like to be in my shoes?  
Do you really understand why it takes time for me to learn the things you do?  
Do you really understand why some of us can do better than others in sports?  
Do you really understand how much it would mean to me if I won a trophy for academics or athletics?  
Do you really know what it's like to be in a special class?  
Do you really understand why I am disappointed when people confuse me with being physically handicapped?  
Do you really understand that I am not physically handicapped?  
Do you really understand that I am mentally challenged?  
Do you really understand that I want to be treated like everyone else?  
Do you really understand that I want to be treated with respect and dignity?  
Do you really understand that I wish to be independent someday?  
Do you really understand that I like to laugh when things are funny to me?  
Do you really understand that I have dreams just like everyone else?  
Do you really know what it's like to be lonely and without friends?  
Do you really understand that I wish to fall in love and perhaps get married?  
Do you really understand that I only need a chance to be your friend?  
Give me the chance to be your friend and I will prove to you who I really am.  
Talk to me  
be my friend  
make me feel important  
Because, after all...  
I am just like you

**Adria Guidali**  
7 Gerlach Drive  
New City, New York 10956 ■

## Staff Members Praised for Rescue Work

Two members of Seneca ARC's transportation staff played a crucial role at the site of a collision during a December snowstorm. Driver Bill Crow and aide Kathy Vrooman were returning to the ARC after delivering all client passengers to their homes. There were traveling a country route some 15 miles from the nearest village. Snow was falling heavily, it was dark, and visibility was minimal. As they rounded a curve, they came upon two cars which had crashed head on in the opposite lane. A dazed man with an obviously injured arm and his small, screaming son were wandering in the road. Inside one car an unconscious man, bleeding from several places including both ears, was pinned under his steering wheel.

Using the two-way radio with which all ARC buses are equipped, Bill and Kathy reached home base and called for police, ambulances, and the Jaws of Life. They took the ambulatory victim and his child into

their bus where they could provide warmth and reassurance until help arrived. They positioned the bus, flashers on, where it could best alert any on-coming vehicles to the accident scene so that no one else would pile into it. And they broke into the car holding the unconscious victim with blankets which they carefully placed around him.

Without question, Bill's and Kathy's actions helped sustain the accident victims until further assistance arrived, secured that assistance far more rapidly than it would otherwise have arrived, and reduced the likelihood of further collisions. For their selfless efforts, Bill Crow and Kathy Vrooman received thanks from the Sheriff's Department and letters of commendation from the ARC Board of Directors. Their caring and intelligent responsiveness to a life-threatening emergency for strangers exemplified qualities ARC is especially proud to recognize in its staff. ■

## Self-Advocacy Media Package Available

The Human Policy Press announces availability of a self-advocacy media package containing a slide show, "Our Voice is New", three self-advocacy posters, two buttons and an annotated bibliography on self-advocacy. The package is available for \$55, plus \$3.50 for postage and handling.

"Our Voice is New" is a 20-minute presentation consisting of slides, script and tape cassette for caromate, Wallensack or standard tape recorder. It explains what self-advocacy is, why it is important, what issues are important to self-advocates and what self-advocates do. The slide show features pictures, voices and ideas of self-advocates from around the country. The posters include "Don't Think That We Don't Think," "Label Jars Not People" and "Our Voice is New." Items may be purchased separately.

Purchase prices include:

Self-Advocacy Media Package	\$55
Slide Show (only)	\$50
Poster: "Don't Think We Don't Think"	\$4
Poster: "Label Jars Not People"	2
Poster: "Our Voice is New"	\$5

Postage and Handling: Add \$3.50 for media package, \$2.00 for each slide show, 10 percent or \$1.50, whichever is greater, for all others.

Make checks payable to Human Policy Press. Institutions ordering over \$15 may use official purchase order form. Send order to Human Policy Press, P.O. Box 127, Syracuse, New York 13210. ■



# UPCOMING CONFERENCES

## 1. New York State Association of Community Residence Administrators

**Theme:**  
"A Celebration of Today...A Vision of Tomorrow"

**Date:**  
March 2-4, 1988

**Place:**  
The Desmond Americana  
Albany, New York

**For more information contact:**  
NYSACRA  
155 Washington Avenue  
Albany, New York 12210  
(518) 449-7551

## 2. New York State Commission on Quality of Care for the Mentally Disabled

**Theme:**  
Abuse and Neglect Symposium

**Date:**  
March 9-11, 1988

**Place:**  
Sagamore Hotel  
Lake George, New York

**For more information contact:**  
NYSCQCMD  
Abuse and Neglect Symposium  
99 Washington Avenue  
Albany, New York 12210

## 3. Association for Children with Down Syndrome, Inc.

**Theme:**  
"Physical and Occupational Therapies: Methodologies and Techniques for the Child with Down Syndrome"

**Date:**  
March 14, 1988

**Place:**  
2616 Martin Avenue  
Bellmore, Long Island, New York

**For more information contact:**  
Association for Children with Down Syndrome, Inc.  
(516) 221-4700

## 4. Governor's Office for Voluntary Services

**Theme:**  
"Volunteer Power-How To Get It-How To Use It"

**Date:**  
March 28-29, 1988

**Place:**  
Albany Hilton  
Albany, New York

**For more information contact:**  
Ms. Elayne Billups  
GOUS  
2 World Trade Center  
New York City, New York 10047  
(212) 587-2255

## 5. National Association for the Dually Diagnosed

**Theme:**  
"Consideration of the Psychiatric and Emotional Needs of Persons with Mental Retardation"

**Date:**  
March 28, 1988

**Place:**  
Holiday Inn  
Suffern, New York

**For more information contact:**  
NADD  
110 Prince Street  
Kingston, New York 12401  
(914) 331-4336

## 6. National Industries for the Severely Handicapped

**Theme:**  
National Conference

**Date:**  
April 17-20, 1988

**Place:**  
Holiday Inn Crowne Plaza  
Orlando, Florida

**For more information contact:**  
1988 NISH National Conference  
2235 Cedar Lane  
Vienna, Virginia 22180  
(703) 560-6800

## 7. New York Association for the Learning Disabled

**Theme:**  
"Education-Preparation for Life"

**Date:**  
April 20-22, 1988

**Place:**  
Ramada Inn  
Niagara Falls, New York

**For more information contact:**  
NYALD Conference  
155 Washington Avenue  
Albany, New York 12210  
(518) 436-4633

## 8. Young Adult Institute

**Theme:**  
"Employment, Integration and Community Competence"

**Date:**  
April 27-29, 1988

**Place:**  
Hilton Hotel  
New York City, New York

**For more information contact:**  
YAI  
460 West 34th Street  
New York City, New York  
(212) 563-7474

## 9. American Association on Mental Retardation

**Theme:**  
"The Conquest of Mental Retardation"

**Date:**  
May 29 - June 2, 1988

**Place:**  
Washington Hilton Hotel  
Washington, D.C.

**For more information contact:**  
Stephen H. Stidinger  
1719 Kalorama Road, N.W.  
Washington D.C. 20009  
(800) 424-3688

## 10. New York State Association of Rehabilitation Facilities

**Theme:**  
"Rehab '88 - Preparing for the Second Decade"

**Date:**  
September 28-30, 1988

**Place:**  
Albany, New York

**For more information contact:**  
NYSARF  
155 Washington Avenue  
Albany, New York 12210  
(518) 449-2976

## 11. The Association for Persons with Severe Handicaps

**Theme:**  
"Empowerment: Choices and Change"

**Date:**  
December 8-10, 1988

**Place:**  
Washington, D.C.

**For more information contact:**  
TASH  
7010 Roosevelt Way N.E.  
Seattle, Washington 98115  
(206) 523-8446 ■

## NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

### SAFETY GROUP MANAGEMENT COMMITTEE

Commends those chapter employees whose individual actions have prevented loss of life or saved the life of another. These actions often undertaken despite personal danger manifests the strength of character, self sacrifice and respect for human life shared by all NYSARC staff.

### DUANE RHUDE

Duane evacuated a burning bus saving the lives of 40 clients. Duane works for the Steuben County Chapter.

### WILLIAM CROSS KATHLEEN VROOMAN

Kathy and Bill administered first aid at an accident scene which prevented the further injury and death of the victims. They are employed at the Seneca County Chapter.

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# ASSOCIATION CALENDAR OF EVENTS

## MARCH

- 2 Community Residential Services Committee Meeting  
Delmar, New York
- 3 Guardianship Committee Meeting  
Delmar, New York
- 4 Youth Committee Meeting  
Delmar, New York
- 9 Education Committee Meeting  
Delmar, New York
- 18 Executive Committee Meeting  
Sheraton Inn Hotel  
Syracuse, New York
- 18-19 Chapter Presidents and Executive Directors Meeting  
Sheraton Inn Hotel  
Syracuse, New York
- 25 Insurance & Pension Committee  
Delmar, New York
- 26 Budget and Finance Committee Meeting  
Delmar, New York
- 31 Public Information Committee Meeting  
Delmar, New York

## APRIL

- 8 Legislative Committee Meeting  
Delmar, New York
- 15 Adult Services Committee Meeting  
Delmar, New York
- 16 Ad Hoc Committee to Review the Issue of Re-affiliation with National ARC  
Delmar, New York
- 22 Scholarship and Awards Committee Meeting  
Delmar, New York

- 22-23 Spring Board of Governors Meeting  
Sheraton Airport Inn  
Albany, New York

NYSARC Safety Group Management Committee Regional Meetings on Safety for Supervisors  
Date, time and location to be scheduled.

## MAY

- Prevention Committee Meeting  
Delmar, New York
- 20 Day First Annual Recreational Retreat  
Elmira, New York
- 25 Guardianship Committee Meeting  
Delmar, New York

## JUNE

- 24 Resolutions Committee Meeting  
Delmar, New York

## JULY

- 8 Community Residential Services Committee Meeting  
Delmar, New York
- 12 Family Support and Outreach Committee Meeting  
Delmar, New York
- 14 Supplementary Recreation and Special Olympics Committee Meeting  
Sheraton Airport Inn  
Albany, New York
- 15 Youth Committee Meeting  
Delmar, New York
- 21 Education Committee Meeting  
Delmar, New York

NYSARC Safety Group Management Committee Meetings on Infectious Disease, Client Safety Training. Date, time and location to be scheduled.

## AUGUST

- 12 Prevention Committee Meeting  
Delmar, New York
- 26 Resolutions Committee Meeting  
Delmar, New York

## SEPTEMBER

- 15 Public Information Committee Meeting  
Syracuse, New York

## OCTOBER

NYSARC Regional Meetings  
Date, time and location to be scheduled.

## NOVEMBER

- 2-4 Executive Directors Association Meeting  
Concord Resort Hotel  
Kiamasha Lake, New York
- 3 Executive Committee Meeting  
Concord Resort Hotel  
Kiamasha Lake, New York
- 3 Scholarship and Awards Committee Meeting  
Concord Resort Hotel  
Kiamasha Lake, New York
- 3-4 Board of Governors' Meeting  
Concord Resort Hotel  
Kiamasha Lake, New York
- 3-6 NYSARC Annual Convention  
Concord Resort Hotel  
Kiamasha Lake, New York
- 6 Board of Governors' Meeting  
Concord Resort Hotel  
Kiamasha Lake, New York ■

## THREE CHANGES TO NYSARC BY-LAWS RATIFIED BY CHAPTERS

*New Standing Committee on Family Support and Outreach Services formed.*

At the October, 1987, Convention, two-thirds of the voting delegates approved three revisions to the N.Y.S.A.R.C., Inc. By-Laws. The proposed changes were then submitted to the chapters. The By-Laws call for a majority of chapters which were chartered at the time of the adopting convention must approve the changes in order for the amendments to be adopted.

In February, 1988, a majority of chapters voted in the affirmative and three changes and/or revisions to the NYSARC, Inc. By-Laws went into affect.

The adopted By-Law revisions were:

**1. Article IX, Section 1** Establishment of a permanent NYSARC standing committee called, *FAMILY SUPPORT AND OUTREACH SERVICES COMMITTEE*.

**2. Article IV, Section 1**  
IN THE EVENT THAT LESS THAN TWO OF THE EXECUTIVE COMMITTEE IS A PARENT OR BLOOD RELATIVE OF AN INDIVIDUAL RESIDING IN A DEVELOPMENTAL CENTER OR IS A REPRESENTATIVE OF A DEVELOPMENTAL CENTER CHAPTER, ADDITIONAL MEMBERS WHO ARE SUCH PARENTS OR BLOOD RELATIVES AND/OR REPRESENTATIVES OF A DEVELOPMENTAL CENTER CHAPTER SHALL BE ELECTED TO THE EXECUTIVE COMMITTEE, SO THAT THERE SHALL BE A MINIMUM OF TWO SUCH INDIVIDUALS

**3. Change of name of Legislative Committee to GOVERNMENTAL AFFAIRS COMMITTEE. ■**

## NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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