

# OUR Children's Voice

## Retarded Children Can Be Helped

### Senator Moynihan Addresses Putnam Chapter's Preschool Graduation

On Sunday, August 14, 1988 the Putnam County Chapter of NYSARC, Inc. held their Twentieth Annual Preschool Commencement exercise in the Mahopac Falls School in Mahopac Falls, New York. Twenty-four preschoolers, their families, teachers and friends gathered to hear a special address from New York State's Senior Senator, Daniel Patrick Moynihan.

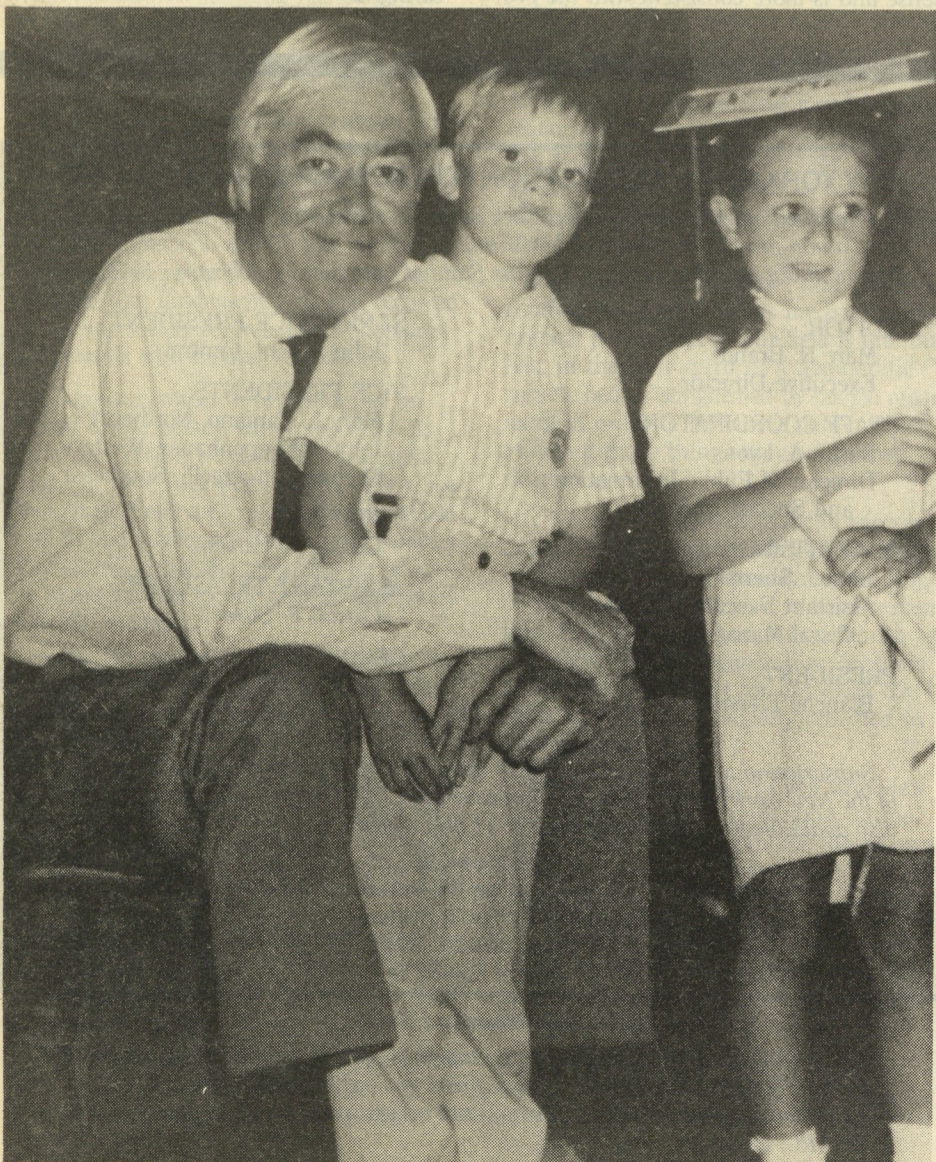
Senator Moynihan flew in from Washington, D.C. to address over 200 individuals. The Senator presented each of the twenty-four children their diplomas and gave them each flowers.

In his address, Senator Moynihan pledged his on-going support in assur-

ing that the government will continue its efforts to assist children who are handicapped.

The Director of the Putnam Chapter's Preschool, Ms. Nancy Miringoff gave welcoming remarks as did Mr. John Kemmer, Special Assistant to the Executive Director of NYSARC. Mr. Stuart Greif, Executive Director of the Chapter gave the introductions.

Also on hand for the day's event were Assemblyman Vincent Leibell, Assistant County Executive, Arlene Rice and Supervisor of the Town of Carmel, Richard Othmer. ■



**BLANCHE FIERSTEIN  
ELECTED 15TH PRESIDENT  
OF NYSARC, INC.**

See Story on Page 5

### 39th Annual Convention Draws Record Attendance

*The Delegates' adopted 1989 Legislative Platform, Blanche Fierstein elected President, over 700 persons hear Banquet Speaker Michael Dowling, Deputy Secretary to the Governor for Human Services and Keynote Address to Delegate Assembly by Dr. Thomas Bellamy, Director, Office of Special Education Programs for the Federal Department of Education, Mr. George Hirsch receives Volunteer Award*

The largest attended NYSARC, Inc. Convention was held at the Concord Resort Hotel on November 3-6, 1988. Over 725 persons registered and were in attendance in what has been called "one of the finest conventions in the history of our Association." The thirty-ninth annual convention has as its theme, "A Legacy of Love - 39 Years of Caring."

Those present had an opportunity to participate in 34 different workshops. Included in the array of workshops were demonstrations of the Association's activities, programs and services as well as current trends in the field of mental retardation and developmental disabilities. There were also a number of outstanding workshops presented by individuals outside of ARC. In addition to the workshops, a

film forum and numerous exhibits were also part of the convention activities.

On Friday night, November 4, 1988 a standing room only Delegate Assembly heard the beautiful and touching words of Beth Hyman, representing the Orange County Chapter. Her remarks were followed by a special presentation of the Pathfinder Bell Choir.

The Delegate Assembly heard a strong message concerning the future direction of programs and services for children who are handicapped from the Director of the Office of Special Education Programs for the Federal Department of Education, Dr. Thomas Bellamy. His presentation was well received and set the tone for the convention.

(Continued on Page 5)



# EDITORIALS

## The State Budget: It Won't Be The End Of The World

The State Budget for the next fiscal year is beginning to loom ominously before us. Particularly troubling is the massive State Budget deficit that the Governor claims has reached \$2.3 billion. Throughout the State rumors are spreading that we are all in for an era of unprecedented austerity. Thus we are told, depending on who one talks to or on what particular day it is, that we must either choose between preserving the stability of the existing system or continued development. Or, worst of all, we'll have no choice at all.

Undoubtedly a fiscal crisis does exist. The deficit is large and growing larger. It is expected to persist into the next fiscal year and the Governor, so far, is committed to a further reduction in State taxes. Clearly, the outlook for the next State fiscal year does not appear bright at this point in time.

Yet, the developmental disabilities service field in New York State has seen bad times before. In 1983, when Governor Cuomo first came to office, the State was faced with a deficit comparable to the one we face today. The Governor proposed massive cutbacks in developmental center staffing and in key appropriations funding not-for-profit providers. The Legislature restored much of what the Governor cut out but not all of it. Still, we not only survived but ultimately, we began to thrive.

Today, the developmental disabilities field in New York State is stronger than it was in 1983. Rate and fee mechanisms have essentially locked in a rationale basis for funding all residential programs and day treatment. The regulatory basis for these mechanisms has the force and effect of law and arbitrary cutbacks are simply illegal. Though we may argue how rationale rate and fee methodologies really are when it comes to taking into account what we consider to be our real program needs, their ability to stabilize the system in the face of a crisis is undeniable.

In 1983, we also did not have the level of supplemental services we have now. Family support services, as a distinct funding category, didn't exist. Today it totals \$20 million. Supportive work was also non-existent and today it totals \$6.5 million. The mere fact that we are better equipped to serve more persons at home and in competitive work environments shields more traditional services from the impact of potential funding restrictions.

Also, in 1983 there were 3,000 more individuals in developmental centers than there are today. The placement of these individuals into superior community settings, has reduced their vulnerability to the effect of fiscal cutbacks; cutbacks that can have an especially devastating impact on the quality of institutional care. In addition, new federal ICF/MR regulations make

reductions in direct care staffing nearly impossible without risking federal decertification action and the loss of desperately needed federal revenue.

Finally, and most significantly, in 1983 total funding for not-for-profit providers was \$196 million; today it is up by 120% and totals \$430 million.

Clearly, today's developmental disabilities system is not impervious to the effects of a severe fiscal crisis. There are many unmet needs for both residential and day program services. Problems of work force recruitment and retention continue to be severe. Developmental center staffing is woefully inadequate. These problems will not improve in the face of a budget crisis and we cannot forget about them or fail to bring them to the attention of State officials while we wait for the State's fiscal health to improve.

Yet, since the crisis of 1983, we have come a long way. Now, with 1989's State budget fast approaching we need to bear in mind that the system has been expanded and strengthened. Nor should we fail to give credit where credit is due. Commissioner Webb deserves our special appreciation for building a system over the past five years which is more durable and resilient than ever before.

Certainly, if we can survive 1983 and go on to thrive, we believe that with hard work and aggressive advocacy, we will do even better over the years to come, regardless of what may transpire in 1989. ■

## New ICF/MR Regulations: Panacea Or Prescription For Failure?

On June 3, 1988, new federal ICF/MR regulations were published in the Federal Register by the Health Care Financing Administration (HCFA). Significantly, these regulations are industry based and reflect the collective input of scores of providers gathered over the course of the last two years. This is a distinct departure from past practice; HCFA has rejected input regarding its old regulations which have remained unchanged for 15 years.

The fact that HCFA has finally instituted new regulations, and that these standards do reflect, in some measure, a more contemporary philosophy of care, is being hailed by provider and advocacy organizations throughout the nation. Are they a panacea? Of course not. Regulation by its very definition is a necessary evil: "good" regulation strikes that all important balance between the need for accountability and the desire to put all resources to use in caring for persons who are mentally retarded; time spent fulfilling governmental accountability requirements is time spent away from providing care for the individuals we serve.

Still we believe that, *conceptually*, HCFA has designed a "pretty good" set of regulations. Under the former regulations the attitude of the surveyors was, "if it wasn't documented, it didn't happen." Yet, we all know that good paperwork is not a prescription for a good program.

The new regulations and survey process require that the survey will focus on observing the actual delivery of care to persons with mental retardation.

This is a profound change. It is one that everyone who has ever complained about regulations — and that includes providers as well as OMRDD — have always said they wanted. Thus, it is not surprising that we believe this shift in the focus of the survey process — from "paper to people" — could have a significant and positive impact on the quality of ICF/MR programs.

Yet, now that we are all getting what we always said we wanted, many of us have suddenly come to recognize the inherent risks in shifting to a performance-based compliance system. It requires a higher degree of judgement and reasonableness on the part of the surveyors and of course it requires us, in real terms, to do a better job. Nonetheless, if we are to move towards an accountability system which makes sense and is more consistent with the *pro-*

*vision* of care than the *documentation* of care provision, we must have the courage to take this risk.

We believe the new regulations, in concept, give reason for optimism. OMRDD disagrees. They have opposed the new ICF/MR regulations and have urged providers and advocates to carry their message to Washington. But again the irony of OMRDD's position can hardly escape notice. For years they have complained that the old regulatory system emphasized paper and not program. Now they've gotten something akin to what they said they wanted.

And clearly, under the scrutiny of these new performance-based standards, OMRDD should be concerned. Developmental Centers do not have sufficient hands-on staff to meet active treatment requirements which are almost totally unchanged by the new regulations. This fact is borne out by the wealth of parent outcries that meaningful treatment and activity is all but non-existent in many of the developmental centers, and it is confirmed by the state and federal survey reports.

NYSARC has concluded that it would be premature, at this time, for our Association to formally endorse these regulations. Instead, we have taken it upon ourselves to collectively examine the new requirements and prepare ourselves to meet new challenges and opportunities which they present.

We clearly realize that in shifting to a performance-based system of regulation, our ability to fulfill our real mission, to care for persons with mental retardation, will be tested. Yet we are convinced that we will meet this test since we will be asked to do nothing more than most of us have always done: to truly care for the persons with mental retardation whose well-being has for so long been entrusted to our judgement, good sense and deep sense of caring. ■

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

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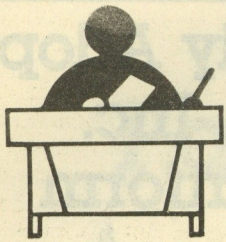
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## From The Executive Director's Desk

Just a few weeks ago, our Association held its 39th Annual Convention at the Concord Hotel. The turnout was excellent, the events were well received and the mood was distinctively upbeat.

To be sure we still have our differences. But at this convention I noticed that our differences no longer seemed self-defeating. Rather they seemed to inspire us into engaging in the kind of constructive dialogue that can only work to facilitate the pursuit of our most fundamental goals. It is very timely therefore, that I use this opportunity, as I did when I gave my report to the Board of Governors, to restate the fundamental mission and purpose of NYSARC and why I believe that we are such a unique organization.

Thirty-nine years ago NYSARC was founded in order to represent the most intimate concern of our members: the instinctive need of parents to care for their children. Few other organizations can claim to be bound by a single purpose that is held so dearly by its membership.

It is this founding principle which has given our organization an unassailable claim to legitimacy in the eyes of numerous Governors, Legislators and other public officials over the course of the last 39 years. This uncommon standing has come to exemplify the ability of people to coalesce around a common set of principles in order to compel fundamental change.

In short, our organization exists in the best spirit of a democratic society: a spirit in which people organize and aggressively speak out on those issues they hold to be most important.

And speak we did. It was because of NYSARC that fundamental change occurred in the way society regards, treats and cares for persons with mental retardation.

Today we continue to speak out on behalf of the person whom we serve. As an organization we now stand almost alone in New York State as the only voice that consistently and vigorously calls attention to and challenges those public policies that clearly violate the principles for which all organizations in our field should stand for. For example:

- We are the only provider organization in New York State playing an active role in Federal Medicaid reform initiatives.
- We forced legislation to the Governor's desk calling for the first uncompromising analysis of the pathetic staffing conditions at our state's developmental centers.
- We led the fight against proposed hazardous waste disposal plants at Letchworth and Wassaucott Developmental Centers.
- We alone sued the state to attempt to prevent co-location of convicts and residents at Rome Developmental Center.



by Marc N. Brandt  
Executive Director

— We initiated legislation leading to the eventual reform of OMRDD's regulatory system.

— And finally, we alone caused many other important bills to be introduced, discussed and debated dealing with issues from rate setting to the least restrictive education of handicapped children. Issues that, frankly, except for our efforts, would be forgotten.

Let me tell you that despite NYSARC's efforts, New York State is not regarded as a hotbed of activism on behalf of persons with mental retardation. Quite the contrary. We are seen as a state where parents and advocates have dutifully yielded their voice to a patriarchal state bureaucracy; a bureaucracy that proclaims it knows what is best for our children despite the dictates of common sense.

These perceptions were shared with me when I attended the National ARC Convention in Albuquerque, New Mexico. They are painful for two reasons.

Firstly, they do not reflect our Association's current efforts. I am, however, confident that as NYSARC continues to speak out, the National view of a weak developmental disabilities advocacy effort in New York State will give way to a much stronger and more vital image. The recent nationwide publication of our first public policy monograph, "Reconciling Funding and Philosophy," which details our support of the "Chafee Bill", will prove once again that there are strong advocates in our state who will dare to openly dispute the powers that be in New York.

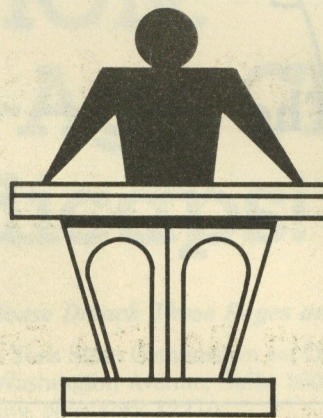
The second reason why I find these perceptions so painful brings me back to my original point. That is, our field is one that has, in the best spirit of a democratic society, been distinguished by people organizing in order to influence public policy affecting those things they hold most dearly.

Thus, the perception that the wisdom of parents has been replaced by the wisdom of the state rejects all we stand for. But, of course, that perception is a misperception. One that I am sure will diminish as the efforts of this organization continue along the path we set for ourselves 39 years ago and have recently returned to with renewed vigor.

And finally, for those of you who view this path with some trepidation let me quote you words that capture the essence of the spirit of the founders of this organization; words that are as valid as our democratic institutions are old.

Simply stated, "When public officials have no opposition, the people will soon have no choice."

As parents and friends of parents we must be doubly sure that our choices and those of our children are always preserved. ■



## The President Speaks

This is the first time I have the pleasure of addressing our members and friends in Our Children's Voice. As your newly elected President, I want to sincerely thank all of our chapters and membership for your confidence in electing me President of our Association. I hope in the coming months I will have the opportunity to meet many of you and visit our chapters to see first hand the wonderful programs, services and advocacy we are providing.

Since becoming President, I have received numerous letters and telephone calls from throughout our Association congratulating me and wishing me well. I thank you one and all for your support, words of encouragement and good wishes. I have always respected and admired our past leadership and look forward to carrying on the tradition of our Association.

We will in the coming months be faced with some very difficult decisions. The State of New York is faced with a large deficit which ultimately will affect the programs, services and unmet needs of those we serve. As your newly elected President, I want to inform our chapters that we will collectively take whatever action will be necessary in order to protect our past efforts as well as assure that current and future needs are not neglected.

I also want to take this opportunity to thank the Immediate Past President, David Lettman, for a smooth and orderly transition. I look forward to his continual involvement with our organization.

At the Saturday night banquet when I was installed as President, I could not help but reflect on the words and wisdom of our Association's first President and Executive Director, Joseph T. Weingold. Jerry captured the essence of our life-long commitment when he stated:

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

I pledge myself to this task and look forward to serving our Association as its 15th President. ■

Blanche Fienstein

*Blanche Fienstein*

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## Letters To The Editor

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August 29, 1988

Mr. Marc Brandt  
Executive Director  
NYS Associations of Retarded Children  
393 Delaware Avenue  
Delmar, New York 12054

Dear Marc:

I just wanted to take this opportunity to thank you, your staff, the Chapters and membership of the Association for the cooperation and support you gave me during the 1988 Legislative Session.

Through our joint efforts we were able to secure several major items in the 1988-1989 State Budget. We were able to appropriate \$2.4 million to provide an additional 3% increase for contracts in unified services, local assistance, direct sheltered workshops and Chapter 620 programs. This will provide a total increase of over 6% for these contracts and will enable agencies to offer enhanced salaries to their employees. Along with this appropriation, we were able to place language in the budget directing OMRDD to work with providers to review current indexing methodologies for inflationary increases and the impact of fringe benefits on the recruitment and retention of employees.

In addition, your assistance was vital in obtaining passage of several pieces of legislation in the Senate. Among these was a bill directing CQC to evaluate services at the Developmental Centers and another mandating that the position of ombudsman in each of the developmental centers be full time.

I especially wanted to express my appreciation for your support for the package of Site Selection bills that were introduced in the Senate this past session.

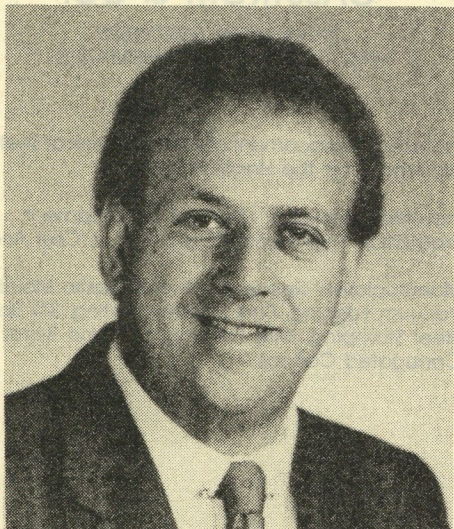
Your constructive comments enabled me to shape the bills into a package that encourages development of community residences while creating an equitable balance of the residents of these facilities and their surrounding neighbors.

I look forward to our continued cooperation in the years ahead.

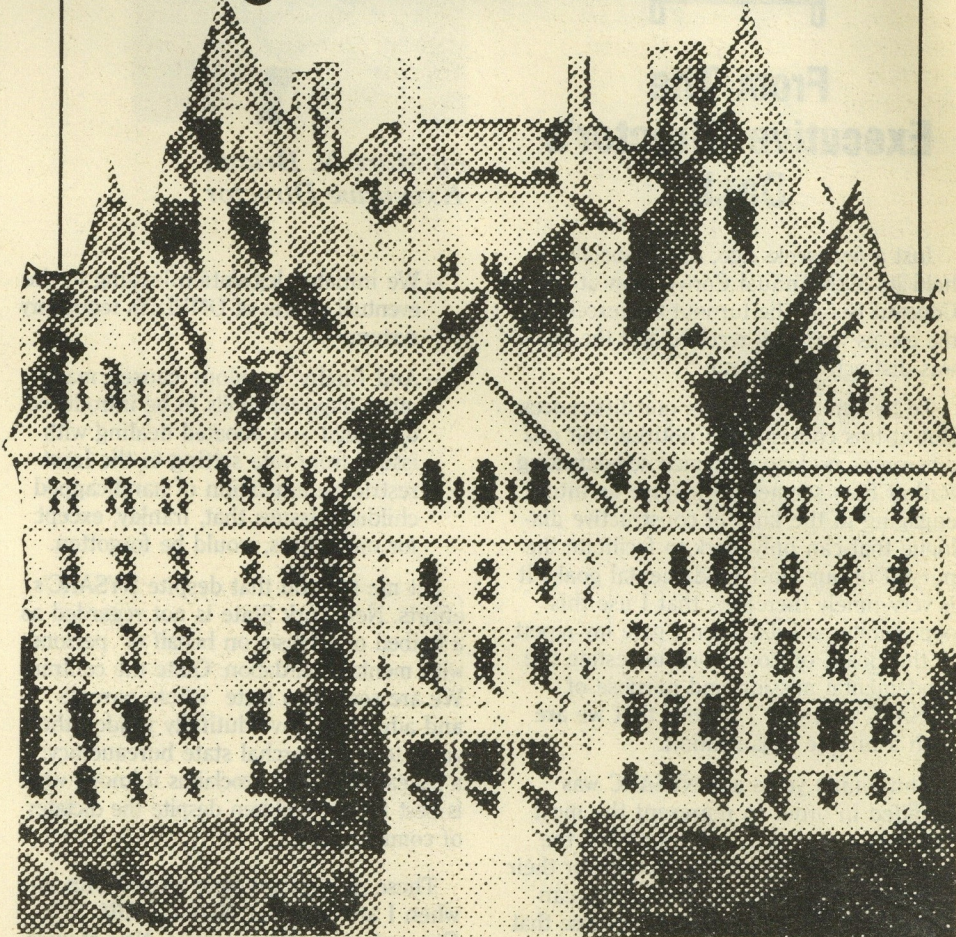
Sincerely,

NICHOLAS A. SPANO  
Senator

NAS:marm



## Delegate Assembly Adopts 1989 NYSARC, Inc. Legislative Platform



*Platform calls for Local Assistance Reform, prohibition of discrimination in the placement of persons in community residences, prohibition of co-location, full-time Ombudsman, integration of children with handicapping conditions into public school settings and public education for children birth to five under the State Education Department.*

At its thirty-ninth Annual Convention, the Delegate Assembly representing the 57,072 membership of the NYSARC, Inc. sixty-five chapters adopted the Association's 1989 Legislative Platform.

Commenting on the adopted platform, the Chairman of the NYSARC, Inc. Governmental Affairs Committee, Mr. John Bryant, stated, "the platform as approved by the Board of Governors and ratified by the Delegate Assembly represents the most important elements of legislation that our chapters feel should be presented to the Legislature during the 1989 session. It truly represents the grass roots of our organization."

The following is a brief overview of the adopted NYSARC, Inc. 1989 Legislative Platform. The issues are not listed by order of importance and each area reflects either long-term concerns or new initiatives for our Association.

### Appropriations and Budget

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

This includes reviewing and responding to appropriations for the Office of Mental Retardation and Developmental Disabilities (OMRDD), the State Education Department (SED), the Office of Vocational Rehabili-

tation (OVR), and the Office of Education of Children with Handicapping Conditions; and selected appropriations for the Department of Health, Social Services, Commission on Quality of Care for the Mentally Disabled and for certain other agencies whose program affect persons who are mentally retarded.

Our Association will initiate a proactive role that will advise, educate and encourage the development of a state budget which is responsive to the needs of those residents of New York State who are mentally retarded and developmentally disabled.

### CIVIL PRACTICE LAW

#### Client Transfer Placement

To seek reintroduction and passage of legislation deleting the state's authority to automatically stay a court order regarding the care and treatment of a person who is developmentally disabled.

NYSARC has supported legislation deleting a provision of the law which allows the state or a municipality to obtain an automatic stay of any lower court order regarding the care and treatment of a developmentally disabled person. The power to automatically stay a court order in such instances denies the right of clearly responsible individuals (i.e. parents and guardians) to seek appropriate care for persons who are developmentally disabled.

(Continued on Page 10)

(Continued from Page 1)

Mr. George G. Hirsch was then recognized for his years of outstanding service to the Association. He received this year's NYSARC, Inc. Volunteer Award.

Election of Officers and Board of Governors to the State Association was carried out. As reported on page one of this edition of O.C.V., Mrs. Blanche Fierstein was elected President of the Association.

One of the most important business items transacted at the General Assembly was the review and adoption of the Association's 1989 Legislative Platform. The platform was introduced by the 1988 Governmental Affairs Chairperson, John Bryant. The platform is reported in detail in this issue of O.C.V.

On Saturday, November 5, 1988 the Delegates had a lively discussion on seventeen proposed resolutions. All of the adopted resolutions have been printed in O.C.V.

A special presentation of awards luncheon was held on Saturday. Mr. Richard E. Sheppard, Manager, Office of Plans, Projects and Services for the President's Committee on Employment of People with Disabilities spoke at the luncheon. Mr. Sheppard presented the NYSARC, Inc. Employer of the Year Award to Mr. Ralph Houseknecht, President of Pepsi-Cola Batavia Bottling Corporation.

The convention festivities reached a peak at the Saturday night banquet. Master of Ceremonies, David Kaufman, Chairman of the Sullivan County Board of Supervisors gave words of welcome and kept the program moving. An inspiring invocation was given by Mr. Ed Shon, representing the Ulster County Chapter.

This year's banquet speaker, Mr. Michael Dowling gave an exceptional address which was well received by the Association. Mr. Dowling is the Deputy Secretary to the Governor for Human Services. For many in the Association this event provided the first opportunity to meet first hand Mr. Dowling.

A special presentation was given to the outgoing President, David B. Lettman who served the Association for almost five years as President. Mr. Lettman thanked the Association for "the honor and privilege to serve the finest organization of its kind."

The Master of Ceremonies, Mr. David Kaufman installed the newly elected Board of Governors and Officers for the Association. Newly elected President, Blanche Fierstein, eloquently spoke to the banquet attendees and thanked the Association for their confidence in her ability to lead the organization.

The Executive Director of the State Association, Marc N. Brandt, commented that the "1988 ARC Convention was one of the most productive and well organized conventions ever held. There are many people who should be thanked for their efforts; our staff, our various committees who participated in the planning and those volunteers who helped at the convention."

Next year's 40th Convention will be held from October 25-29, 1989 at the Kutsher's Country Club, Monticello, New York. ■



**The founder of NYSARC, Mrs. Ann Greenberg being recognized at the Delegate Assembly.**

## Over 700 Individuals Attend Installation Ceremonies at Annual Convention



**Newly elected NYSARC President, Blanche Fierstein (right) seen talking with Scholarship and Awards Committee Chairperson, Kay R. Nogaj.**

The Delegate Assembly, representing the 65 chapters and 57,072 membership of the NYSARC, Inc. at their 39th Annual Convention unanimously elected Blanche Fierstein President. Mrs. Fierstein was installed at the Saturday night, November 5, 1988 banquet.

Mrs. Fierstein becomes the 15th President of NYSARC. She has been a member of the Association for the past 37 years. Mrs. Fierstein served on numerous State ARC committees and most recently chaired the Community Residential Services Committee. She was the Vice President of the Southeast Region in 1988.

For the past twenty years, Mrs. Fierstein has been a Board of Director of the New York City Chapter and served as the Chapter's President for three years. Mrs. Fierstein has been extremely active in the City Chapter and has over the past two decades served on numerous committees.

Mrs. Fierstein is a Principal in a Special Educational School in the New York City school system. Her school has an enrollment of 550 students from the ages of 14

through 21 years of age. She has held that position for the past 15 years. Prior to her being Principal she was a Special Education teacher.

Mrs. Fierstein is married to Eugene Fierstein and they live in Woodmere, New York. She has a son, Richard and a daughter Andrea. Andrea lives in a community residence operated by our Nassau County Chapter. Mrs. Fierstein also is the proud grandmother of Leigh and Russell.

Mrs. Fierstein commented to O.C.V. that she is most excited and looking forward to being President of the Association.

She stated that "as Principal of a Special Education school you quickly learn that you can't think of the whole world as only your child. You can only help your child by helping someone else's at the same time."

The entire Association extends to Mrs. Blanche Fierstein congratulations and the best of success on becoming NYSARC's 15th President. ■

## Association Joins as Amicus Curiae in U.S. Supreme Court Case

**Penry vs. Lynaugh to be heard by high court. NYSARC, Inc. joins ten leading national advocacy organizations in submitting brief to Supreme Court.**

On Thursday, June 30, 1988, the United States Supreme Court agreed to hear the case of *Penry vs. Lynaugh*. Mr. Penry was convicted of homicide and sentenced to death by a Texas Court. Attorneys for Penry appealed that decision to the Court of Appeals on the basis that Penry is mentally retarded and that his execution is prohibited by the Eighth Amendment to the Constitution. The Court of Appeals rejected this argument thus setting the stage for the Supreme Court hearing.

Mr. James Ellis, a distinguished disabilities attorney and law professor at the University of New Mexico prepared an amicus curiae brief for this hearing. He has done the work pro bono and invited a number of major national organizations to join as amicus curiae in this case.

The Executive Committee approved NYSARC, Inc. joining as amicus curiae pending a review of an ad-hoc committee formed by the President. The committee consisting of Mr. Hector Dowd, Mr. Jack Schuppenhauer, Mr. Michael Rosen and Ms. Lois Fairclough recommended NYSARC's participation. NYSARC, Inc. has been included in the case and it is now before the U.S. Supreme Court.

The Supreme Court has agreed to address two questions: whether the Eighth Amendment prohibits the execution of persons with mental retardation, and whether the Texas system of jury instructions permitted adequate consideration of mental retardation as a mitigating factor in determining whether a defendant was to be sentenced to death or life imprisonment. Our principal interest is in the first question, but it may be necessary for counsel to devote some attention to the second in order to address adequately the Eighth Amendment issue.

It is our position that the Eighth Amendment forbids any execution of a person with mental retardation. Fewer than two percent of all convicted murderers are sentenced to death, and the Supreme Court has held that they must be selected on the basis of unusual "personal responsibility and moral blame worthiness." It is our contention that while people with disabilities should be held responsible for their actions, no individual with mental retardation matches that extra ordinary standard. The attorneys in this case have as their function the informing of the Court about the nature of the disabilities that people with mental retardation experience and their relationship to the issue of criminal responsibility.

In addition to NYSARC, Inc. organizations joining as amicus curiae in support of the petitioner are:

— American Association on Mental Retardation

- American Psychological Association
- Association for Retarded Citizens of the U.S.
- The Association for Persons with Severe Handicaps
- American Association of University Affiliated Programs for the Developmentally Disabled
- American Orthopsychiatric Association
- National Association of Private Residential Resources
- National Association of Superintendents of Public Residential Facilities for the Mentally Retarded
- Mental Health Law Project
- National Association of Protection and Advocacy Systems

# Association Launches Statewide Media Campaign

Early in 1987 the NYSARC, Inc. Board of Governors' established a goal to develop a statewide media-campaign to be implemented by the Public Information Committee. In response to this charge, the Public Information Committee chaired by Robert F. Katz, appointed a sub-committee to develop an all-media Public Service Campaign to be used by NYSARC, Inc. chapters. This subcommittee, chaired by Jack Decker of the Monroe County ARC, included representatives from a dozen chapters of various sizes and areas of the state. The purpose of the assignment was to develop a theme to give our organization's public awareness efforts a sense of continuity and commonality. The specifics were two-fold:

1. Reach consensus on a statement, motto, concept, catch-phrase that would be acceptable to all chapters and would include the specific mission of each chapter.
2. Create a multi-media campaign that would demonstrate how the approved theme could be integrated into a series of Public Service messages for newspaper, broadcasting and other print media.

## Implementation:

In order to achieve the widest possible input, two regional "brain-storming" meetings were held in July and August 1987 at Rochester and Poughkeepsie. Almost 50 chapters participated in the two sessions. Based on a distillation of ideas, the task force reached an agreement and presented its theme to the full Public Information Committee. It was enthusiastically accepted by the NYSARC, Inc. Board of Governors in October of 1987.

The theme, "We're Your Neighbors — Get to Know Us," used separately or in tandem thus became the basis for the Public Services Media Campaign.

The sub-committee then resumed its work focusing its efforts on the creation of suitable material. Throughout 1988 several meetings were held at various locations and the campaign was created. Copy, concepts, graphics, production facilities and financial considerations became an integral part of each meeting. Since all chapters were invited to participate in the planning and because of the broad-based nature of the deliberations, the committee feels its end product is a true cross section of representative chapters across the state.

This is the first time NYSARC has attempted to capture the spirit and common goals of every chapter and transform them into a single message. ■

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

### RADIO PSA SCRIPTS

#### 30 second spot

*Hello, we're your neighbors — The New York State Association for Retarded Children — for forty years a national leader in developing services for people with mental retardation. Our statewide organization has pioneered innovative care programs, advocated for legislative reform and created opportunities for independent living and employment in our community.*

**"GET TO KNOW US! WE'RE YOUR NEIGHBORS!"**

**Tag #1:** Over \_\_\_\_\_ of your neighbors are served by the \_\_\_\_\_ County Chapter at the \_\_\_\_\_

**Tag #2:** Over 25 thousand of your neighbors across the state are served by the New York State ARC.

## New York State Association for Retarded Children, Inc.

### RADIO PSA SCRIPT

#### 30 second spot

*For forty years the New York State Association for Retarded Children, and its 65 chapters across the state have been helping our neighbors with mental retardation to lead full and rewarding lives. They live, work, learn and contribute to the richness of our community.*

*For more information contact your local ARC chapter.*

**GET TO KNOW US! WE'RE YOUR NEIGHBORS!**

# We're your neighbors.



# Get to know us.

We're the New York State Association for Retarded Children, Inc., 40-year old private, non-profit human service agency with 65 chapters serving over 25,000 children and adults with mental retardation and/or developmental disabilities in New York State.

We're an array of clinical, training, counseling and advocacy services designed to help individuals with mental retardation integrate into the community and reach their highest level of independence.

Get to know us. Contact your area ARC chapter. Or write/call: NYSARC, 393 Delaware Avenue, Delmar, New York 12054, (518) 439-8311.



## New York State Association for Retarded Children, Inc.

### RADIO PSA SCRIPT

#### 15 second spot

*Get to know us! We're the New York State Association for Retarded Children — helping 25 thousand individuals with mental retardation achieve independence in the community. The ARC — We're your neighbors.*

**Sample  
Local  
Tag**

*For more information, contact the \_\_\_\_\_ County ARC, a United Way Agency at the \_\_\_\_\_*

# WAXMAN HEARINGS: MEDICAID REFORM

## BACKGROUND

NYSARC has closely followed and endorsed legislation sponsored by Senator John Chafee (R - R.I.), the "Medicaid Home and Community Quality Services Act," which seeks to make sweeping reforms in Medicaid funding for services to persons with developmental disabilities. This legislation is sponsored in the House of Representatives by Representative James Florio (D - New Jersey) and would vastly expand the ability to utilize Medicaid to pay for community-based services while placing limitations on the use of Medicaid to pay for institutional services.

The "Chafee/Florio" legislation has become the subject of much controversy. While it is strongly supported by many parents and advocates, it is opposed with equal fervor by many other persons and organizations who feel that limitations on Medicaid funding to large institutions poses a threat to both jobs and services.

Over the past few months, additional legislation aimed at Medicaid funding for developmental disabilities services has been drafted and introduced by Representative Henry Waxman (D - California), Chairman of the House Subcommittee on Health and the Environment. This legislation, H.R. 5233, "The Medicaid Quality Services Amendment for the Mentally Retarded of 1988" is less sweeping than the "Chafee/Florio" proposal. Unlike the "Chafee/Florio" proposal, it would not mandate the national expansion of community-based Medicaid services, but rather it would leave such expansion up to the discretion of each state. Nor would the "Waxman" Bill place restrictions on the use of Medicaid for institutional services.

The "Waxman" proposal is a potentially important piece of legislation. Not only does it seek to break the impasse caused by the controversial provisions of the Chafee Bill but, as introduced by Representative Waxman, it is sponsored by perhaps the most influential member of either the House or Senate when it comes to issues pertaining to Medicaid.

On Friday, September 30, Representative Waxman held hearings to gather testimony regarding both his legislation and the "Chafee/Florio" proposals. These hearings are expected to provide the basis for continued work on Medicaid reform legislation when the 101st Congress convenes in January.

## THE HEARINGS

Representative Waxman began the hearings by stating that "the large Medicaid investment in ICF/MR services, and the relatively small investment in community-based services, has touched off a major debate among parents, client advocates, state officials, treatment professionals, workers, and others"... "I am concerned that this debate, which has been focused on the Florio (Chafee) Bill, is devicive. I believe that all parties to this debate share a common interest in improving the way Medicaid works for the disabled. I have introduced H.R. 5233...in an effort to redirect the debate toward finding that common interest."

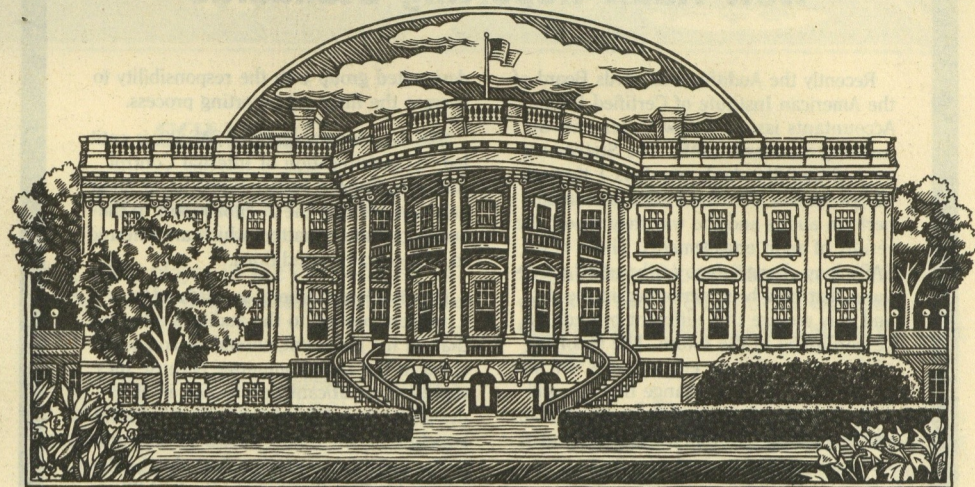
Representative Waxman went on to say that "I am hopeful that out of this hearing will develop discussions that lead to a consensus on Medicaid reform that clients, parents, advocates, workers and state officials can support. I would then hope that the subcommittee could consider legislation on this issue early in the next Congress."

Among the first individuals to testify at the hearings was Senator Chafee. Disagreeing with critics, the Senator stated that the current version of his legislation, "the Medicaid Home and Community Quality Services Act," is "compromise legislation." The Senator explained that previous versions of this bill were "deinstitutionalization bills" but he became convinced that these "bills went too far" and the current version "is not a deinstitutionalization provision."

The authors of the two competing pieces of Medicaid reform legislation engaged in a dialogue when Representative Waxman asked Senator Chafee to "give me criticism on my bill."

Senator Chafee responded by praising H.R. 5233 for "decoupling Medicaid funding from the need for institutional care." However, the Senator cited as negatives the bills "optional" expansion of Medicaid funding for community services and lack of any limitation on facility size.

Gerald McEntee, President of the American Federation of State, County and Municipal Employees (AFSCME) also spoke before the committee regarding both the "Waxman" and "Chafee/Florio" bills. He stated that "our union has vehemently



opposed the "Chafee/Florio" proposal "which creates incentives to close existing ICF/MR facilities without any provision for retaining the skilled, experienced human resources in the new community." Mr. McEntee stated that "residents and caregivers could be harmed by the enactment of such a massive privatization scheme."

On the other hand, Mr. McEntee remarked that the "Waxman bill" represents a measured incremental approach to Medicaid ICF/MR reform" and does not "summarily displace the very caregivers who have the expertise to care for the severely and profoundly disabled." Mr. McEntee summarized the AFSCME position by saying that "we are guardedly optimistic about the direction Congressman Waxman has taken to address problems in the Medicaid ICF/MR program."

Mr. McEntee indicated that rapid deinstitutionalization has led to "sub-standard" care in private facilities and that this trend would be exacerbated by the "Chafee/Florio" proposals. When questioned by Congressman Waxman about quality assurance problems in state-operated facilities, Mr. McEntee stated that these difficulties could be traced to historic underfunding and had dramatically improved over the past decade.

The opinions of those parents who testified at the hearings were mixed when it came to comparing the "Chafee/Florio" proposals and the "Waxman proposal."

Typical was George O'Donnell of Milwaukee, Wisconsin and parent of a daughter with mental retardation. Mr. O'Donnell indicated that the "Chafee/Florio" proposal would result in the closure of institutional facilities and the placement of many residents into inappropriate settings. He suggested that the "Waxman" proposal appeared more reasonable in this respect since it does not contain a freeze on institutional funding.

On the other hand, Dr. Harvey Lapin of Northridge, California, the father of a son with mental retardation, favored the "Chafee/Florio" proposal. He stated that "Chafee/Florio" would ensure the provision of critical community-based services by including these as entitlements under Medicaid. The "Waxman" proposal would not provide such guarantee since it leaves

it up to the states to determine whether or not to use Medicaid to pay for community care.

Representatives of state organizations agreed that Medicaid reform is desirable and echoed common concerns regarding the two legislative proposals. One such concern pertained to provisions in the "Waxman" bill delegating a much stronger and more direct oversight role to the federal government in regulating Medicaid funded programs. James Toews, speaking on behalf of the National Association of State Mental Retardation Program Directors (NASMRPD), stated that such provision is an "ill advised approach to assuring the high quality of services." He went on to state "Chafee/Florio" proposal is "a more appropriate way" of assuring compliance with minimum program standards since it leaves the setting of specific standards to the states while ensuring that such standards, and plans for their enforcement are reviewed by the federal government.

OMRDD's Commissioner, Arthur Webb, agreed with Mr. Toews. He stated that the "federalization of the survey and certification process," as proposed by the Waxman proposal, "must not be allowed" and that "this is the single most negative aspect of the bill."

However, Commissioner Webb did indicate that he strongly prefers the "Waxman" proposal over the "Chafee/Florio" proposal. He pointed out that the freeze in Medicaid funding to institutional facilities, as proposed by "Chafee/Florio," was "inappropriate" and would constitute "a real cut" in funding to New York State by the Federal government; a point with which NYSARC takes strong exception. The "Waxman" proposal, however, by not including such freeze, "is an approach that will not divide the developmental disabilities field and will not pit one group of parents against another." It could "become the basis for meaningful Medicaid reform."

The hearings were adjourned by Representative Ron Wyden (D - Oregon) acting on behalf of Chairman Waxman who left midway through the testimony. It is not expected that there will be any significant action on either the "Chafee/Florio" proposal or "Waxman" proposal until the 101st Congress convenes in January. ■

## New Audit Reporting Standards

Recently the Auditing Standards Board of the American Institute of Certified Public Accountants issued 9 new Statements on Auditing Standards (SAS). The Statements on Auditing Standards numbers 1 through 61 govern how Certified Public Accountants perform audits and the way they report the results of audit engagements. The 9 new SAS's may change some of the audit procedures that have been performed in the past and may require that different procedures be performed in the future. The reporting of the results of audit engagements will also be affected. The first change that you will notice is the new form of the auditor's standard report on financial statements which will read as follows:

### Independent Auditor's Report

We have audited the accompanying balance sheet of ANY County Chapter New York State Association for Retarded Children, Inc. as of December 31, 1988 and the related statements of activity and cash flows for the year then ended. These financial statements are the responsibility of the Chapter's management. Our responsibility is to express an opinion on these financial statements based on our audit.

We conducted our audit in accordance with generally accepted auditing standards. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of ANY County Chapter New York State Association for Retarded Children, Inc. as of December 31, 1988 and the results of its operations and its cash flows for the year then ended in conformity with generally accepted accounting principles.

This new Auditor's Standards Report is the result of SAS number 58, "Reports on Audited Financial Statements" and is effective for reports issued on or after January 1, 1989.

New SAS's, numbers 60 and 61, govern how we communicate with those who have responsibility for oversight of the financial reporting process; in other words the audit committee, finance committee or a formally

designated group with the responsibility to oversee the financial reporting process.

SAS 60, which supersedes SAS 20, is entitled, "Communication of Internal Control Structure Related Matter Noted in an Audit" and requires that the auditor report to the audit committee matters which are referred to as reportable conditions.

Reportable conditions are defined as, "...matters coming to the auditor's attention that, in his judgment, should be communicated to the audit committee because they represent significant deficiencies in the design or operation of the internal control structure...". These deficiencies are important to the audit committee because they could adversely affect the organization's ability to record, process, summarize and report financial data. These are significant to the audit committee and the Board of Directors because the internally generated financial data that the Board is relying on could be affected by the deficiencies. These matters should have been reported in the past as part of the auditor's management letter.

SAS 61, which establishes a new reporting requirement, requires that the auditor determine that certain matters related to the conduct of an audit are communicated to the audit committee. Some of the matters required to be communicated to the audit committee include:

- the auditor's responsibility under generally accepted auditing standards;
- significant accounting policies and their effect on the financial statements;
- the process used by management in formulating sensitive accounting estimates and the basis of the auditor's conclusions regarding these estimates;
- significant audit adjustments;
- disagreements with management regarding various audit matters; and
- difficulties encountered in performing the audit.

This communication is obviously a new requirement and will be reported separately from the communication discussed above under SAS 60.

As a result of the above communications audit committees should now be more informed about the audit process and the results of the audit. The reporting standards under SAS numbers 60 and 61 are effective for audits of financial statements for periods beginning on or after January 1, 1989, however, earlier application of the provisions of these statements is permissible. ■

*Providing Services to Agencies  
Serving the Needs of the  
Developmentally Disabled*

# Marvin & Co.

CHARLES L. MARVIN AND COMPANY, P.C.  
CERTIFIED PUBLIC ACCOUNTANTS

One Steuben Place  
Albany, New York 12207  
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## HCFA Promulgates New ICF/MR Regulations

The Federal Health Care Financing Administration (HCFA) recently promulgated new final regulations governing the operation of Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). These regulations were originally proposed by HCFA in March of 1986; 236 providers and advocates across the country, including NYSARC, filed written comments in response to the proposal.

The new regulations, 42 CFR Part 483, attempt to establish a performance-based system of regulation. In short, the regulations and, more specifically the survey process, attempt to focus on whether or not "active treatment" is *actually* being received by the program residents, not simply whether or not the documentation indicates the program is *capable* of providing active treatment. Active treatment is defined as the continuous, aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible, and the prevention or deceleration of regression of loss of current optional functional status.

While the overall requirements for active treatment are much the same under both the old and the new regulations, in our opinion it is the change in the survey process which is most dramatic. Appendix "J" of the new interpretive guidelines for 42 CFR Part 483 instruct the surveyors to select a representative sample of no less than four residents and conduct a 30 to 45 minute review of their clinical records (the comprehensive functional assessment of strengths and needs; the behaviorally stated goals and objectives; and the pro-

gress being made toward achieving the objectives in the individualized program plan). The remainder of the survey is to focus on observation of these residents receiving active treatment in accordance with their individualized program plan. The survey is to include observation of carryover and consistency of active treatment at the day program.

The new regulations are organized around eight "Conditions of Participation" which are those general requirements which must be met in order to be certified. The conditions of participation are as follows: 1) governing body and management; 2) client protections; 3) facility staffing; 4) active treatment services; 5) client behavior and facility practices; 6) health care services; 7) physical environment; and, 8) dietetic services.

The new regulations appear to promote legal guardianship for adults incapable of giving informed consent to behavioral interventions which pose some risk to "client protections", and to those incapable of understanding their rights. The regulations also appear to promote a greater degree of consistency and carryover of treatment practices and objectives from the residence to the day program. And, the new requirements provide for much greater freedom in exercising the right of individual choice - in recreation and leisure time activities, bedroom decoration, clothing and personal items and other aspects of daily living.

These new requirements will present many new challenges to the service system, which includes voluntary and state-operated community ICFs/MR as well as developmental centers. These regulations became effective on October 3, 1988. ■



Representatives of Montgomery County Chapter study new ICF/MR regulations during a recent NYSARC seminar held in Albany. (L to R, Terry Kimball, Althea Giaquinto and Frank Capone). 80 participants representing 30 chapters attended the day-long seminar.

## Annual Convention Scrapbook See Pages 16-18!

## Fall Board of Governors' Meeting Responds to Many Issues

*1989 Legislative Platform Adopted, Committee Goals Established, Adult Services Paper Adopted and Strategic Long-Range Planning Committee Formed*

The governing body of the NYSARC, Inc., the Board of Governors, met on Thursday and Friday, November 3 and 4, 1988 and again on Sunday, November 6, 1988 at the Concord Resort Hotel in Kiamesha Lake, New York. The Association is governed by the Board of Governors who have the responsibility of setting policy for the Association.

The Board is comprised of 124 individuals representing the 62 chapters of NYSARC, Inc. A summary highlighting the major actions of the Board of Governors' Meeting are as follows:

- Reviewed and recommended to the Delegate Assembly for approval the 1989 NYSARC, Inc. Legislative Platform.
- Adopted the 1989 Board of Governors' Committees' Goals.
- Elected John Bryant as Senior Vice President.
- Elected the following regional representatives to the Executive Committee: David Keymer (Central Region), Lois Fairclough (Northeast Region), Dr. Irving Caminsky (Southeast Region), and Warren Heilbronner (Western Region).
- Elected Ellen Owens (West Seneca D.C.) and Bernice Volaski (Welfare League — Letchworth Village D.C.) to represent the Developmental Center Chapters on the Executive Committee.
- Formed an Ad-Hoc Committee on Strategic Long-Range Planning.
- Adopted the Adult Service's Position Paper, "Advocacy in the 1990's: NYSARC's Perspective on Future Services for Persons Who are Mentally Retarded."
- Received and reviewed the report and findings of the Chapters' Medication

Administration Surveys submitted by the Community Residential Services Committee.

- Received and discussed the report of the Ad-Hoc Committee to Review the Issues of Re-affiliation with National ARC-US. The Board approved the recommendations of the Committee to:
  - A) Continue discussions with National ARC-US concerning possible re-affiliation and to negotiate with National ARC-US concerning the issues of representation on the National ARC Board and financial requirements of on-going participation in National ARC-US, and
  - B) The Ad-Hoc Committee will report its findings to the Board of Governors at their Spring 1989 meeting.
- Discussed the current status of the Ombudsman position in developmental centers and resolved to send a letter to the Governor stating the concerns of the Association.
- Dissolved the Wilton D.C., Newark D.C. and Tompkins County Chapters due to inactivity.
- Adopted resolutions concerning Albany, Montgomery and Rensselaer County Chapters regarding Dormitory Authority financing.
- Reviewed the request of the Schuyler County Chapter to form the Schuyler-Tompkins County Chapter.
- Approved the Herkimer and Schenectady County Chapters' By-Law revisions and referred the Madison County request to the Legal Committee.
- Approved the Spring Board of Governors' Meeting to take place in Rochester, New York. ■

## NYSARC's First Statewide Meeting Held on Corporate Guardianship Program

A statewide meeting on the Association's corporate Guardianship Program was held on September 23, 1988 in Albany, New York. This event, which was sponsored by NYSARC's Guardianship Committee, marks the first time since the inception of the program in 1970 that chapter board and staff members throughout the state have come together to exchange information and collaborate on common issues and concerns pertaining to guardianship.

More than 100 individuals representing 42 chapters participated at this forum, including 38 board of directors, eight (8) executive directors and 58 additional staff members.

The morning plenary session commenced with a warm welcome given by Peter Pierri, Executive Director of Ulster County Chapter and member of the State Association's Guardianship Committee. Peter welcomed the participants and provided a brief overview of the day's events while also explaining the purpose of the statewide meeting.

Marc Brandt, Executive Director of NYSARC, Inc. was also present to give the opening remarks and discuss the historic as well as current perspective on the corporate program.

The role and goals of the NYSARC Guardianship Program were described by Paul Dhalles, Chairperson of the State Association's Guardianship Committee while James Hayes, an attorney and also a committee member discussed the philosophy and value of guardianship as a planning alternative for persons with mental retardation.

An overview of NYSARC's Policies and Procedures on Guardianship was presented by Erica Berman, NYSARC staff to the Guardianship Committee. A newly revised guardianship application was also introduced for the first time and the changes to the old format were highlighted and, included in each of the participants information packets.

Before adjourning for lunch, participants broke into small discussion groups of 30 and addressed such issues as chapter funding for guardianship services (staffing and administrative costs), decision-making considerations for establishing guardianship, and varying roles of chapters in the guardianship process. Members of the NYSARC Guardianship Committee served as facilitators, including, Peter Pierri, Gene Flagello, Debbie Weiss, Kathryn Edmundson, Ellen Owens, James Johnson, James Hayes and Paul Dhalles.

Small group breakout sessions were conducted in the afternoon and participants discussed the role and function of chapter Guardianship Committees and staff coordinators.

A feedback session followed at which time several of the issues confronting chapters in implementing guardianship services were shared with the entire group attending the forum.

Several common concerns expressed included the funding of staff to provide necessary guardianship services, local chapter's standing Guardianship Committees and composition of members, lack of attorneys in certain regions of the state who are willing or experienced in guardianship proceedings and estate planning, conflict of interest issues regarding chapters as providers of service while also serving as guardians and advocates.

Mr. Dhalles was very pleased by the tremendous turn out from the chapters and complimented both board and staff members for sharing their time, energy and ideas. Paul as well as other committee members emphasized the importance of educating the membership and attorneys as well as networking and developing chapters' policies and procedures on guardianship for purposes of quality assurance and accountability. ■

## Important Breakthrough In Advertising

By  
Emily Perl Kingsley

**FLASH!** After years and years of talking to brick walls, knocking on locked doors and generally pulling our hair out, there has finally been a historic milestone in the attempts to integrate television advertising!!

*A child with Down syndrome is currently being prominently featured in a television commercial for Crest Toothpaste!!*

Procter and Gamble, and its main advertising agency, DMB&B, has a strong commitment to the disabled and to Special Olympics. They have led the field in integrating people in wheelchairs and people using sign language. And now, at last, one of our own kids with Down syndrome has been used to demonstrate a sunny (Crest) smile!

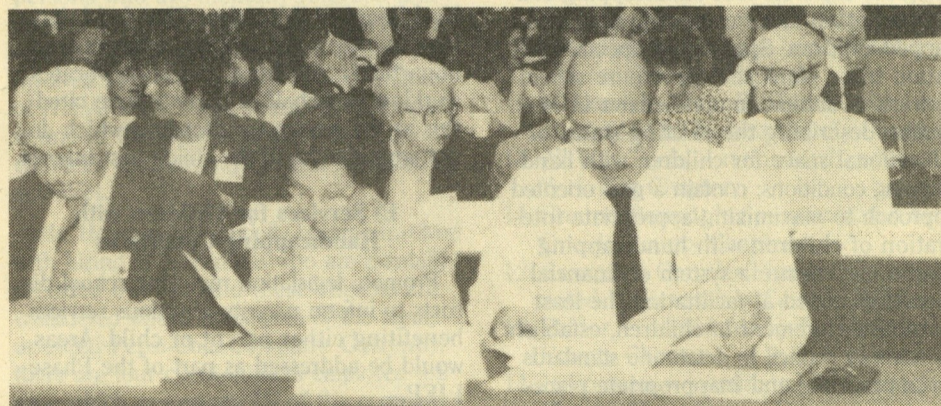
*It is my firm belief that, just as it is important to complain when you run into*

*prejudice and discrimination, it is also important to commend the people who go out of their way to help us in the fight against that discrimination. I would like to ask each of you to drop a note to the executive responsible for the Crest commercial (called "SMILE") and say THANKS. We must let them know that we notice their efforts and that we're grateful. Only if we express our appreciation can we hope that this integration will become more and more routine and commonplace in the advertising field.*

Please write to:

Ms. Sherry Valan  
Senior Vice President  
Darcy, Masius, Benton & Bowles  
909 Third Avenue  
New York, NY 10022

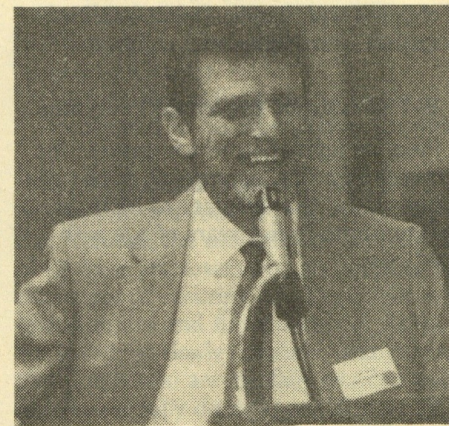
I don't know about your house, but the Kingsleys will be brushing with Crest from now on!



Some of the 130 participants reviewing guardianship materials.



Peter Pierri, member of Guardianship Committee speaks to group.



Paul Dhalles, Chairperson, Guardianship Committee addresses meeting.

## **CRIMINAL JUSTICE LAW**

### **Treatment of Offenders who are Developmentally Disabled**

Require that statutes regarding persons with mental retardation who commit or are accused of an offense be studied and revised to reflect the unique problems and characteristics associated with these individuals.

Laws pertaining to developmentally disabled persons who may come into contact with the criminal justice system often inadequately address the needs posed by their disabilities. For example, there are insufficient means to identify these individuals and direct them to appropriate settings; and standards used to assess their culpability in the commission of a crime are inappropriately based on the standards used to determine when mental illness is a mitigating factor in the commission of a crime.

## **EDUCATION LAW**

### **A) Educational Space**

Upon review of regulations implementing Chapter 552 determine necessity for legislative action dealing with this issue.

Students with mental retardation and developmental disabilities are being inappropriately placed in classrooms in segregated facilities based upon the lack of space in public school buildings.

Last session both the Senate and Assembly approved of an alternative measure (S.8484 by Donovan; A.11788 by Hevesi), which requires all school districts to prepare a special education space plan every five years beginning on February 1, 1989. The Governor subsequently signed this legislation on August 11th as Chapter 552 of the Laws of 1988.

NYSARC will continue to advocate for regulations implementing Chapter 552 which will effectively and appropriately integrate children with handicapping conditions within facilities serving nonhandicapped children. Specifically, special education space plans should: require school districts to submit comprehensive information describing the existing status of educational space for children with handicapping conditions; contain a goal oriented approach to maximizing appropriate integration of children with handicapping conditions; require a system of financial incentives aimed at facilitating the least restrictive placement of children, establish an advisory council to determine standards for appropriate and inappropriate placement; and, provide resources (i.e. teacher aids) to facilitate the appropriate integration of children with handicapping conditions in facilities serving normal children.

### **B) Provision of Preschool Programs**

Promote legislation which ensures the provision of a free, appropriate public education under the auspices of SED for children birth-to-five years of age with handicaps.

Such legislation must ensure that the private, not-for-profit service system which has evolved over the past four decades is not dismantled; that decisions regarding program placement and services are based upon the recommendations of individuals with expertise in early intervention and preschool special education, and provide parents with opportunities for meaningful input and appropriate choices.

Preschool programming for children from ages 0-5 is determined by Family Court. The inappropriateness of this approach has been a long-standing issue with NYSARC. Additionally, New York State has decided to opt into the Title I Grant authorized by the recently signed federal law (P.L. 99-457) which will substantially impact upon the oversight, provision and coordination of early intervention programs and services.

### **C) Prior Approval for Home Instruction**

Promote legislation requiring that placement of school-age children on home instruction receive prior approval.

In most instances, prior approval for school-age children must be obtained from SED before a handicapped child can be placed into a non-public school setting. This is to ensure that children are not being placed in segregated settings inappropriately.

However, prior approval is not required in order to place a child on home instruction. Consequently, there is no way to ensure that home instruction is being used appropriately.

### **D) Selection of Hearing Officers**

Promote legislation that would alter the school district's current role as the sole determinant of who the hearing officer will be at hearings for special education services.

Impartial hearing officers who conduct hearings to settle disputes between parents and school districts are appointed by the local Board of Education. That fact brings into question the hearing officers true impartiality. Attorneys and lay advocates working on behalf of parents have cited this as the reason for decisions which do not appear to be in the child's best interest.

### **E) Services for Children with Handicapping Conditions**

Promote legislation requiring school districts to inform parents of various services benefiting either parent or child. Areas would be addressed as part of the Phase I IEP.

Children with handicapping conditions may require a wide variety of individual and family services. The main source of contact for these children and their families is often the school and the Committee on Special Education (CSE). However, schools and CSEs frequently show little concern with the critical provision of the wide range of family and individual services which can only be provided outside of the school environment.

## **MENTAL HYGIENE LAW**

### **A) Community Residences**

#### **1. Admission Criteria**

To promote legislation that will eliminate the current discriminatory practice of basing community residential placement decisions on whether a person currently resides at home or in a developmental center.

Persons who reside in developmental centers are disproportionately selected for placement into community residential facilities while many equally needy persons who reside at home are denied these services.

During the 1988 session, NYSARC was finally able to obtain the introduction of legislation (S.8511 by Spano and A.11444 by Connelly) prohibiting discriminatory placement practices which are based on place of residence.

Though A.11444 was held in the Ways and Means Committee while S.8511 was held in the Senate Rules Committee, these bills did serve to increase the focus of key legislators and executive branch officials on this issue.

#### **2. Reimbursement of Land Costs**

To seek reintroduction and passage of legislation reimbursing voluntary providers for the cost of obtaining land to establish community residential facilities.

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

Once again S.2044 by Spano remained in the Senate Mental Hygiene Committee while A.2879 by Kremer was held by the Assembly Ways and Means Committee. Both bills reimburse providers for the cost of land used to establish community residential facilities.

We will continue to advocate for the passage of this legislation during the 1989 legislative session.

#### **3. Timely Response to Rate Appeals**

To seek a legislative remedy, if necessary, to ensure that OMRDD responds to rate appeal applications in a timely fashion.

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

At the request of NYSARC, bills were reintroduced in both houses requiring that OMRDD and the Division of the Budget promulgate amended fees within 90 days of the receipt of a completed rate appeal application to amend a fee for an existing program.

S.1629 by Spano passed the Senate while A.2446 by Connelly was held by the Assembly Ways and Means Committee.

NYSARC will continue to promote passage of this legislation in the event that rate appeal applications are not processed in a timely fashion.

#### **4. Size of Community Residences**

Promote legislation that requires OMRDD to appropriately revise capital and operational funding policies to facilitate the development of smaller homes; protect existing small homes, and treats both state operated and voluntary-operated homes equally in terms of site selection.

OMRDD has increasingly adopted policies aimed at the exclusive establishment of new community residential facilities that contain a minimum of 12 persons. Many persons strongly feel that 12, 13 and 14 person facilities are too large; that they do not constitute a "homelike" environment; and that they violate the fundamental precepts of the deinstitutionalization movement. They note that these facilities, with their vans, large parking lots and many staff, stand out rather than blend in with local neighborhoods. This outcome, they add, is anything but the normalization that our Association intended to achieve for persons with mental retardation when NYSARC was founded 39 years ago.

### **B) Developmental Centers**

#### **1. Prohibition of Co-Location**

Seek reintroduction and passage of legislation prohibiting the co-location of developmental centers and correctional facilities.

Our Association has worked diligently over the years to educate society to recognize that persons with mental retardation are entitled to be treated as normal citizens. Co-locating these individuals with persons incarcerated by the Criminal Justice System only reinforces a public perception that persons who are developmentally disabled are undesirable individuals who should be segregated from the rest of society. Such perception encourages the discriminatory attitudes which we have fought against for years.

During the 1988 legislative session, NYSARC finally obtained sponsorship in both the Senate and Assembly of legislation which flatly prohibits the co-location of developmental centers with correctional programs.

S.8604 by Padavan and Spano finally passed the State Senate on July 11th. However, A.11677 by Sanders was held in the Assembly Mental Health Committee.

NYSARC will continue to promote legislation clearly prohibiting co-location from occurring.

#### **2. Waste Disposal**

Seek reintroduction and passage of legislation limiting the disposal of waste at a developmental center to only that waste generated by such developmental center.

In the Fall of 1987, OMRDD announced plans to establish a medical waste disposal facility at Letchworth and Wassaic Developmental Centers for hospitals located in surrounding regions. NYSARC was outraged by the State's attempt to utilize these developmental centers, which serve as a residence for so many persons with mental retardation, for purposes which no other group of citizens would tolerate.

In response to this, we sought legislation prohibiting the utilization of developmental centers to dispose of waste generated from outside of those facilities. The State Senate responded by introducing and passing legislation (S.7462 by E. Levy) containing such prohibition. No such legislation was however introduced in the State Assembly.

### 3. Staffing

To promote reintroduction of legislation which requires that staffing levels be formulated based on a rational analysis of current client needs and disability levels.

In recognition of the fact that current developmental center staffing methodologies do not adequately take into account client needs, NYSARC successfully obtained the introduction of S.8513 by Spano and A.11418 by Connelly. These bills required OMRDD to study staffing needs of developmental center residents and, based on such study, to propose revised staffing methodologies. As discussions with legislative staff progressed, it was determined to amend this legislation in order to transfer the responsibility for the study from OMRDD to the Quality of Care Commission. It is felt that such action will increase the likelihood that the final study will contain valid recommendations.

Both the Senate and Assembly approved this legislation. Unfortunately, this legislation was subsequently vetoed by the Governor.

### 4. Parental Notification of Arbitration Proceedings

Support legislation requiring parents and guardians to be informed regarding actions taken with respect to an alleged perpetrator of client abuse.

Parents, guardians and advocates are frequently not informed of significant developments once civil service arbitration proceedings are commenced with respect to an alleged instance of client abuse or mistreatment. Consequently, such persons may not have the opportunity to advocate on behalf of a client who may remain under the care or supervision of employees either under investigation for or convicted of client mistreatment or abuse.

Through OMRDD promulgated regulations enabling parents and guardians to be informed to action taken to protect an allegedly abused client, information relating to the assignment and disposition of the alleged perpetrator is still unavailable. Consequently, the concern that such individual may come into contact with a client they have abused, is still unresolved.

Our Association believes that responsible persons should have whatever information is necessary for them to advocate for the well-being of the person with mental retardation.

### 5. Humane Placement

Legislation will be sought requiring the State, when placing an individual, to consider such factors as preservation of friendships; proximity to home; consent of parent, guardian and client; and the permanency of the placement under consideration.

Deinstitutionalization and closure of State developmental centers has resulted in the placement of thousands of persons into new homes across the state. The uprooting of these persons from an environment which may have served as their place of residence for many years, is an undertaking which must be conducted in a humane fashion that emphasizes sensitivity to individual needs. As the state has rushed to depopulate its developmental centers this sensitivity has often been sorely lacking.

The Association will advocate for a state policy of Humane Placement.

### 6. Amendment of Ombudsman Law

To seek reintroduction and passage of legislation amending the Ombudsman Law so as to mandate the position to be full time.

With the passage of Chapter 57 of the Laws of 1987, OMRDD was required to appoint an Ombudsman at every developmental center. However, despite the great volume of concerns and complaints to which the Ombudsman must respond, OMRDD determined that the Ombudsman would be only a half-time position.

NYSARC strongly objected to OMRDD's decision. To enforce our belief that this position must be full time in order to be effective, the Association successfully obtained sponsorship of S.8512 by Spano and A.11443 by Connelly. These bills would make such full-time status an explicit legal requirement.

S.8512 was passed by the Senate. However, A.11443 was held in the Assembly Mental Health Committee pending a six-month review of the Ombudsman by OMRDD.

OMRDD has indicated that this review will enable an appropriate determination to be made with respect to whether or not the Ombudsman should be continued and, if so, whether or not it should be a full or part-time position.

### C) Local Assistance

#### 1. Equity of Funding

Seek reintroduction and passage of legislation providing 100% state funding for all individuals without regard to whether or not they have been institutionalized.

The existing local assistance funding system creates incentives to serve persons who have had a history of institutionalization at the expense of individuals without such history. During the 1986 legislative session, the Legislature eliminated these discriminatory funding distinctions for persons who are mentally ill.

In order to achieve the same reform for services to persons with mental retardation, NYSARC successfully obtained the introduction of S.5866 by Spano and A.7605 by Connelly, which makes all persons with developmental disabilities eligible for 100% net deficit local assistance financing regardless of whether they have a history of institutionalization.

NYSARC will continue to promote passage of this legislation during the 1989 legislative session.

### 2. Local Assistance Reform

Promote legislation *mandating* that OMRDD develop a Local Assistance Reform proposal which will ensure the provision of necessary and adequate funding for programs currently funded through Local Assistance.

The Local Assistance funding system is the backbone of almost 300 million dollars worth of day programming services throughout New York State. Yet, this funding system is both antiquated and ineffective. It provides insufficient funding to many providers and fails to recognize the variety of circumstances with which they must contend in order to successfully operate workshops and care for severely disabled individuals.

Though OMRDD has proclaimed that Local Assistance must be reformed, the Office has shown little initiative towards preparing or developing any new proposals.

### D) All Programs

#### 1. Employee Verification

Seek reintroduction and passage of legislation enabling chapters to check on the criminal history of prospective employees.

Providers serving persons with developmental disabilities must rely upon staff who can be trusted to work with a severely disabled and highly vulnerable population. Therefore, it is essential that the backgrounds of such staff be checked thoroughly before they are hired in order to ensure that they do not have a history of violent or dangerous criminal behavior.

S.5997 by Spano and A.7806 by Connelly were once again considered by the Legislature. These bills authorize voluntary services providers to check backgrounds of prospective employees by accessing criminal history records maintained by the Division of Criminal Justice Services.

NYSARC will continue to seek passage of this legislation during the 1989 legislative session.

#### 2. Tax Exempt Capital Financing

Seek introduction and passage of legislation making low interest, tax exempt financing available to all chapters.

A number of our chapters and other providers throughout the state have been able to secure legislation authorizing them to utilize low interest, tax exempt financing on a project-by-project basis.

It would be far more convenient to modify existing statutes so that such financing could be available to all chapters for all capital projects without requiring each of them to request legislation for specific projects.

### PUBLIC HEALTH LAW

#### A) Prevention of Lead Poisoning

Seek the reintroduction and passage of legislation aimed at screening for and preventing lead poisoning.

It is a well-documented medical fact that one of the leading causes of mental retardation is the ingestion of lead by young

children. Lead is everywhere in the environment as a result of industrialization. Hence, the sources of lead are many including air, water, food, paint and gasoline. Increased public awareness is essential to the prevention of childhood lead poisoning. Therefore, it is vital that the general public be better educated regarding this serious problem. Additionally, it is important that the number of screening centers which now exist be expanded so that many more children can be tested for lead poisoning.

### B) Fetal Alcohol Syndrome (FAS)

To seek reintroduction and passage of legislation requiring warning labels on alcoholic beverages regarding the danger of ingestion during pregnancy.

A leading cause of mental retardation is the ingestion of alcohol by pregnant women. In recognition of this, NYSARC has supported legislation requiring that labels appear on alcoholic beverages warning of this danger.

### FEDERAL LEGISLATION

#### A) Medicaid Reform

Promote the passage of the "Medicaid Home and Community Quality Services Act."

Medicaid is the primary funding source of services to persons who are developmentally disabled. Yet, despite the growing need for a wide variety of community-based services, Medicaid continues to emphasize a narrow range of services with a primary emphasis on institutional care.

Comprehensive federal legislation, the "Medicaid Home and Community Quality Services Act" was introduced last year by Senator John Chafee (R-Rhode Island). This legislation substantially broadens the ability to use Medicaid to pay for services aimed at integrating persons with developmental disabilities with their communities and families.

NYSARC will continue its efforts to seek passage of this legislation.

#### B) Prohibiting Discrimination Against Persons with Disabilities

Promote the passage of the Americans with Disabilities Act (ADA) of 1988. This federal legislation prohibits discrimination on the basis of mental and physical handicaps in areas such as employment, housing, public accommodations, travel, communication and activities of state and local government.

Persons with disabilities are the frequent target of a wide variety of discrimination in employment, housing, public accommodations and many other areas. This discrimination transcends the political jurisdiction of state and local governments. Consequently, there is a need to promote federal statutory changes banning discrimination across the nation. ■

ADVOCACY FOR PERSONS WHO ARE  
MENTALLY RETARDED AND DEVELOPMENTALLY  
DISABLED: A POLICY MONOGRAPH SERIES

Presented by:  
NEW YORK STATE  
ASSOCIATION FOR RETARDED CHILDREN, INC.

ADVOCACY  
*monograph*  
NUMBER ONE

# Reconciling Funding and Philosophy

## *A Review of the "Medicaid Home and Community Quality Services Act"*

Current Co-sponsors — August 10, 1988

"Medicaid Home and Community Quality Services Act of 1987"

S.1673 (48 co-sponsors) and H.R.3454 (193 co-sponsors)

### ALABAMA

Sen. Richard Shelby (D)  
Sen. Howell Heflin (D)  
Rep. Tom Bevill (D)  
Rep. Ben Erdreich (D)  
Rep. Claude Harris (D)

### ALASKA (full delegation)

Sen. Ted Stevens (R)  
Sen. Frank Murkowski (R)  
Rep. Don Young (R)

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Rep. Don Edwards (D)  
Rep. Duncan Hunter (R)  
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Rep. Ron Packard (R)  
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Rep. Barbara Boxer (D)

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Sen. Timothy Wirth (D)  
Rep. Hank Brown (R)  
Rep. Ben Nighthorse Campbell (D)  
Rep. David Skaggs (D)  
Rep. Daniel Schaefer (R)\*\*  
Rep. Patricia Schroeder (D)

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Sen. Christopher Dodd (D)  
Rep. John Rowland (R)  
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Rep. Nancy Johnson (R)  
Rep. Barbara Kennelly (D)  
Rep. Christopher Shays (R)  
Rep. Sam Gejdenson (D)

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Rep. Thomas Carper (D)

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(full delegation)  
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Rep. Lawrence Smith (D)  
Rep. Earl Hutto (D)  
Rep. Connie Mack (R)  
Rep. Bill Grant (D)  
Rep. William Lehman (D)  
Rep. Claude Pepper (D)  
Rep. Bill Nelson (D)

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Sen. Wyche Fowler, Jr. (D)  
Rep. Charles Hatcher (D)  
Rep. J. Roy Rowland (D)  
Rep. George Darden (D)  
Rep. John Lewis (D)  
Rep. Robert Lindsay Thomas (D)  
Rep. Ed Jenkins (D)

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Sen. Spark Matsunaga (D)\*  
Rep. David Akaka (D)  
Rep. Patricia Saiki (R)

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Rep. Kenneth Gray (D)  
Rep. Jack Davis (R)  
Rep. Sidney Yates (D)

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Rep. Jim Jontz (D)  
Rep. Peter Visclosky (D)  
Rep. Andrew Jacobs (D)  
Rep. Frank McCloskey (D)

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Sen. Barbara Mikulski (D)  
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Rep. Brian Donnelly (D)  
Rep. Joe Moakley (D)  
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Rep. William Ford (D)  
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### MISSOURI

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Rep. Christopher Smith (R)  
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Rep. Jim Saxton (R)

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Rep. Sherwood Boehlert (R)  
Rep. Major Owens (D)  
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Rep. Douglas Applegate (D)  
Rep. Thomas Luken (D)\*\*

Rep. Bob McEwen (R)  
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Rep. Donald Pease (D)

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Rep. Peter Kostmayer (D)  
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Rep. Solomon Ortiz (D)  
Rep. Charles Stenholm (D)  
Rep. John Bryant (D)\*\*  
Rep. Mickey Leland (D)\*\*(2)

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Rep. James Hansen (R)

### VERMONT (full delegation)

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Sen. Robert Stafford (R)  
Rep. James Jeffords (R)

### VIRGINIA

Rep. Frank Wolf (R)

### WASHINGTON

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Sen. Daniel Evans (R)  
Rep. Thomas Foley (D)  
Rep. Norman Dicks (D)  
Rep. Mike Lowry (D)  
Rep. Don Bonker (D)  
Rep. John R. Miller (R)

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Rep. Nick Rahall (D)  
Rep. Harley Stagers (D)  
Rep. Bob Wise (D)

### WISCONSIN

Rep. Les Aspin (D)  
Rep. Robert Kastenmeier (D)  
Rep. Jim Moody (D)  
Rep. Steven Gunderson (R)

### WYOMING

Sen. Malcolm Wallop (R)\*

\*Member of Senate Finance Committee  
\*(1) Member of Subcommittee  
on Health

\*\*Member of House Energy and  
Commerce Committee

\*\*\*(2) Member of Subcommittee on  
Health and the Environment

# First Advocacy Monograph Acclaimed Nationwide

Dear Sirs:

Thank you for sending your monograph "Reconciling Funding and Philosophy." Maryland shares your view that federal medicaid policies affecting delivery of services to persons with developmental disabilities should be reformed. As indicated on page 2 of your publication, Maryland's entire Congressional delegation currently co-sponsors the "Chafee Bill."

Again, thank you for sending us a copy of your first publication. It was very well prepared and does an excellent job of presenting the issues around the "Chafee Bill."

Sincerely,

Lois M. Meszaros, Ph.D.  
Director  
State of Maryland  
Department of Health and Mental Hygiene

Dear Mr. Brandt:

Thank you for forwarding me a copy of "Reconciling Funding and Philosophy" published by your Association. I appreciate your insight.

I agree that there are enormous inconsistencies between what we as a nation have proclaimed as our goal for persons with mental retardation and the means, which we have chosen to reach those goals. Please be assured that I will put forth my earnest effort to address this issue in the 101st Congress.

Sincerely,

Robert H. Michel  
Republican Leader  
United States House of Representatives

Dear Mr. Bryant:

Thank you for your communication. I appreciate hearing from you.

I understand the concern many people have regarding the impact of S. 1673, "The Medical Home and Community Quality Services Act of 1987," on the lives of severely handicapped people. While the ultimate goal of this legislation is the improved care and comfort of the severely disabled in the least restrictive environment possible, I believe the long-term implications of this bill must be closely examined. No precipitous action should be taken to jeopardize the quality of care for developmentally disabled individuals who are in need of institutional care.

S. 1673 is pending in the Senate Finance Committee. I will keep your views in mind should this legislation come before the Senate.

Thank you again for writing.

Very sincerely yours,

Howard M. Metzenbaum  
United States Senator

Dear Marc:

I just received my copy of the Monograph: Reconciling Funding and Philosophy-A Review of the "Medicaid Home and Community Quality Services Act." I felt I had to write to you immediately to acknowledge you and your office on this excellent edition.

It is well written and does a good job of clearly explaining the Chafee Bill legislation and its impact on several levels. I am most pleased to see the use of language that dignifies persons with mental retardation and other developmental disabilities. Finally people of New York State have the opportunity to be fully informed on the Chafee legislation in language that we can all understand.

Congratulations again on this superb product.

Bernard J. Carabello  
Director  
Self-Advocacy Association of New York State, Inc.

Dear Mr. Brandt:

Thank you for your letter and the copy of your report, "Reconciling Funding and Philosophy."

I'm sure the report will be useful when we take up these important issues again in the 101st Congress.

Thanks again for sharing the information with me.

My best wishes.

Dear Mr. Brandt:

I would like to take this opportunity to thank you for the information regarding critical issues of importance to persons with mental retardation that you sent my office.

As a United States Senator, I follow a variety of issues daily and need to know of your concerns and interests. The information contained within the monograph that you forwarded was very interesting and insightful and I have asked my staff to go over it carefully. I appreciated your thinking of me and hope to keep this line of communication open.

Best regards,

Sincerely,

John Glenn  
United States Senator

Dear Mr. Brandt:

Thank you very much for sending me a copy of your monograph, "Reconciling Funding and Philosophy."

I appreciated your taking the time to provide me with this information. Please feel free to send me any other materials you may wish to bring to my attention.

Best wishes.

Bill Bradley  
United States Senator

Dear Marc:

I am writing to congratulate you and everyone involved in the preparation of the *Advocacy Monograph - Number One: Reconciling Funding and Philosophy*. With skill and superb writing you have presented a very complex issue, and made it understandable. Even more critical, you have presented a compelling rationale for making major changes in how we deliver services.

I am delighted the NYSARC is embarking on preparing a series of monographs. I am looking forward to subsequent issues.

Sincerely,  
Sue Lehr  
Publications Consultant  
The Center on Human Policy  
Division of Special Education  
and Rehabilitation  
School of Education  
Syracuse University

Dear Mr. Brandt:

Thank you for sending me a copy of NYSARC's report, "Reconciling Funding and Philosophy."

I appreciate your taking the time to send me this information, which addresses an issue of utmost concern to my legislative colleagues and to me. As a member of the Senate Select Committee on the Disabled, I am aware of the need to reform the Medicaid funding system so that mentally disabled persons are afforded the opportunities to live comfortably within a community-based setting. Your report has heightened my awareness of the initiative being taken at the federal level to address this matter and it is my sincere hope that Senator Chafee's bill will successfully pass both the Senate and the House of Representatives during the 101st Congress.

Thank you again for your thoughtfulness in sending me this information. Best regards.

Hugh T. Farley  
Senator  
State of New York

Dear Marc:

This is to acknowledge and thank you for your October 14 letter with enclosure which I received in my office today.

I appreciate your sending me a copy of your recent publication "Reconciling Funding and Philosophy." Please know this information will be of use to my staff and me.

I have also noted your support for H.R. 3454/S. 1673, the Medicaid Home and Community Quality Services Act. I look forward to working with you during the 101st Congress regarding relevant legislation.

Again, many thanks for writing. Please contact me at any time.

With best wishes for you, I am

Sincerely yours

Carroll Hubbard  
Member of Congress

Dear Mr. Brandt:

I greatly appreciated receiving the information that you recently forwarded to my office. I am certain that this publication will serve as useful and informative background reference material for me and my staff. Information, such as that you have provided is invaluable to me as I address the various issues and concerns facing the Congress today.

Again, I thank you for taking the time to share this information with me. Please do not hesitate to contact my office in the future on issues of concern and importance to you. With warmest regards, I am

Sincerely,  
Robert H. Michel  
Republican Leader  
Floyd H. Flake  
Member of Congress

Dear Mr. Brandt:

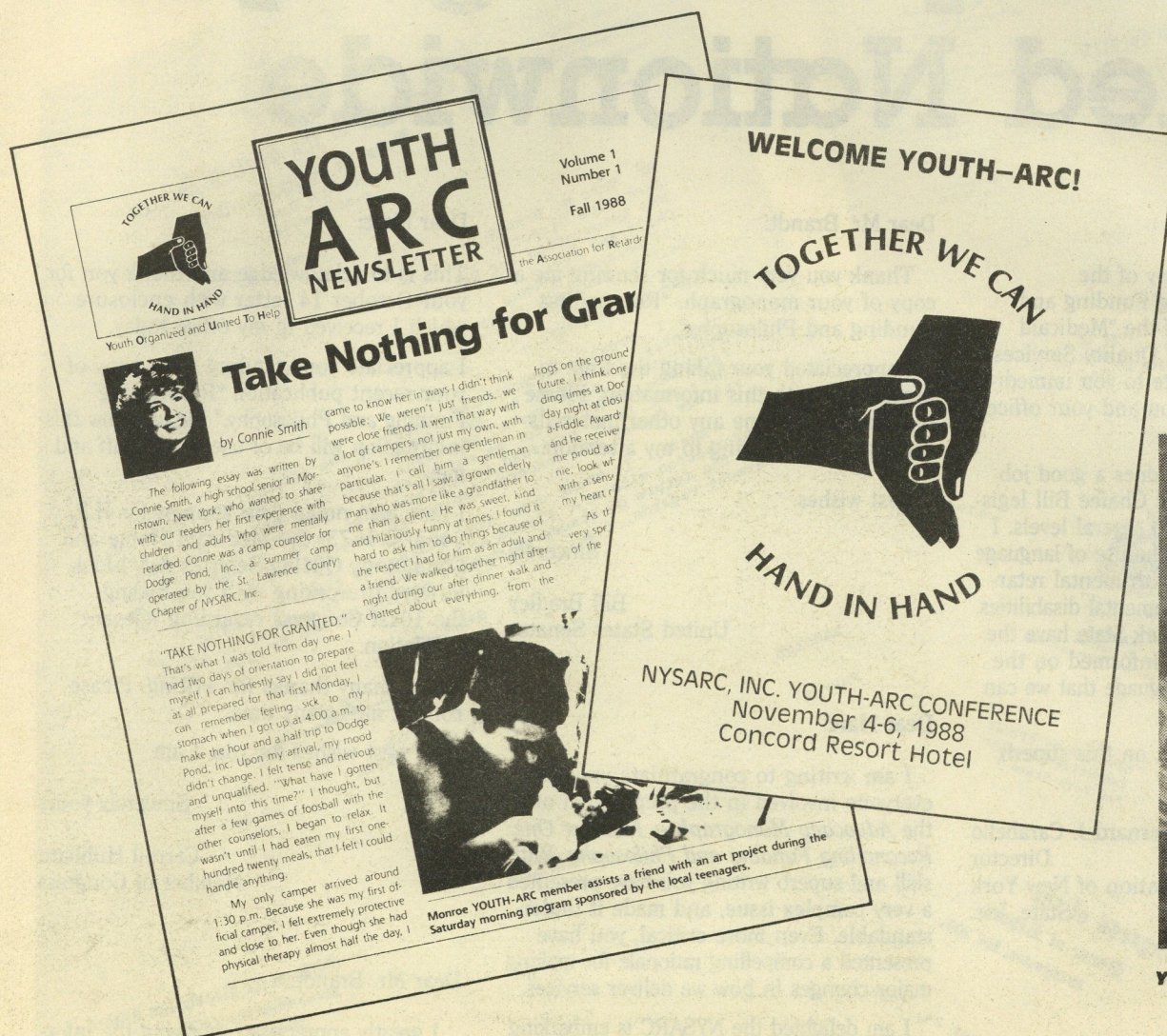
This will acknowledge your recent letter and the copy of "Reconciling Funding and Philosophy." I appreciate your sending it along and am glad to know this is one of several being planned to address national policies concerning health needs.

Although I will not be in the 101st Congress to work toward those goals, I am confident the new congressman from the 23rd Congressional District of New York will be interested in your views and guidance.

Sincerely yours,

Samuel S. Stratton  
Former Member of Congress

# YOUTH-ARC Reactivated



Two YOUTH-ARC participants greet each other at NYSARC convention



YOUTH-ARC conference participants

## AMERICA'S ROADWAYS — AN UNSAFE ENVIRONMENT

When people think of the environment, they think of the nation's lakes and rivers and their freedom from harmful pollutants, or the quality of air, or how forests are withstanding the ravages of acid rain. But our roadways are another common environment we share; and, it is one that is substantially less safe than it can be.

According to a report from the Insurance Information Institute, traffic fatalities in the United States rose 4.4% in 1986, an increase that reverses an overall downward trend which saw traffic fatalities declining an average of 3% a year since 1980. This 1986 toll amounted to 45,708 fatalities.

The Institute also estimates that traffic accidents increased last year about 3% and traffic injuries about 4.3%; based on Federal government and National Safety Council statistics.

These are grim statistics, indeed, and the increase in accidents reflects observable recent developments. Stable gasoline prices, continuing economic expansion and more driving vacations mean more people on the roads. Long distances to travel translate into high speeds. A recent Federal Highway Administration report says that 58.8% of drivers exceeded the speed limit.

America's road environment is unsafe, but much is being done by property/casualty insurers to help make it safer. Our commitment to improving highway safety is more than enlightened self-interest. It is a natural extension of our basic economic charter to protect people — here through action to conserve life and property. We see our social role as more than a pass-through mechanism of premiums and loss payments. The Insurance Institute for Highway Safety has the resources, staff and experience to go nose-to-nose with other industries and government agencies. When it speaks, legislators and regulators listen because it is a respected voice.

Property/casualty insurers, through the Insurance Institute for Highway Safety, came to a new, different and programmatic view of road safety; namely, that this complex environment needed to be treated as a whole and that focusing on driver education, for example, while ignoring the crash-worthiness of vehicle design, or seat belt use, or wrist-slap penalties for drunk driving, was a counterproductive strategy.

Accordingly, since the mid-1960's, IIHS has focused on all of these factors through research and advocacy. A central thrust of its effort has been to demonstrate that simple cost-efficient technology exists to minimize the human, social and economic cost of road accidents. ■

### Safe Driving Tips: Glass Care

Glass that is seriously damaged should be replaced to insure good, driver visibility and passenger safety.

The following points will help keep all vehicle glass in good, safe condition:

1. Keep the windshield washer reservoir filled.
2. Turn the wipers off after every use before you stop the engine. This will eliminate dry cleaning of the windshield, which can scratch the glass. It can also save the wiper motor should the wiper blades freeze to the windshield.

3. Do not clean glass with a dry cloth.
4. Clean wiper blades when you clean the windshield. Replace worn blades as soon as they start to streak.
5. Clean snow or ice from glass with a brush or plastic scraper.
6. Keep a safe distance behind other vehicles, especially on dirt or gravel roads, as tire thrown stones can damage glass.
7. Keep all mirrors, reflectors and car lights (especially headlights) clean and free from dirt, mud and snow. This will enable them to maintain maximum reflection and illumination. ■

## We Can Help You!

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## Chairman of the Sullivan County Board of Supervisors Installs Association's Officers and Governors

At the thirty-ninth Annual Convention, the Delegate Assembly representing the Association's sixty-five chapters and over 57,000 members, elected the Officers and Board of Governor members of the Association.

At the banquet held on Saturday night, November 5, 1988, the Chairman of the Sullivan County Board of Supervisors, David Kaufman, installed the State Association's Officers and Board of Governors.

Mrs. Blanche Fierstein was unanimously elected as President of the Association (see story Page 1). In her acceptance speech, Mrs. Fierstein reminded the gathering of Joseph T. Weingold's commitment to the Association and thanked the chapter for giving her the honor to serve.

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

Blanche Fierstein  
*President*  
John Bryant  
*Senior Vice President*  
Vice President, Central Region  
Mary L. Caniano  
*Vice President, Northeast Region*  
Michael Limongelli  
*Vice President, Southeast Region*  
John Schuppenhauer  
*Vice President, Western Region*  
George G. Hirsch  
*Treasurer*  
Carroll F. Stowell  
*Assistant Treasurer*  
Sadieann Mazzotta  
*Secretary*

The following individuals were elected to serve on the Board of Governors for the 1988-90 term of office:

Gary Enderle *Allegany*  
Ida Rios *Bronx D.C.*  
Robert Salankiewicz *Broome-Tioga*  
Ethel Card *Cattaraugus*  
Helen Emerson *Cayuga*  
Judith Fox  
Joseph Trusso, Jr. *Chautauqua*  
William Fowlston *Chenango*  
Jeanne Coffin *Clinton*  
Karen Alvarez *Columbia*  
Beverly Epstein *Community*  
Florence Siegel *League D.C.*

Linda Ziemba *Delaware*  
Celeste Rudberg *Dutchess*  
Donald Enslin *Erie*  
Sophia Dabrowski  
Helen McDonald *Essex*  
Jane Meier *Genesee*  
Henry Valerych  
James Riley *Greene*  
Marjorie Reese *Herkimer*  
To be determined *Jefferson*  
Cheryl Englert *Livingston-Wyoming*  
Lois Jones *Madison*  
Eileen Patricia  
Warren Heilbronner *Monroe*  
Kay R. Nogaj  
George Hirsch *New York City*  
Betty Pendler  
Walter Redfield  
William Hughes *Niagara*  
Robert Taylor *O.D. Heck D.C.*  
Shirley Fredenburg *Ontario*  
John Schuppenhauer  
Jean Black *Orange*  
Audrey Strickland *Orleans*  
Bettye Hughes *Oswego*  
Dr. John Readling  
Ellie Pattison *Rensselaer*  
Audrey Tarantino *Rockland*  
Patricia Campanella *St. Lawrence*  
Carroll Stowell *Schenectady*  
Bella Stuart  
Bonnie Bowes *Schoharie*  
Bonnie Baker *Schuyler*  
Paul Greenfield *Steuben*  
Fred Salzberg *Suffolk*  
Elizabeth Radzieski *Sullivan*  
John Keller *Syracuse D.C.*  
Joseph Pecora *Ulster*  
Lois Fairclough *Warren-Washington*  
Bernice Volaski *Welfare League D.C.*  
Hector Dowd *Westchester*  
Charles Kingsley  
Dr. Louise Weston  
Mary Ellen Murphy *West Seneca D.C.*  
Ellen Owens  
To be determined *Yates*

## Audrey Strickland Praised

At the November 6, 1988 Board of Governors' Meeting, Audrey Strickland from the Orleans County Chapter was praised for her service to the Western Region as its Vice President.

The following resolution was passed recognizing Audrey's dedication.

**WHEREAS:** For several years past, Audrey Strickland has served competently and loyally in the capacity of Western Region Vice President to NYSARC, Inc.

**WHEREAS:** Her dedicated service in such capacity has had significant impact on this Association.

**NOW THEREFORE BE IT RESOLVED:** That this Association extend its profound gratitude and appreciation to Audrey Strickland for such service.



Immediate Past President, David B. Lettman (L) and NYSARC Executive Director, Marc N. Brandt, wish outgoing Western Regional Vice President, Audrey Strickland the best of luck.



Board members eagerly await being called to order



NYSARC 1988-89 Officers being installed by Mr. David Kaufman, Chairman, Sullivan County Board of Supervisors.



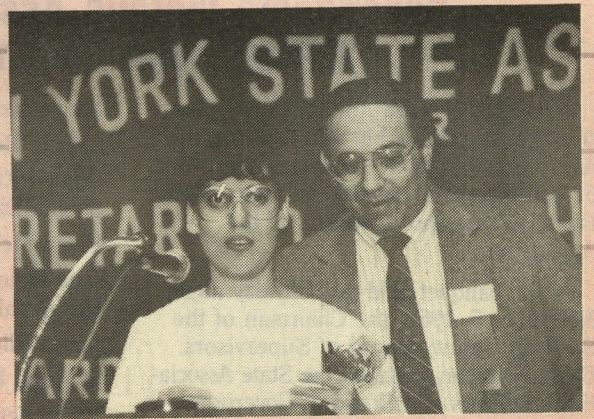
Newly elected President, Blanche Fierstein conducts first board meeting.



The Lettman family, Linda, Judy and Brian



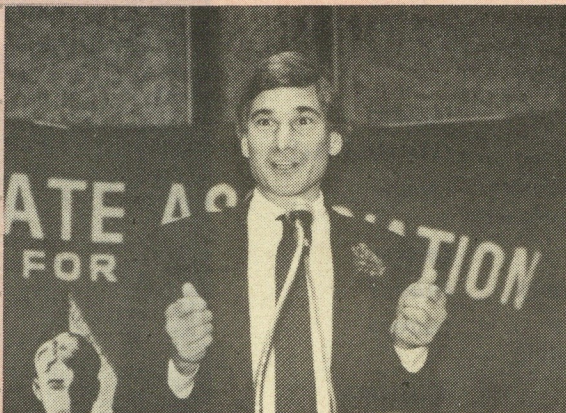
Marc N. Brandt, Executive Director of NYSARC delivering a report to Board of Governors



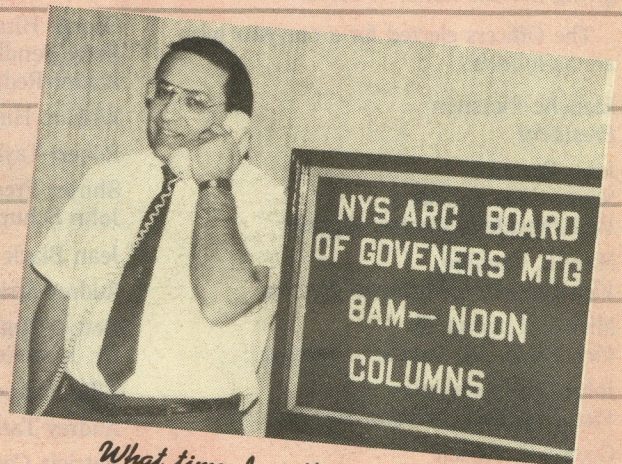
Ms. Beth Hyman, representing the Orange County Chapter welcomes Delegates to the 39th Annual Convention while President David Lettman looks on



David Lettman being presented with gift from the Association by Marc N. Brandt and Senior Vice President, John Bryant



Dr. Thomas Bellamy, Director, Office of Special Education Programs for the Federal Department of Education delivers Keynote Address



What time does the meeting start?



Maureen Dart and Diane Haase greet conventioners as they stop at the exhibit to learn more about recreation



NYSARC's Volunteer of the Year recipient reaping the benefits



Executive Director, Marc N. Brandt, addresses banquet while Mr. and Mrs. David Lettman (L) and Mr. and Mrs. David Kaufman (R) look on



Some of the 725 attendees enjoying the cocktail party



Master of Ceremonies David Kaufman, Chairman of the Sullivan County Board of Supervisors thanks Mr. Ed Shan, representing the Ulster County Chapter for his invocation at banquet



One of the many highly attended workshops



Recipient of NYSARC's 1988 Volunteer of the Year Award, George Hirsch receiving congratulations from President Blanche Fierstein



David and Marsha Lettman look on as a special presentation recognizing David's accomplishments is being made



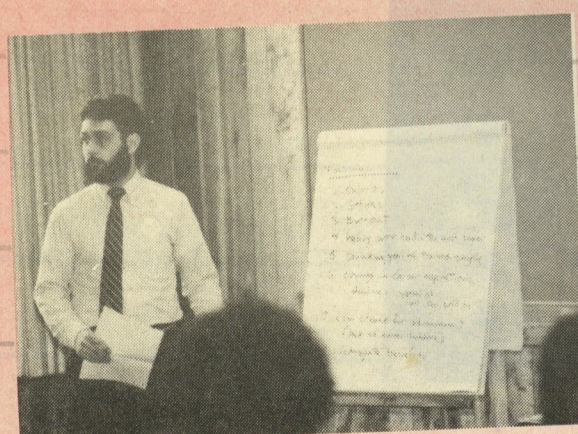
Delegates' representing the 57,072 membership voting on proposed resolutions



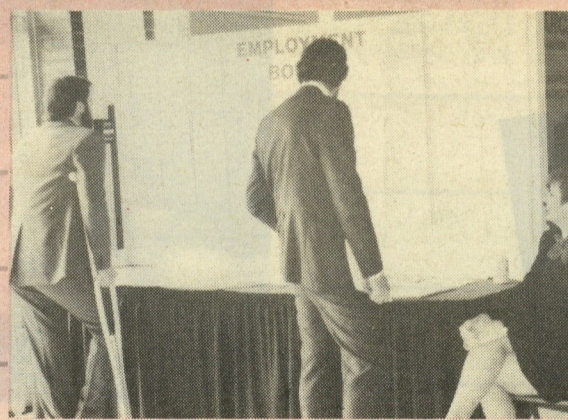
Judy Lettman gives Association prayer at Delegate Assembly meeting



Step right up — we will sell you a computer you can't refuse



Manny Pelligrin, Otsego ARC presents one of the many workshops offered to Conventioneers



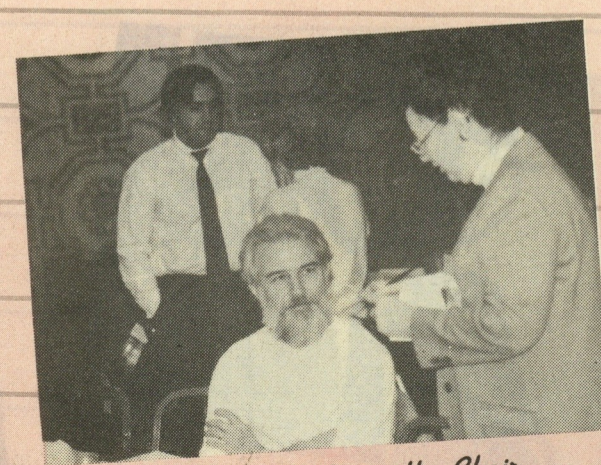
Never hurts to look



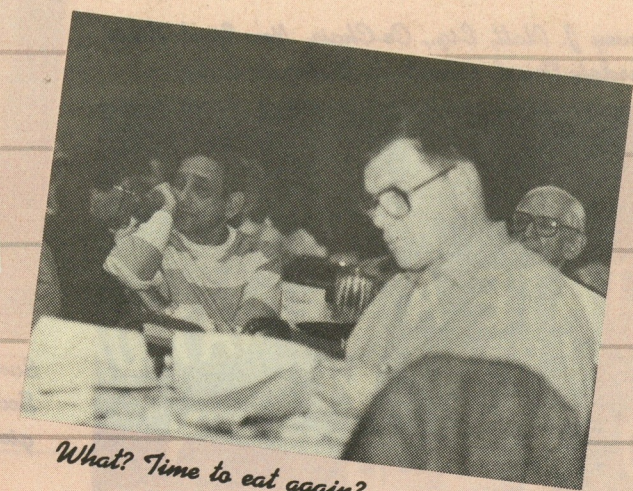
A senior citizen participant of the Sullivan County ARC's Aging Program proudly displays his work



One of the many exhibits at the Convention



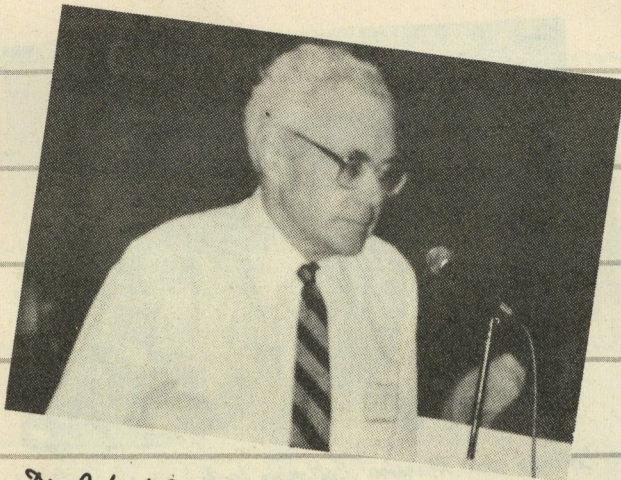
Robert Lehr, Education Committee Chair, conferring with Kay R. Nogaj, Scholarship and Awards Committee Chairperson with John Schuppenhauer in background



What? Time to eat again?



Michael Rosen, NYSARC Counsel, reporting legal matters to the Board



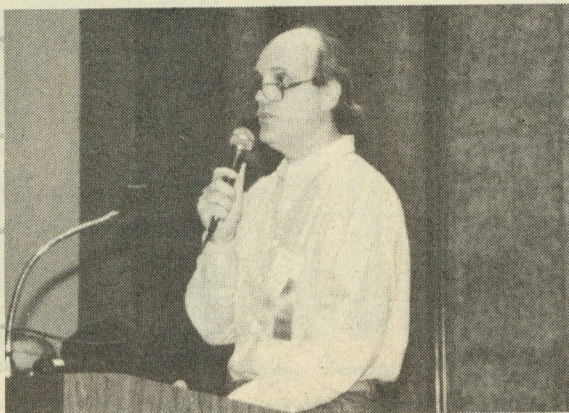
Dr. Robert Porter, Board of Governor representative from Otsego County Chapter speaking to Legislative Platform



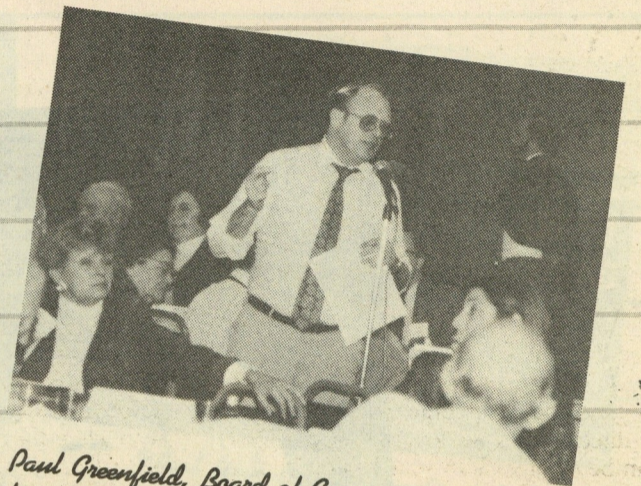
Betty Pendler, New York City Chapter, speaking to an issue



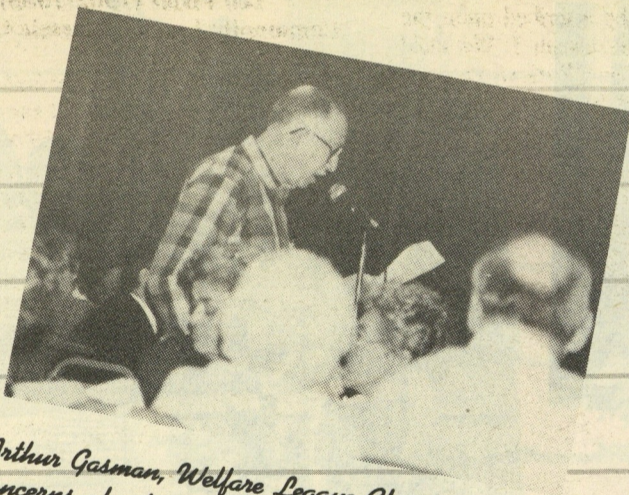
Board of Governors being installed as NYSARC State Office staff observe



Dr. David Keymer presenting Adult Service's position paper to Board of Governors



Paul Greenfield, Board of Governor representative from Steuben County Chapter makes a point

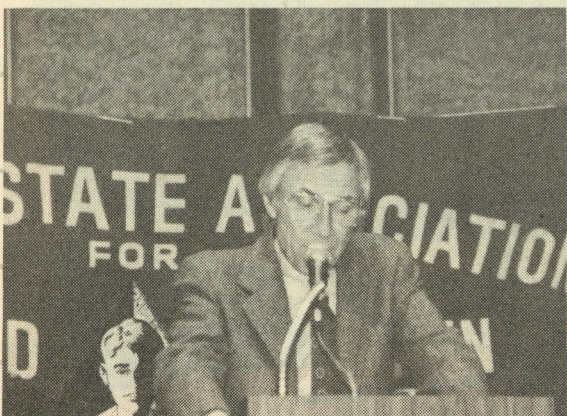


Arthur Gasman, Welfare League Chapter, raising concerns about implementation of Ombudsman position



Dr. Irving Caminsky, Rockland County Chapter, debating the issue

Harvey J. Platt, Esq., Co-Chair, New York State Retardate Trust, reports to Delegate body



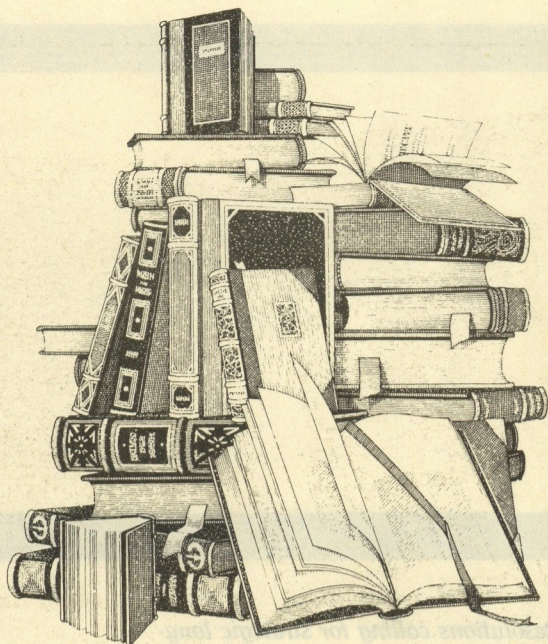
Banquet speaker, Michael Dowling, Deputy Secretary to the Governor for Human Services gives presentation to gathering



Mr. Richard E. Sheppard, President's Committee on Employment of People with Disabilities delivering address at Awards Luncheon

## NYSARC Library Corner

By: Mary Meachem,  
NYSARC Library Consultant



Time hanging heavy on your hands? Nothing but holidays to keep you busy? Three recent books which have been taken into the ARC Library at Delmar will fill your free time and help you finish this year up with a bang.

It isn't necessary to be part of the medical profession to realize that we live in a "sue-happy" society. The Board of Governors and the local Boards of Directors play a large part in our organization, and many of you play a large part in the composition of these boards. Volunteering to be officers or directors of a not-for-profit organization can be dangerous to your health. You should be aware that liability is more than just a word on your automobile insurance policy. Daniel L. Kurtz's book, **BOARD LIABILITY**, a one-of-a-kind book is a guide to legal principles that control the liabilities and legal responsibilities of those who serve in leadership positions of non-profit organizations. It is written in non-legal language, meant for the layman's understanding and spells out in no uncertain terms the duties and dangers of holding such offices. The first few chapters discuss how boards are set up; who serves on them, and the functions these boards should perform. Check out chapters five and six carefully, for these explain why directors get sued and what protections each organization should take to cover its directors and officers.

No chapter can afford to be without at least one copy of this book.

The volume is published by Moyer Bell Limited, Colonial Hill/RFD 1, Mount Kisco, New York 10549 and is available in hardcover for \$19.95 and in paperback for \$12.95 (\$2.50 for postage)

I realize that books on special education are hardly scarce, but this one has a little different approach. Public Law 94-142 and Public Law 98-199 has been explained and analyzed in many sources, but **RELATED SERVICES FOR HANDICAPPED CHILDREN**, by Morton Esterson and Linda Bluth examine these laws and the purpose of special education in regard to the related services provisions which are called for in this legislation.

Each chapter is written by a specialist working a particular field who explains that speciality in relation to the whole concept of special education. The writing is clear, informative, well organized and based on professional experiences covering

such topics as: audiology, counseling, services, early identification, medical services, occupational therapy, parent counseling and training, physical therapy, physiological services, recreation, school health services, social work services in schools, speech pathology and transportation.

There is a bibliography section for further reading, although I would have liked a more extensive one. This lack is somewhat balanced by an excellent glossary. This is a book that any parent, educator, advocate or therapist will profit from having read when they need to understand or are called upon to explain the relationship between the field of special education and the related services required by law.

It is published by College-Hill Press, 18 Tremont Street, Boston, Mass. 02108 and costs \$24.50

Another area that you may think has been well covered in print is Down Syndrome, but a recent book by Carol Tingey, (a name I'm sure you recognize) is well worth your time and money. It's called simply, **DOWN SYNDROME: A RESOURCE HANDBOOK** and is illustrated by Elaine Sorenson with some of the most touching black and white sketches I've seen since those of Martha Perske. If I had printed this book, her name would have been on the cover, since she has added just the right tone to the purpose of this volume. Carol Tingey, a mother of a young man with Down Syndrome has compiled a generous and compassionate collection of information on the genetic, medical, social and family aspects of this disability. If you are a professional well versed in the field of mental retardation, you may not learn anything new from this volume, but you will profit from being able to recommend this well organized, concise and comprehensive handbook to a new parent or a beginning clinician who comes to you requesting information. The author has called on many sources to write each chapter and has divided her book into medical issues, the family, early developments and education and community activities. There are extensive references, which are easily located for further research by the reader.

This book is also published by College-Hill Press (a division of Little, Brown & Co.) and costs \$19.50 ■

## WITH LOVE AND THANKS NYSARC SALUTES FORMER MEMBERS

*No person was ever honored for what he received  
Honor has been the reward for what he gave*

Calvin Coolidge

The New York State Association for Retarded Children, Inc. honored three of its former members on Friday evening, November 4, 1988 before the Delegate Assembly at the statewide convention.

These individuals, including Henry Cox from Orange County Chapter, Gladys Delahoy from Chautauqua County Chapter and Leo Fixler from the Community League, Wassaic Developmental Center Chapter, were recognized for their individual as well as collective accomplishments and lifelong achievements in promoting and fostering the quality of life for persons who are mentally retarded.

To be considered for this distinguished honor, each nominee must be a deceased, former member of the NYSARC Board of Governors; have served a minimum of 15 years cumulatively as a Board of Governor representative; and be recommended by a Board of Governor representative who is currently a member of the chapter proposing the nominee.

These three highly respected individuals have close to 100 years of dedicated service between them on behalf of the Association and their names will be inscribed upon the memorial plaque in the Joseph T. Weingold Building in Delmar, New York where the corporate office of the State Association is located.



**Beverly Epstein and Dorothy Vine  
acknowledging receipt of the NYSARC  
Memorial Plaque in memory of Leo Fixler.**

In remarks made before the five hundred people attending the General Session, Kay Nogaj, Chairperson of the Scholarship and Awards Committee, described some of the contributions made by these former members.

### **Henry Cox (1916-1987) Orange County Chapter**

Mr. Cox was a charter member of the Orange County Chapter, a parent of a son who is mentally retarded and a devoted member of the Association for close to 35 years. He served as an officer of the chapter all during this time, ten (10) years of which he served as President. Mr. Cox's lifelong achievements will always be remembered by the Association.

### **Gladys R. Delahoy (1915-1976) Chautauqua County Chapter**

Mrs. Delahoy was one of the original founders of the Chautauqua County Chapter in 1958. She served as President for over ten (10) years and was a member of the Board of Governors for almost 20 years. Mrs. Delahoy helped to promote the goals of her chapter and the needs of persons who are mentally retarded. Mrs. Delahoy, through her skills in public relations, has left a special legacy for the chapter and Association to follow.

### **Leo Fixler (1902-1988) Community League, Wassaic Chapter**

Mr. Fixler was the founder and "father" of the Community League of the Wassaic Developmental Center and served on its Board for more than 30 years. He served as an active, committed and caring member of both Boards of the chapter as well as state organizational levels. Through his tireless dedication, Mr. Fixler's efforts to promote the areas of guardianship and advocacy in New York State on behalf of persons with mental retardation will always be remembered and cherished.

Representatives from the three chapters who accepted the triangular designed plaques on behalf of the memorialized individuals spoke movingly of their commitment and dedication to people with mental retardation.

Our Association salutes all of these individuals who devoted much of their adult lives to assisting others and through their achievements, have left behind them footprints on the sands of time. ■

**See  
State Commission  
on Quality of Care  
SURVEY  
Pages 29-30**

# George G. Hirsch Recipient of 1988 NYSARC Volunteer Award

The second annual NYSARC Volunteer Award was presented to George Hirsch of the New York City Chapter at the thirty-ninth State Convention on Friday, November 4, 1988 in Kiamesha Lake, New York.

This prestigious award which was the first established by action of the Board of Governors at its Spring meeting in 1986, was announced by Kay Nogaj, Chairperson of the Association's Scholarships and Awards Committee before the delegate assembly on Friday evening. This tribute was paid to Mr. Hirsch for his more than 40 years of commitment, dedicated service and advocacy on behalf of persons who are mentally retarded.

A leather binder containing a biographical profile, a tie pin and Corning glass were among the gifts received by George on the eve of the General Session. In accepting the highly regarded award, George gave special thanks to his wife Mina, his children and recognized the continued support of the New York City chapter.

George and Mina have three children, one of whom is mentally retarded. George through his countless activities and positions held in the State Association, has directed much of his energy and passion to promoting a better quality of life not only for his daughter, but for all persons who are mentally retarded.

Mr. Hirsch who currently serves as the Treasurer of NYSARC, Inc., was one of several individuals instrumental in establishing the Association in 1949. In previous years he served the State Association for three terms as President from 1975-1978, five terms as Vice President and eight terms as Treasurer which Mr. Hirsch continues to be actively involved in. In addition, George is the only member who has served on NYSARC's Board of Governors for the past 39 years since the inception of the organization.

In 1949, he was one of the prime movers in developing the New York City chapter's constitution and articles of incorporation.

Among his other contributions to the field of mental retardation, Mr. Hirsch participated in one of the first conferences on the handicapped in 1974 and in 1975, attended the first White House Conference on Employment of the Handicapped. He was also a member of the Governor's Advisory Committee on the Handicapped.

On both the chapter and state levels, Mr. Hirsch has been actively involved on various committees, including Budget and Finance, Occupation Day Training, Education, Scholarship and Awards, Vocational Rehabilitation, Clinic and Residential Services.

Some of the special achievements and recognitions awarded to George Hirsch include the National Association for Retarded Children President's Service Award and Mayor Lindsay's Award as member of the Organizational Task Force for Comprehensive Health Planning.

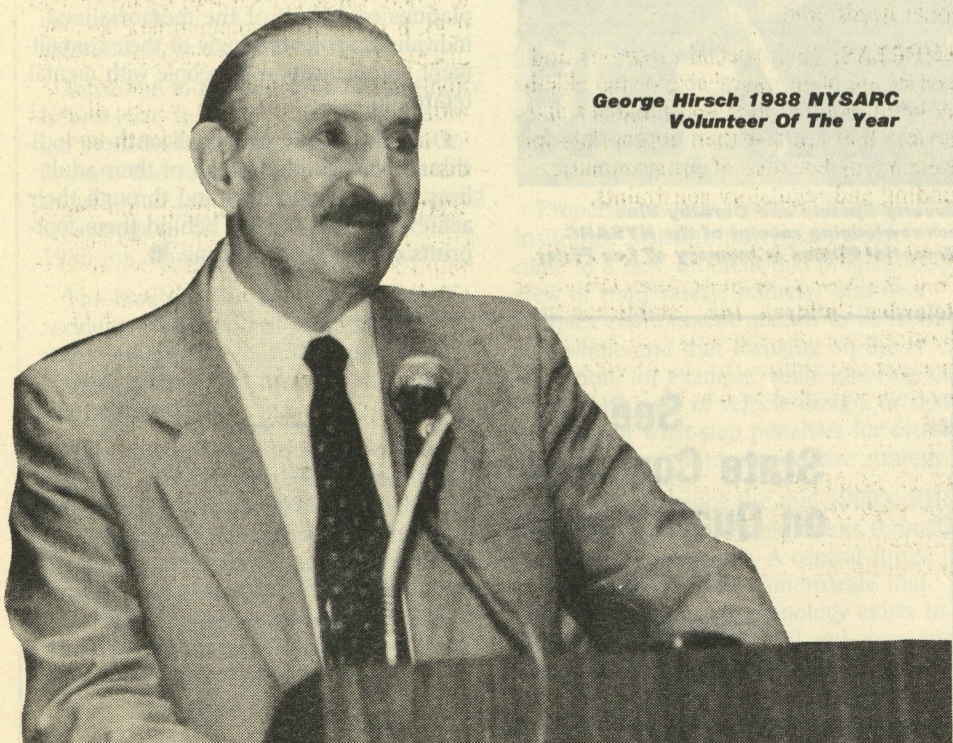
The criteria for a nominee to be considered for this honor consists of the following:

- (1) The nominated individual must be a current member of the New York State Association for Retarded Children, Inc., for a minimum of ten (10) years, and
- (2) Nominations must be submitted to the NYSARC's Scholarship and Awards Committee from the chapter's Board of Directors accompanied by a resume. The resume or profile of the individual must include personal data, volunteer activities and achievements (ARC and others), reasons why the nominee is deserving of the award and letters of recommendation and support.

The New York City chapter's Board of Directors in nominating George stated it most eloquently that George Hirsch "exemplifies the caring and energetic parent advocate. George is a living testimonial to the fact that commitment, energy and compassion can change the world and make it a better place to live."

The Association unanimously agrees...

George Hirsch 1988 NYSARC Volunteer Of The Year



*Resolutions calling for strategic long-range planning and limiting the use of Accutane were defeated.*

On Saturday, November 5, 1988, the Delegate Assembly, representing the NYSARC, Inc. 62 chapters and 57,072 members, voted on nineteen resolutions. Seventeen of the resolutions were adopted by the Delegates.

The most controversial and debated resolution pertained to the Columbia County Chapter's resolution calling for strategic long-range planning. While the resolution was defeated, newly elected Association President, Blanche Fierstein, announced at the Sunday Board of Governors' Meeting the formation of such a committee.

Another resolution that was defeated called for the limiting of use of Accutane. The resolution was defeated due to the feelings of the delegates that it was poorly worded.

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

## 1 PROMPT TIMELY PAYMENTS FOR NON-MEDICAID SERVICES

**WHEREAS:** The Office of Mental Retardation and Developmental Disabilities serves nearly 60,000 people throughout New York State in community living and day programs operated by the State and by voluntary providers, and

**WHEREAS:** Substantial waiting lists for services in many areas and planned developmental center closings have prompted plans for considerable further development in both residential and day program areas, and

**WHEREAS:** Payments from the Office of Mental Retardation and Developmental Disabilities for Non-Medicaid services continue to often be late, resulting in needless expense and operational difficulties for many chapters, and

**WHEREAS:** The "prompt payment" regulation has had little impact on this problem since the applicability of this requirement is limited and often not the issue.

**NOW THEREFORE BE IT RESOLVED:** That the State Association endorse and support the United Way initiatives or seek other legislative solutions to ensure prompt, timely payments for non-Medicaid services.

## 2 LOW-INTEREST CORPORATION FINANCING

**WHEREAS:** The Office of Mental Retardation and Developmental Disabilities serves nearly 60,000 people throughout New York State in community living and day programs operated by the State and by voluntary providers, and

**WHEREAS:** Substantial waiting lists for services in many areas and planned developmental center closings have prompted plans for considerable further development in both residential and day program areas, and

**WHEREAS:** Chapters often experience cash flow difficulties at certain times of the year due to payment lags from the Office of Mental Retardation and Developmental Disabilities and other State offices, and

**WHEREAS:** Resultant short-term operational shortcomings must be addressed through lines of credit and other commercial borrowings, whose interest is reimbursable only to the limits of contractual allocations, and

**WHEREAS:** Further funds so spent could be better used to advance and improve programs for those we serve.

**NOW THEREFORE BE IT RESOLVED:** That the State Association investigate low-interest corporation financing of such short-term debt when outstanding public funding receivables are the sole reason for this deficiency.

## 3 USE OF AVERSIVE THERAPY

**WHEREAS:** People who are mentally retarded have been subjected to a variety of inhumane forms of "therapy" in order to change their behaviors, and

**WHEREAS:** People who are mentally retarded are among the most vulnerable members of our society, and

**WHEREAS:** A major goal of NYSARC is to advocate for people who are mentally retarded, and

**WHEREAS:** NYSARC supports the development and use of humane treatment procedures that successfully habilitate people

# Delegate Assembly Adopts Seventeen Resolutions

*Delegate body proclaims 1989 to be "Year of the Parent and Volunteer Advocate" to coincide with NYSARC's 40th year.*

who are mentally retarded and display problem behaviors.

**NOW THEREFORE BE IT RESOLVED:** NYSARC condemns and opposes the use of inhumane forms of aversive "therapy" techniques used to modify the behaviors of people who are mentally retarded. We urge the elimination of aversive practices which:

1. result in obvious signs of physical pain by the individual,
2. have actual or potential physical side effects, including tissue damage, physical illness, severe stress, and/or death, and
3. dehumanize the individual, through means such as social degradation, social isolation, verbal abuse, or other age-inappropriate techniques, procedures that are out of proportion to the behavior being modified, and methods that would be unacceptable for nonhandicapped individuals.

**NOW THEREFORE BE IT FURTHER RESOLVED:** That careful analysis of the possible environmental factors that may contribute to these behaviors must be done. In addition, an analysis of the physical and psychological condition as well as the intentions of the person should be assessed; and interventions should focus on teaching the person appropriate behaviors rather than the mere suppression of inappropriate behaviors.

## 4 ESTABLISHMENT OF A CONTINUED GUARANTEED FUNDING SOURCE FOR RESPITE SERVICES

**WHEREAS:** Many parents and families with developmentally disabled family members have committed themselves to sustaining their family member in the community, and

**WHEREAS:** Such families must provide for the care of the disabled person on a 24 hour, per-day basis, and

**WHEREAS:** The family members, including other children, require opportunities to fulfill their participation and enjoyment of the community and family unit, and

**WHEREAS:** The family unit can be strengthened and the commitment to sus-

tain a disabled family member can be a long-term reality, and

**WHEREAS:** Current respite programs are funded through annual grant awards which are subject to variation or elimination in keeping with available funds, and

**WHEREAS:** Our Association and the families it represents are in agreement with OMRDD's goals to reduce the enrollment in institutions and expand the spectrum of community-based family support services.

**NOW THEREFORE BE IT RESOLVED:** That the New York State Association for Retarded Children, Inc., calls upon the Governor, the Legislature and the Office of Mental Retardation and Developmental Disabilities to enact a State policy which sets in place a consistent funding source, thereby assuring respite service options to families and the developmentally disabled in all areas of the State.

## 5 DEVELOPMENT OF A STATE POLICY, REQUIRING OMRDD TO ALLOCATE FUNDS AND STAFF TO PROVIDE A BROAD-BASED SYSTEM TO THE COMMUNITY PROVIDERS AND PARENTS IN ORDER TO MAINTAIN CLIENTS WITH MEDICAL OR BEHAVIORAL IN A COMMUNITY SETTING WHERE SUCH PLACEMENTS ARE THE MOST APPROPRIATE.

**WHEREAS:** The Office of Mental Retardation and Developmental Disabilities has committed to the closure of developmental centers and the expansion of community services for the developmentally disabled, and

**WHEREAS:** The success of the past decade has seen thousands of previously institutionalized individuals move into the community, and

**WHEREAS:** Some clients now being placed demonstrate more complex medical and behavioral needs, and

**WHEREAS:** Resources in some communities are limited, both in terms of available medical professionals and psychological/behavioral professionals, and

**WHEREAS:** Proactive provision of services in addressing both medical and behavioral problems will assure continued placement and integration into community life, and

**WHEREAS:** Parents or families who elect to maintain a disabled member in their home frequently need professional support services, and

**WHEREAS:** Given that the Association is committed to the enhancement of quality of life in the most appropriate setting, it is essential that each client be given the services which can enable them to improve their functioning in their respective setting.

**NOW THEREFORE BE IT RESOLVED:** The NYSARC calls upon the Governor, the Legislature and the Office of Mental Retardation and Developmental Disabilities to enact legislation and state policy which sets in place staff and resources to provide medical and behavioral support systems for persons residing at home in community settings or newly placed in community settings.

## 6 ADEQUATE PROGRAMS FOR THE ELDERLY POPULATION

**WHEREAS:** There are a large and ever increasing number of mentally retarded people who are elderly, and

**WHEREAS:** The elderly require programs and services that will address their unique developmental, physical, medical, dietary, social, occupational, housing, and recreational needs, and

**WHEREAS:** Such special programs and services are often unavailable or the elderly are often required to attend programs and services that are less than appropriate for their needs because of programmatic, funding and regulatory constraints.

**NOW THEREFORE BE IT RESOLVED:** That the New York State Association for Retarded Children, Inc. establishes the development of programs and services to meet the unique needs of elderly mentally retarded as one of its priorities, and

**BE IT FURTHER RESOLVED:** That the New York State Association for Retarded Children, Inc. should take the lead role in coordinating and networking existing

programs and services for the elderly mentally retarded, developing appropriate models for delivery of service to them, and training chapter personnel to meet the needs of our elderly mentally retarded people, and

**BE IT FURTHER RESOLVED:** That the New York State Association for Retarded Children, Inc. should take such actions as are necessary and proper to assure the development of programmatic, regulatory, and funding models by OMRDD and other appropriate governmental agencies, that meet the needs of elderly mentally retarded.

## 7 NEWBORN SCREENING PROGRAM FOR CYSTIC FIBROSIS

**WHEREAS:** The New York State Newborn Screening Program is a service provided by the State Department of Health to families with newborn babies, and is responsible for testing infants at birth for various disorders in body chemistry resulting in approximately 250,000 babies tested every year in New York State for seven (7) metabolic disorders including: Phenylketonuria; Branched-chain ketonuria; Galactosemia; Homocystinuria; Hypothyroidism; Sickle cell disease; and Sickle cell trait, and

**WHEREAS:** Although Cystic Fibrosis is not a cause of mental retardation, it is an inherited disease, present at birth, which causes certain glands to malfunction. One in 2,000 babies is born with Cystic Fibrosis (CF). It is the most common fatal genetic disease. One in 20 Americans is a carrier (that's about 12 million potential parents with the CF gene). Among genetic diseases CF is the leading cause of death and disability in children, and

**WHEREAS:** There is currently no known cure, but proper treatment allows babies with CF to grow up to lead active, productive lives, and therefore early detection is essential to the welfare of the child.

**NOW THEREFORE BE IT RESOLVED:** That NYSARC will support the Department of Health in securing additional funds (\$750,000) to add the newborn screening test for CF to the New York State Newborn Screening Program.

## 8 PREVENTION OF CHILD ABUSE AND NEGLECT

**WHEREAS:** Awareness of the reality and understanding of the scope of child abuse has made dramatic advances over the past decade in this state and nationwide, and

**WHEREAS:** Over two (2) million children were reported to have been abused in 1987 in the United States and 172,490 in New York State.

**NOW THEREFORE BE IT RESOLVED:** That NYSARC will support and encourage the New York State Federation on Child Abuse and Neglect and its national organization, the National Committee for the Prevention of Child Abuse in its established priority of ensuring the prevention of child abuse and neglect on behalf of all children and families in New York State, and

**NOW THEREFORE BE IT FURTHER RESOLVED:** That NYSARC will encourage the New York State Department of Education to include in its family-life skills curriculum that children diagnosed with mental retardation/developmental disabilities are at greater risk for child abuse and neglect; and that physical abuse or neglect of children can lead to and/or cause mental retardation/developmental disabilities as is strongly suggested in the research literature to date.

## 9 SCREENING FOR FRAGILE X SYNDROME

**WHEREAS:** The condition identified as Fragile X Syndrome, a genetic disorder virtually unknown to doctors five (5) years ago, has now been recognized as a leading cause of mental retardation in New York State, and

**WHEREAS:** Fragile X Syndrome produces disabilities ranging from learning difficulties to mental retardation and may be the cause of one out of ten cases of autism.

**NOW THEREFORE BE IT RESOLVED:** That NYSARC support the Office of MR/DD in its efforts to screen for Fragile X especially individuals who are MR/DD and reside in the community, and that families of individuals found to be affected, have access to genetic counseling.

## 10 SEXUAL AWARENESS AND PREVENTION OF SEXUAL ABUSE

**WHEREAS:** Due to the vulnerability of persons who are MR/DD for sexual abuse

because of their lack of sexual awareness (it is estimated that in 1981 approximately 100,000 rapes were committed against disabled persons).

**NOW THEREFORE BE IT RESOLVED:** NYSARC will to the best of their ability, educate the clients they serve with information and training about sexual awareness and prevention of sexual abuse so that they can learn how to best prevent this type of abuse, and encourage other agencies to provide such training to the persons they serve.

## 11 STATEWIDE MARKETING CAMPAIGN

**WHEREAS:** The New York State Association for Retarded Children, Inc. has 40 years of history in advocating for the needs of individuals with mental retardation and developmental disabilities and in providing a vast range of essential services to these individuals throughout the State of New York through its various chapters, and

**WHEREAS:** It is imperative in today's environment for any organization to effectively communicate to the general public its mission, the fulfillment of its purpose, and its hopes and achievements, and

**WHEREAS:** Each chapter of the New York State Association for Retarded Children, Inc. has an urgent need to utilize a professionally developed marketing campaign for multi-media purposes in order to have the greatest impact on the local community in educating the public on the capabilities of people served, and in obtaining broad and strong social, political, and financial support to our cause, and

**WHEREAS:** The New York State Association for Retarded Children, Inc. has the potential to collectively pool resources and efficiently develop and make available a multi-media marketing campaign plan and tools for the utilization by the many regional television, radio, newspapers, and other publications markets, and

**WHEREAS:** The NYSARC Public Information Committee has been and continues to work diligently to pursue a fully developed marketing campaign, and

**WHEREAS:** This collective approach would be cost efficient for all chapters in a most critical area of operation which has the least amount of financial resources support.

**NOW THEREFORE BE IT RESOLVED:** That in recognition of NYSARC's 40th year and NYSARC chapters need to develop and implement a professionally based marketing campaign program for multi-media utilization to be realized through the State Association and made available for chapters' utilization on an individual or regional basis; that efforts be undertaken by each NYSARC chapter to support this effort.

## 12 PROCLAIMING 1989 THE YEAR OF THE PARENT AND VOLUNTEER ADVOCATE

**WHEREAS:** 1989 will mark the 40th anniversary of the founding of the New York State Association for Retarded Children, Inc. by a group of parents and volunteer advocates, and

**WHEREAS:** 1988 has marked the 10th anniversary of the successful culmination of NYSARC's efforts and those of its member parents and volunteer advocates, to establish a separate OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES, and

**WHEREAS:** 1988 has marked a year of continued progress towards the establishment of appropriate programs and services for persons with mental retardation and developmental disabilities that would not have been possible without the tireless efforts of parents and volunteers, and

**WHEREAS:** The events of 1988 have served to remind us of the essential role played by parents and volunteer advocates in shaping those public policies upon which the well-being of persons with mental retardation and developmental disabilities is ultimately and critically dependent.

**NOW THEREFORE BE IT RESOLVED:** That the New York State Association for Retarded Children, Inc. proclaims that 1989 shall be the year of the parent and volunteer advocate in order to emphasize the invaluable accomplishments of these persons in the past and the continuing need for their irreplaceable efforts in the future.

**AND BE IT FURTHER RESOLVED:** That the New York State Association for Retarded Children, Inc. request the Governor of the State of New York to acknowledge the parent and volunteer advocate by proclaiming in New York State the month of October 1989 as the month of the parent and volunteer advocate to coincide with the NYSARC 40th Annual Convention.

## 13 RESOLUTION ACKNOWLEDGING CONTRIBUTION OF SENATOR SPANO AND ASSEMBLYWOMAN CONNELLY

**WHEREAS:** Senator Nicholas Spano and Assemblywoman Elizabeth Connelly have shown consistent sensitivity and support for the rights and needs of persons with mental retardation and developmental disabilities and their families, and

**WHEREAS:** Senator Nicholas Spano and Assemblywoman Elizabeth Connelly, through their advocacy efforts both within and without the State Legislature, have consistently focused the attention of the public and key officials, including the legislative leadership and the Governor, on

the need to maintain and protect the rights and well-being of persons with mental retardation and developmental disabilities, and

**WHEREAS:** Senator Nicholas Spano and Assemblywoman Elizabeth Connelly have consistently sponsored legislation and budget initiatives endorsed and supported by our Association, and

**WHEREAS:** Senator Nicholas Spano and Assemblywoman Elizabeth Connelly have successfully advocated for the passage and approval of numerous laws and appropriations that have enhanced the well-being and protected the rights of persons with mental retardation and developmental disabilities.

**NOW THEREFORE BE IT RESOLVED:** That the New York State Association for Retarded Children, Inc. honors and commends these two fine legislators for their leadership and outstanding efforts and contributions on behalf of persons who are mentally retarded and developmentally disabled.

## 14 REFORM OF MEDICAID FUNDING FOR PERSONS WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

**WHEREAS:** Medicaid has become a major source of funding for many services for persons with mental retardation and developmental disabilities in New York State and pays for almost 70% of such services, and

**WHEREAS:** Medicaid rules and regulations continue to promote the inappropriate institutionalization of persons with mental retardation and developmental disabilities and the use of other highly intensive and restrictive services, and

**WHEREAS:** Our Association has, over the course of its 40 year history, embraced a philosophy of care that is inconsistent with the current Medicaid program and which emphasizes the need for least restrictive home and community-based services, and

**WHEREAS:** We recognize that to the extent that persons must remain in developmental centers in order to receive appropriate care, such care can only be rendered according to the very highest standards that take into account the needs of each individual, and

**WHEREAS:** We realize that to fully and finally achieve appropriate services for all persons with mental retardation and developmental disabilities we must have in place a Medicaid system which helps rather than hinders us in achieving our goals.

**NOW THEREFORE BE IT RESOLVED:** That the New York State Association for Retarded Children, Inc. strongly supports the reform of Medicaid funding at the state and national level and be in the forefront of developing proposals form-

## Pepsi-Cola Batavia Bottling Corporation Named 1988 NYSARC Employer of the Year



Mr. Ralph Houseknecht, President of Pepsi-Cola Bottling in Batavia, New York receiving Employer of the Year Award from Kay R. Nogaj and Mr. Richard E. Sheppard, President's Committee on Employment of People with Disabilities.

Pepsi-Cola Batavia Bottling Corporation, a Genesee County based company was honored at the annual NYSARC Convention on Saturday, November 5, 1988 as the New York State ARC's 1988 Employer of the Year. This award was presented at a special luncheon in recognition of the Corporation's meritorious and outstanding commitment to employment opportunities for citizens who are mentally retarded in the Genesee County community.

The award was presented to Ralph Houseknecht, the President of Pepsi-Cola Batavia Bottling Corporation, by Richard Sheppard, an official representing the President's Committee on Employment of People with Disabilities from Washington D.C.

Mr. Houseknecht, a life-long resident of Batavia and a well respected community leader joined Pepsi-Cola in 1974 and he became President of the Bottling Corporation in 1979.

Due to a special personal interest in persons who are mentally retarded and developmentally disabled, Mr. Houseknecht and his wife Aggie have been extremely involved with the Genesee County Chapter of NYSARC for many years. The Company is one of the largest supporters of the chapter's various projects and fundraising activities.

Mr. Houseknecht initially became involved with hiring of individuals who are mentally retarded in 1981 and these citizens are considered valued employees of the family-oriented Pepsi-Cola Company. Currently, there are four client-workers employed full time which represents 7% of the company's total work force. Through their continued support, this business has provided these individuals the opportunity to become active and productive members of the competitive work force, increasing their self-esteem and assisting them to reach their employment goals and fullest potential.

In addressing over 600 participants attending the Saturday awards' luncheon, Mr. Sheppard presented a plaque to Mr. Houseknecht in recognition of his company's outstanding achievements. Mr. Sheppard also emphasized the critical importance of providing supported-work opportunities for all individuals who are disabled in the work force and to enable them to become contributing members of their communities.

The Pepsi-Cola Batavia Bottling corporation was selected from 17 other nominees by the Association's Scholarship and Awards Committee as the recipient of this year's award, however, these other individuals and businesses are also deserving of recognition for their contributions to enriching the personal growth of workers who are mentally retarded and developmentally disabled.

Certificates of Appreciation were sent to the following employers in honor of their achievements:

1. Wegman's Food Markets, Inc. — nominated by Cayuga County Chapter.
2. Horseheads McDonald's — nominated by Chemung County Chapter.
3. Howard Johnson's — nominated by Clinton County Chapter.
4. Burger King — nominated by Columbia County Chapter
5. Hallmark Management — nominated by Erie County Chapter
6. Great American Food Store — nominated by Herkimer County Chapter.
7. Collette Manufacturing Company — nominated by Montgomery County Chapter.
8. Friendly's Restaurant — nominated by Monroe County Chapter.
9. McDonald's Klein Kaufman Corp. — nominated by Nassau County Chapter.
10. All-Way Tools — nominated by New York City Chapter.
11. Ground Round, Inc. — nominated by Oneida County Chapter.
12. Evergreen Chrysler/Plymouth — nominated by Rensselaer County Chapter.
13. Caldor — nominated by Rockland County Chapter.
14. Janitronics — nominated by Saratoga County Chapter.
15. The Desmond Americana — nominated by Schoharie County Chapter.
16. Kraft, Inc. — nominated by St. Lawrence County Chapter.
17. Walnut Mountain Nursing Home — nominated by Sullivan County Chapter.

Kay Nogaj, Chairperson of NYSARC's Scholarship and Awards Program remarked that "through the commitment and efforts of all these employers who are meeting the challenges of ensuring equal employment opportunities and full citizenship rights, our society is slowly but surely recognizing that people who are mentally retarded and developmentally disabled are, first of all, our fellow citizens who happen to have disabilities." ■

ing an agenda that promotes the best interest of persons with mental retardation and developmental disabilities.

### 15 ESTABLISHMENT OF STATE POLICY ENSURING HUMANE PLACEMENT OF INDIVIDUALS WHEN CLOSURE OF DEVELOPMENTAL CENTERS OCCUR

**WHEREAS:** New York State operates 19 developmental centers which serve as home for 9,900 residents of New York State who are mentally retarded and developmentally disabled, and

**WHEREAS:** New York State has undertaken the process of closing several of these developmental centers, including Bronx, Craig, Manhattan, Newark, Rome and Westchester Developmental Centers as well as buildings located on many other centers, and

**WHEREAS:** New York State has targeted some of these facilities for "alternative uses" which are detrimental to the well-being of persons with mental retardation and developmental disabilities, and

**WHEREAS:** New York State in its haste to pursue these "alternative uses" has done so irrespective of their impact on the mentally retarded and developmentally disabled residents of such centers, and

**WHEREAS:** Such action on the part of the State inhumanely and unfairly places the burden of solving the State's most enormous and difficult crisis on the backs of some of its most vulnerable citizens, and

**WHEREAS:** Such action on the part of the State eliminates any possibility for the humane care or placement of those residents of centers that are affected, and

**WHEREAS:** In the face of such State actions, our Association recognizes the needs and rights of individuals for humane care and placement must supercede all other needs.

**NOW THEREFORE BE IT RESOLVED:** That the New York State Association for Retarded Children, Inc. calls upon the Governor, the Legislature and the Office of Mental Retardation and Developmental Disabilities to enact a State policy which sets the need to humanely care for and place all individuals from developmental centers above all other interests which the State may have at such centers.

### 16 APPRECIATION OF NYSARC STAFF

**WHEREAS:** The NYSARC annual convention continues to grow and expand to respond to the need and issues regarding persons with mental retardation/developmental disabilities, and

**WHEREAS:** NYSARC has a long-standing history of advocacy to ensure quality of life on behalf of persons with mental retardation/developmental disabilities, and

**WHEREAS:** At this 39th Annual Convention we once again have had the opportunity to exchange and discuss ideas and focus on priority issues, and

**WHEREAS:** If it were not for the tireless efforts of the NYSARC staff supporting the energies of our many volunteers, state and local Board members and delegates alike, we would not be in a position to impact the broader arena both on a state and federal level,

**NOW THEREFORE BE IT RESOLVED:** That at this 39th Annual Convention held at the Concord Resort Hotel in Kiamesha Lake, New York from November 3-6, 1988, we, the collective delegate body acknowledge and applaud our NYSARC staff members for once again spearheading, organizing and ensuring that our annual convention both in content and process has been a quantitative and enriching experience.

### 17 APPRECIATION TO DAVID B. LETTMAN

**WHEREAS:** David Lettman has served NYSARC as its President since 1983, and

**WHEREAS:** David has staunchly and consistently stood for our Association's fundamental belief that all persons with mental retardation must be accorded the rights and dignity which are their birthright as citizens of this country, and

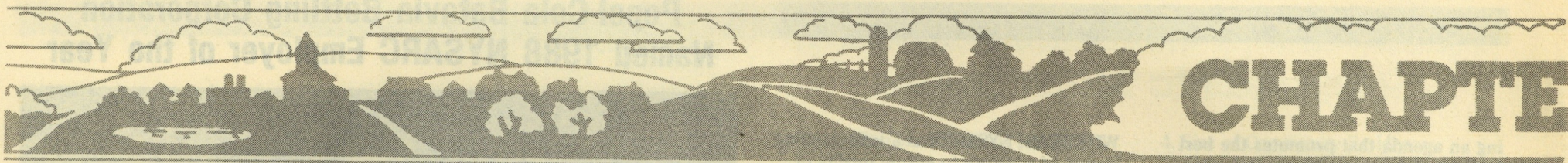
**WHEREAS:** David's leadership as an advocate has been instrumental in fostering the cohesiveness of our Association around a common set of values, and

**WHEREAS:** David has never hesitated to forcefully advance the views of our Association despite the efforts of powerful entities and individuals to subvert these views and aim to preclude them from the public-policy dialogue in the field of developmental disabilities, and

**WHEREAS:** David has performed his duties in an exemplary manner that has been a credit to our Association, and

**WHEREAS:** David, Marsha and their children have collectively taken upon themselves the responsibilities of David's presidency despite the enormous personal sacrifice which it has entailed over the course of the last five years.

**NOW THEREFORE BE IT RESOLVED:** That this entire Association recognizes the magnificent job David Lettman has performed as the President of this Association; and that we extend our heartfelt gratitude to David, Marsha and their children for their devotion, patience, persistence and sacrifice on behalf of our Association and all that it stands for. ■



## MADISON

### *Grant Funds Countywide Recycling Program*

The Madison County Chapter has received a \$600,000 HUD Grant for the construction of and equipment for a countywide Recycling Program. According to ARC's Project Coordinator, Ed Wool, "The ARC, in concert with County of Madison officials, is attempting to tackle the waste disposal crisis countywide."

The ARC will be managing, staffing and operating the recycling center for the County. Mike Hulland, Industrial Director of the ARC's workshop, Alternatives Industry, says, "It's a natural for our clientele. They've been trained to perform these jobs and I'm happy for them."

"It's no secret that perhaps the most critical issues facing us today are those of preserving our precarious habitat" says Ray Lewandowski, Executive Director. "Initially, 13 jobs will be created for the mentally retarded as a result of this grant. This grant represents a new beginning, an awakening of our efforts to maximize human resources in order to make the most of our environmental resources."

The project is currently in its initial stages — countywide legislative action to mandate recycling, meeting with haulers and building design. Operation of the recycling center manned with our clientele will begin in the Fall of 1989. ■

## CAYUGA

### *Last Quarter Brings Major Accomplishments*

As we approach the last quarter of 1988, Cayuga County ARC can look back on some major accomplishments their workshops and manufacturing departments have achieved. After two years, Comprehensive Training Center has run a successful industrial sewing program. Its work force, beginning with five people, five machines, has expanded to over twenty-five. Products sewn have been diversified from sewing mesh bags for onions, potatoes, etc. to disposable hospital gowns, pollution bags and silt fencing. CIC was awarded a JTPA grant in 1987 to provide industrial sewing training and support services.

Our newest contract line will be the production and bottling of a medicated shampoo for a Federal contract. Long and tedious hours have been applied to produce a shampoo that meets Federal specifications and Federal Drug Administration requirements. A specialized work area necessitating sterile conditions along with a 12 foot high mixing vat and an automatic liquid dispenser unit was built for it's production.

In the midst of all the activity, the manufacturing department contracted with New York State to provide dried vegetable packaging for several varieties of beans and peas. This required a purchase of an automatic dispenser system and a bag stitcher. ■

## CLINTON

### *Workshop Subcontracts with Plattsburgh Press-Republican*

Champlain Valley Industries (Sheltered Workshop, Clinton County A.R.C.) has sub-contracted with the Plattsburgh Press-Republican, effective October 5th, to do the pre-inserts for the Sunday edition of the Press. Many of the advertising and magazine "inserts" including TV update, comics and Parade Magazine in the Sunday Press-Republican have to be collated ahead of time. This contract employs a minimum

of twenty-two workers (clients) and two Work Area Supervisors for two to three days each week. Approximately 26,000 newspapers must be completed within those three days.

All workers and staff are enjoying the challenge and feelings of accomplishments of working at an off-site contract. ■



Champlain Valley Industries workers "pre-inserting" at the Press-Republican.

## SARATOGA

### *Saratoga ARC Enters the Horse-Care Business*

In this most equestrian part of the world, the Saratoga Association of Retarded Citizens is getting into the business of outfitting and caring for horses around the country.

With the opening of Saratoga Horseworks, the ARC will manufacture walking covers, stable sheets, exercise rugs, lead shanks and other equine-care products in the 10,000-square-foot Alpha Industries facility on Route 9 in Ballston Spa.

Saratoga Horseworks will employ 80 of 173 disabled adult workers at Alpha Industries. Ms. Cannon said the goal of the whole operation is to make money, to pour back into the company, which, she said, helps ARC gainfully employ people who might not otherwise have the chance to work. ■

**Equine Bandage** — A horse in training displays the "Saratoga Bandage", part of a line of equine gear manufactured by The Saratoga Horseworks off Route 9 in Ballston Spa. The company will employ 80 disabled adults and officials hope to teach them skills they can use in a job outside the supervision of the Association for Retarded Children. For this year, Saratoga Horseworks expects sales of \$90,000.

## SCHUYLER

### *Chapter Celebrates 10th Anniversary*

On September 14, 1988 the Schuyler County Chapter celebrated its 10th anniversary with a dinner attended by 125 guests at Seneca Lodge in Watkins Glen, New York. Senator John "Randy" Kuhl and Marc Brandt, Executive Director of NYSARC were guest speakers at the event.

James Wilson was honored for ten (10) years of service as the Executive Director of the Schuyler Chapter.

In other chapter news, Schuyler ARC has been awarded an Appalachian Regional Commission grant to sponsor and develop a Recycling/Training Center. Occupational training in solid waste collection and sorting and preparation of recyclables for reclamation will be the primary focus of the center.

The total project cost is \$66,538 and includes the purchase of equipment for the recycling center as well as training costs for the center's first year of operation. With New York State expected to mandate recycling, this program will be particularly valuable to the county and region.

The grant will supplement contracts the Chapter's Work Center has with the Villages of Montour Falls and Watkins Glen for curbside pickups and drop points for the collection of recyclable materials. ■



## CHEMUNG

### First Community Residence for Retirement-Age Clients

Chemung County ARC looks for a late spring opening for its newest community residence, a home in the country for clients who are of retirement age.

On August 30, the chapter purchased a new three-bedroom ranch home in a popular suburban area in northern Chemung county to accommodate 10 adults age 55 or older.

Situated in the hamlet of Pine Valley, the home is surrounded by wooded areas, farmland and a few neighboring properties. Off the dining-room/living-room area is a large deck overlooking lawn and trees. The surrounding locale: a growing residential area close to shopping, churches, hospitals, recreation facilities and varied day programs.

Just minutes away also are the Elmira College Domes, home of Soaring Eagle collegiate hockey and, during summer months, the Mark Twain Musical Drama.

Randy Denierio, Associate Executive director for Residential Programs, said the Chapter's primary goals for clients who live there are two-fold — integrating each individual into this new "retirement" environment and providing a pleasant home-like atmosphere where each can pursue his or her favorite pursuits.

Some clients who will be moving to work in the Chapter's sheltered workshop. They may want to retire completely or continue to work on a part-time basis, he said. Others, coming from the chapter's day program, have expressed the desire for activities that are more recreational and community-related. These, too, are in the works.

Another Chapter activity, clients in the Recreation Program spent September through November making holiday ornaments for a Festival of Trees display sponsored as a promotional fund-raiser for St. Joseph's Hospital in Elmira.

Individuals and businesses in the community were invited to sponsor a tree and have it professionally decorated (or handled as an in-house project). Late in November, the trees were set up in a downtown Mall and tickets sold to the public to show off the results. The decorated trees were then sold to the highest bidders with proceeds going to the hospital.

An anonymous donor outside our agency purchased a tree and paid for the materials for the Chapter's entry. Our theme of "Handi-crafters" was illustrated with hand-crafted designs from a variety of sources, including staff families.

This project offered us the opportunity to demonstrate in a new and different way some of the many contributions to the Chemung County community by people of all ages who are mentally retarded or developmentally disabled. ■

## COLUMBIA

### Day Services Expand

being a key player in the development of services in this only recently acknowledged area.

The Geriatric's Day Treatment Center is the latest program in COARC's rapidly expanding range of services. The Center is dedicated to opening new vistas for those individuals reaching their later years and the point of full retirement.

A team of seven COARC employees are working cooperatively with an O.D. Heck DDSO team. This takes the form of a

Social Recreational Program for the residents of two (SOCR) State Operated Community Residences located on the same property.

Quality of life is more than a philosophy. It is the catalyst for this program. Providing an environment that ensures the opportunity for personal growth, creativity, productivity, fulfillment, choices, options, hobbies, new friends and an array of other experiences is its hallmark. The goal most importantly is meaningful and stimulating activity. ■



**Evergreen Anniversary**

**Elizabeth Collins, 88, cuts a ribbon honoring the first anniversary and grand opening of Evergreen Hall Day Treatment Center on State Farm Road in Valatie. Collins is the oldest resident of the home. Looking on are: Lee Larson, Director of Day Treatment Services; Phyllis Howard, Program Director at Evergreen; Carol Anderson, COARC Executive Director, Clayton VanAlstyne, Kinderhook Town Supervisor; Helene DeSanto, Director of O.D. Heck; Larry Berg, Director of Human Services; James VanAlstyne, Commissioner of Department of Social Services; Harvey Whitbeck, COARC President, and Richard Bassett.**

## YATES

### "On The Road Again"

The third week of September saw participants of the Travel and Recreation Program "On The Road Again". Fifteen members of the Work Center and Day Treatment programs accompanied by four staff members spent three days enjoying the sights and activities of Toronto, Canada.

A visit to the Ontario Science Center, where visitors are encouraged to touch and participate in the exhibits, was one of the highlights of the trip. The travelers enjoyed operating the exhibits. One of the favorite exhibits was the automobile simulator, which tested reaction times. Another was the image maker, which could bring up on a screen multiple images of one person or object.

Another highlight was a night baseball game at Exhibition Stadium where we watched the Toronto Blue Jays beat the Boston Red Sox 1-0. Everyone enjoyed the dinner-theater presentation of "A Little Night Magic", one of the longest running shows in Toronto. The magic continued the next evening for dinner at "The Organ Grinder", a restaurant which features an

old-time theater organ. Diners are treated to musical entertainment and are encouraged to join in a sing-along. We had a very enthusiastic group. Many enjoyed shopping in Eaton Center and the adventure of riding on the subway.

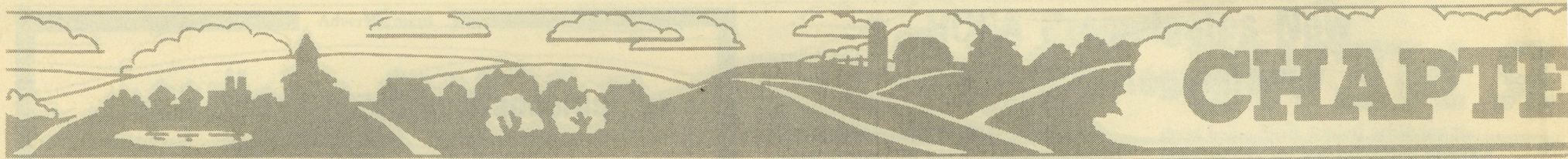
A stop at the African Lion Safari was a feature of the trip back home. Everyone enjoyed the opportunity to see many large and beautiful animals in their "natural"

environment. The monkeys proved to be very curious about the vehicle and created much amusement among the passengers. The monkeys, in turn, were fascinated by the vehicle's reflectors and removed every one of them!

All returned home from this trip a little tired, but happy. The very exciting itinerary was planned with the help and advice of K-Ventures, a charter bus company in Penn Yan. ■



**The Travel/Recreation Group from Yates County at the Ontario Science Museum, Toronto, Canada.**



## ALBANY

### *Construction of New Facility Begins*

On September 20, 1988, the Albany County Chapter, New York State Association for Retarded Children, Inc. conducted their groundbreaking ceremony to mark the start of the construction of their new facility which will house their Day Treatment and Day Training Programs and the administrative offices. The ceremony was held at the building site located at the

junction of Krumkill and Blessing Roads, Town of Bethlehem, County of Albany.

The anticipated opening date is for September of 1989. Three hundred and fifty men and women from Albany County will be receiving specialized services in the Day Treatment and Day Training Programs. ■



Left to right: Richard Minogue, Executive Director, Clinton County Chapter; Lester Parker, Executive Director, Franklin County Chapter; Marc N. Brandt, Executive Director, NYSARC, Inc.; Richard L. Laurin; Richard Oliver, Executive Director, Jefferson County Chapter; John Bryant, Senior Vice President, Central Region, NYSARC, Inc. (Photo by Burns of Ogdensburg, New York).

## WARREN/WASHINGTON

### *Chapter Expands Family Support Services*

The Warren-Washington Association for Retarded Citizens expanded many family support services this year. March 1st marked the opening of our Respite Center and to date over 100 families in the community have benefited. Currently services are provided on a "drop in" basis in addition to weekend and overnight respite.

A Parents' Support Group has been formed to give parents and professionals a chance to informally share experiences and information. The summer camp program was expanded to a three-week session which provided varied recreational experiences for 40 developmentally disabled children. In addition, the Warren/Washington ARC and Rainbow Valley jointly sponsored four two-day overnight camping experiences. The ranch located in Stony Creek provided the perfect setting for swimming, hiking, fishing, campfire sing-a-longs and horseback riding.

Long-range goals for additional family support services include expansion of free-standing respite to a seven day per week, seven bed program and relocation of the center to a new site that would accommodate this growth; the development of a service oriented program for individuals with developmental disabilities who are or become involved with the criminal justice system; and expansion of the summer camp program to provide services for fifty children over a six-week period. ■

## COMMUNITY LEAGUE

### *Wassaic D.C. Chapter Presents Four Performances of Royal Hanneford Circus*

The Wassaic Chapter of Community League presented four performances of the Royal Hanneford Circus on September 10th and 11th at Wassaic Developmental Center.

Over 5,000 people attended the four shows, including a large number of people from the community and parents of the clients residing at Wassaic Developmental Center. Most of the clients residing at Wassaic attended at least one of the four shows — many came back for more! For those clients who could not attend the circus there were several clowns who visited each of the buildings and performed for the clients. This was the first major circus to perform at Wassaic and the event was enjoyable for all who participated. ■

## ONONDAGA

### *Educational Program Moves to Integrated Setting*

Parkside School, the educational division of the Onondaga ARC, has moved from 600 S. Wilbur Avenue, the site of the OARC's headquarters, to a new location with more space and opportunities for interaction between the Parkside students and typical children.

Parkside, which serves 50 preschoolers and 30 infants with special needs, is sharing its new building with Learn As You Grow, a daycare/nursery program for typical children 18 months of age or older. Those children and the Parkside students will interact on the playground, in the hallways and during visits to each other's classrooms.

Most of the interaction will be between Parkside's preschoolers and the Learn As You Grow students, but there also will be some opportunities for integration of the infants who attend Parkside's in-house program. ■

## ONTARIO

### *Ontario ARC Starts "Whole Family Approach"*

Ontario County ARC recently initiated its "Whole Family Approach" to its Parent Group program, with the addition of a Sibling Group and a Respite/Recreation component. Twice each month, these groups meet simultaneously, offering the entire family element an opportunity to meet with peers to discuss similar concerns and problems.

The Sibling Group will offer school-age brothers and sisters the opportunity to meet one another and through the use of films, discussions, role playing and field trips; encourage the "sibs" to exchange feelings and experiences in an atmosphere of fun and support.

The Respite/Recreation component, meeting separately, will offer movies, games and other activities for the handicapped brother or sister. RN Respite is available for medically involved children.

The Parent Group will continue to meet and emphasize its dual focus of educational presentations related to the diverse interests of parents and peer support in times of need and every day. ■

## FRANKLIN

### *Franklin ARC Doubles Respite Program for 1989*

The Franklin County Chapter of the Association for Retarded Children obtained a grant through Sunmount DDSO this past year to develop a voucher-based respite program for families with a disabled child at home. The idea behind this model is to give the family complete control over the time, location and respite provider, as well as over the content of activities and services.

The worker is selected and supervised by the family. (The only constraint is that immediate family members do not qualify for reimbursement.) Franklin ARC sets aside a dollar amount to be used for each qualifying child. After approved hours are used, voucher forms are turned into the agency. The respite worker then receives payment directly from the ARC, up to the allowed hourly and total limit.

The initial grant of four thousand dollars was expended to about nine thousand

dollars for 1988, intended to provide assistance to at least sixteen participants.

In fact, the ARC has been able to sign up twenty-four families so far, with allocations of at least \$250 per eligible child. Some have received more, and there is room for more to join the program before the end of 1988.

For 1989, the state has substantially increased the combined respite grants available in Franklin County. By the end of next year the local ARC hopes to:

- increase the allocation per family to at least \$400
- double the number of families served
- develop better channels to unserved families
- improve assistance to families in obtaining services.

## JEFFERSON

### *JRC Receives Grant from Champion Corporation*

The Jefferson Rehabilitation Center, Chapter of the New York State Association for Retarded Children, Inc. is a recent recipient of a grant from Champion's Deferiet Fund for Community Service.

The check, presented by committee members, Jack Louthain (Chairman) and Angelo Soluri, has been used to purchase a software package for the agencies vocational evaluation unit. The agency has recently put in place, the Valpar System, an extensive vocational evaluation system which can be utilized by all populations.

The new software provides the capability to print out a personalized list of career and vocational options based on the information gathered during an extensive evaluation process. While the system is used for JRC clients, other businesses and organizations in the community (non-handicapped) are taking advantage of the evaluation process for their clients as well. ■

## NASSAU



There was special activity in all the chapters during the holidays. At the Nassau chapter's Vocational Training Centers clients in the food service program prepared festive meals.

## MONTGOMERY

### Chapter Formally Breaks Ground for New Day Treatment Building

On September 26, the Montgomery County Chapter formally broke ground on its new Day Treatment Center on Route 5-S, Amsterdam. This project will be bonded through the Dormitory Authority of the State of New York as part of \$12,000,000 joint issuance with the Albany and Rensselaer Chapters.

The new facility will house 135 severely handicapped individuals, some of whom are presently served at the agency's existing sites in the former Tribes Hill School and

at Liberty Enterprises. The 34,944 square foot building, designed by Cullen Associates of Schenectady, consists mainly of program and therapy rooms, but will also provide space for clinical staff and Residential Services administration. It will be constructed on a site immediately West of the Liberty Enterprises building on Route 5-S.

Construction on the new facility is slated to begin the first week of November, with completion anticipated for Fall, 1989. ■



Montgomery ARC Day Treatment Groundbreaking. Pictured left to right - Richard Bala, Supervisor 5th Ward; Paul Parillo, Mayor of the City of Amsterdam; Senator Hugh Farley; Frances Gargiulo, President, Montgomery County ARC; Assemblyman Paul Tonko, 105th Assembly District; Frank Capone, Executive Director, Montgomery ARC and Dan Donohue, Director of Wilton Developmental Center.

## ST. LAWRENCE

### Center of ARC Officially Named - Bears Name of Executive Director

The St. Lawrence County Chapter of the New York Association for Retarded Children, Inc. named its newest facility after its Executive Director, Richard L. Laurin, during a special ceremony on September 23, 1988.

Members of the Association and sister organizations from across the state gathered at the Gran-View Restaurant to pay tribute to Mr. Laurin, a 20-year veteran of the County ARC.

The highlight of the "surprise party" was a dedication ceremony naming the South-

west Facility on Commerce Lane, Canton, the Richard L. Laurin Center.

The \$2 million facility is the cornerstone of the ARC's activities in the county, providing day services for mentally handicapped adults and will be complete in January, 1989.

ARC Board President, Patricia A. Campanella, explained while Mr. Laurin, 53, is not retiring, the Board felt it was time he was honored for his 20 years of service. ■



Left to right: Richard Minogue, Executive Director, Clinton County Chapter; Lester Parker, Executive Director, Franklin County Chapter; Marc N. Brandt, Executive Director, NYSARC, Inc.; Richard L. Laurin; Richard Oliver, Executive Director, Jefferson County Chapter; John Bryant, Senior Vice President, Central Region, NYSARC, Inc. (Photo by Burns of Ogdensburg, New York).

## ULSTER

### Ulster Chapter Receives Grant to Purchase Diesel Truck

The Ulster Association for Retarded Citizens has received a grant in the amount of \$20,000 from the office of Senator Richard E. Schermerhorn, it was announced by UARC Executive Director, Peter Pierri.

The grant, from Member Item funds, helped purchase a 1988 International diesel truck, to be used by the agency's Pilot Industries Sheltered Workshop. The truck replaces a 1974 model which had over 600,000 miles recorded.

Approximately 90% of the Pilot Industries contracts are from firms located in the New York, New Jersey, Long Island

Metropolitan area, as well as Connecticut and the Hudson Valley. The trucks owned by the agency travel over 55,000 miles a year each to service their accounts.

The Pilot Industries Workshop program of the UARC is a vocational rehabilitation program that helps teach retarded adults work skills. Pilot Industries, which is located in Kingston and Ellenville, currently provides services to 340 handicapped workers.

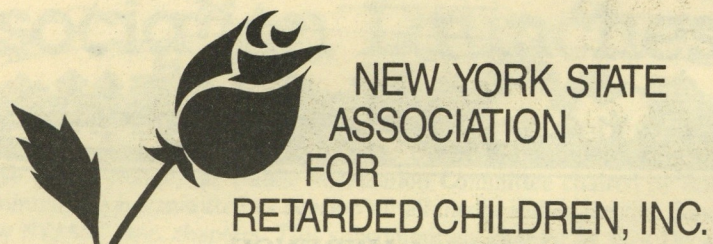
Pierri noted his appreciation for Senator Schermerhorn's commitment to UARC's clients and his support of its work. ■

## ROCKLAND

After three years of careful planning and hard work, Rockland ARC's Director of Residential Services, Ellie Schnell, welcomed fourteen happy people to their spacious new home in New City. With eight residents from the community and six residents from Letchworth Developmental Center, the nine bedroom Muller Court Community Residence opened its doors on October 12th. Everyone's life is very busy with nine people employed at ARC Enterprises, four

people in Supported Work and one person competitively employed with follow along services.

Ms. Schnell recently visited the home during dinner and observed that "watching everyone sitting together at the table conversing about their day and evening plans made it clear that the homelike environment our staff had envisioned during the long preparation process had come to fruition." ■

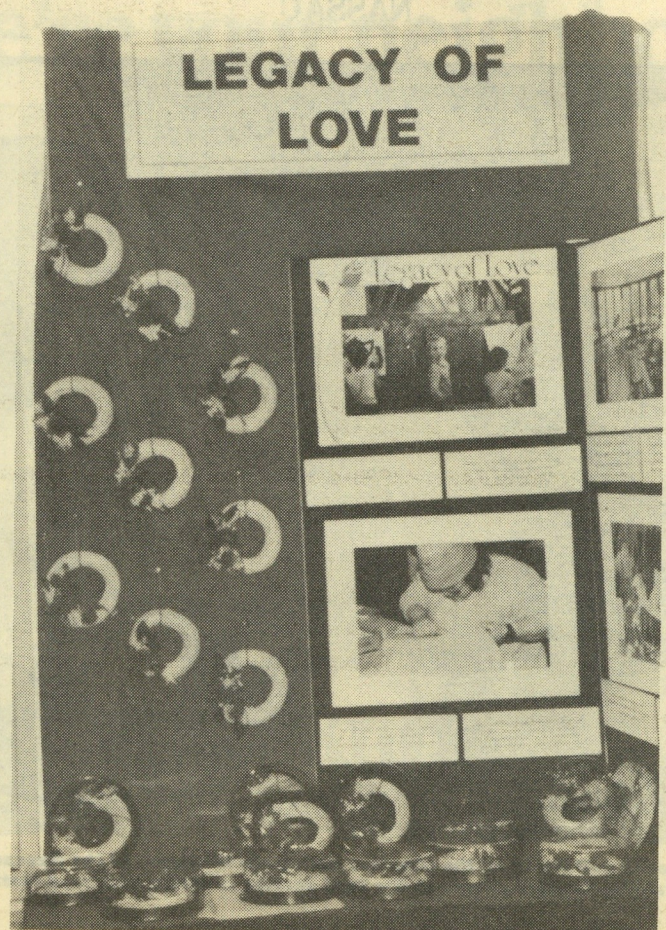


# Legacy of Love

1988 NYSARC AWARENESS WEEK  
FEBRUARY 7-14



## Third Annual "Legacy of Love" Valentine Promotion



### ROCKLAND ARC EMPLOYEE 1989 CONVENTION LOGO COMPETITION WINNER

Mary Ellen Reichard, Principle Account Clerk for the Rockland County Chapter was voted as the winner for her convention design which was recently displayed at NYSARC's 1988 Convention held at the Concord Resort Hotel in Kiamesha Lake, New York.

Mary Ellen was an art major at the School of Visual Arts in Manhattan and had taught arts and crafts classes to adults with disabilities.

The contest sponsored by the NYSARC Public Information Committee offers employees, persons in ARC programs, parents and chapter members an opportunity to be a part of the NYSARC Convention by creating a design that will express graphically the Convention theme and the contribution which NYSARC has made in improving the lives and services offered to persons with mental retardation.

As the winner, Mary Ellen will be the NYSARC's guest for a day at the 1989 Convention and at that time will receive a \$100 U.S. Savings Bond.

Congratulations Mary Ellen! ■



# NYSARC

# ATTENTION: Parents of School-Age Children with Handicaps!

The attached survey is being conducted by the New York State Commission on Quality of Care to obtain important information on the quality of special education programs for school-age children (5 to 21) with handicaps.

The survey may be completed in approximately ten (10) minutes and should be returned by January 15, 1989.

(1:1=1; 2-7= \_\_\_\_\_ )

## SPECIAL EDUCATION SURVEY FOR PARENTS

8-9/ 1. How old is your child? \_\_\_\_\_ years [Note: If you have more than one child with a handicapping condition, please fill out this survey for one of your children only]

2. How did the Committee on Special Education (CSE) classify your child's handicapping condition? (If "multiply handicapped," check all handicapping conditions that apply to your child, in addition to "multiply handicapped.")

- |                            |                                  |                                |
|----------------------------|----------------------------------|--------------------------------|
| 10 _____ don't know        | 14 _____ multiply handicapped    | 18 _____ autistic              |
| 11 _____ learning disabled | 15 _____ speech impaired         | 19 _____ deaf                  |
| 12 _____ mentally retarded | 16 _____ emotionally disturbed   | 20 _____ visually impaired     |
| 13 _____ hard of hearing   | 17 _____ orthopedically impaired | 21 _____ other health impaired |

3. What school does your child attend?

Name \_\_\_\_\_  
City/Town \_\_\_\_\_  
School District \_\_\_\_\_

4. Approximately how many minutes does your child spend traveling to and from his school program each day?  
\_\_\_\_\_ minutes

5. Where does your child receive his/her education? (Check all that apply)

- 32 \_\_\_\_\_ regular class (class in local public school with non-handicapped children)  
33 \_\_\_\_\_ resource room (supplementary instruction for at least three hours a week)  
34 \_\_\_\_\_ special class in home district's public school (self-contained class of special education students)  
35 \_\_\_\_\_ special class in other district's public school  
36 \_\_\_\_\_ BOCES Center  
37 \_\_\_\_\_ private day school  
38 \_\_\_\_\_ hospital  
39 \_\_\_\_\_ at home  
40 \_\_\_\_\_ does not presently attend *any* educational program  
41 \_\_\_\_\_ live-in/residential placement, public or private  
42 \_\_\_\_\_ correctional facility  
43 \_\_\_\_\_ other (specify) \_\_\_\_\_

6. If your child ever had a problem attending any educational program, please indicate why.

- 44/ 1 \_\_\_\_\_ placement not available  
2 \_\_\_\_\_ disagreement with school district about placement  
3 \_\_\_\_\_ child suspended and tutoring not provided  
4 \_\_\_\_\_ other (specify) \_\_\_\_\_

7. On a scale from 1 (low satisfaction) to 5 (high satisfaction), how satisfied are you with your child's school program? (Circle one only)

45/ 1                      2                      3                      4                      5  
Very                      Neutral                      Very  
Dissatisfied                      Satisfied

8. If you are not completely satisfied with your child's school program, why not? (Check all that apply)

- 46 \_\_\_\_\_ too much traveling involved  
47 \_\_\_\_\_ not enough time spent with non-handicapped children  
48 \_\_\_\_\_ child is ridiculed by non-handicapped children  
49 \_\_\_\_\_ teacher is not trained enough to deal with your child's handicapping condition  
50 \_\_\_\_\_ not enough provisions for personal attention/education  
51 \_\_\_\_\_ not enough support services (e.g., aide, interpreter, consultant, etc.)  
52 \_\_\_\_\_ classes too large  
53 \_\_\_\_\_ other (specify) \_\_\_\_\_

Please Detach These Pages and Send to:

New York State Commission on Quality of Care for the Mentally Disabled  
99 Washington Avenue, Suite 1002  
Albany, New York 12210  
ATTN: Special Education Survey

9. What would be your choice for your child's school setting? (Check all that apply)

- |  |                                |
|--|--------------------------------|
| 54 _____ regular class                                   | 60 _____ private day school    |
| 55 _____ special class in home district's public school  | 61 _____ hospital              |
| 56 _____ special class in other district's public school | 62 _____ at home               |
| 57 _____ BOCES Center                                    | 63 _____ correctional facility |
| 58 _____ live-in/residential setting, public or private  | 64 _____ other (specify) _____ |
| 59 _____ resource room                                   |                                |

10. Which of the following meetings regarding your child's Individualized Education Program (IEP) did you attend? (Check all that apply)

- 65 \_\_\_\_\_ meeting (IEP Phase I) with the Committee on Special Education (CSE)  
66 \_\_\_\_\_ planning conference (IEP Phase II) with the teacher to develop IEP recommendation  
67 \_\_\_\_\_ neither

11. If you did not attend any of the meetings, why not? (Check all that apply)

- 68 \_\_\_\_\_ not informed of a meeting  
69 \_\_\_\_\_ time of meeting was inconvenient  
70 \_\_\_\_\_ have confidence in the opinion/decision of the Committee on Special Education (CSE)/teacher  
71 \_\_\_\_\_ no transportation to get to meeting  
72 \_\_\_\_\_ other (specify) \_\_\_\_\_

12. Please indicate the amount of interaction your child has with non-handicapped children in academic programs (e.g., English, Math, Social Studies, Shop, Home Economics, etc.)

73/ 1 \_\_\_\_\_ no interaction    2 \_\_\_\_\_ some interaction    3 \_\_\_\_\_ full interaction    4 \_\_\_\_\_ don't know

13. On a scale from 1 (low satisfaction) to 5 (high satisfaction), how satisfied are you with the amount of interaction your child has with non-handicapped children in academic programs? (Circle one only)

74/ 1                      2                      3                      4                      5  
Very                      Neutral                      Very  
Dissatisfied                      Satisfied

14. Please indicate the amount of interaction your child has with non-handicapped children in social activities (e.g., cafeteria, field trips, etc.)

75/ 1 \_\_\_\_\_ no interaction    2 \_\_\_\_\_ some interaction    3 \_\_\_\_\_ full interaction    4 \_\_\_\_\_ don't know

15. On a scale from 1 (low satisfaction) to 5 (high satisfaction), how satisfied are you with the amount of interaction your child has with non-handicapped children in social activities? (Circle one only)

76/ 1                      2                      3                      4                      5  
Very                      Neutral                      Very  
Dissatisfied                      Satisfied

(2:1=2; 2-7=1:2-7)

16. Please check (1) the services RECOMMENDED for your child, and (2) the services PRESENTLY NOT PROVIDED to your child.

### RECOMMENDED SERVICES

8-9/ \_\_\_\_\_

aide

10-11/ \_\_\_\_\_

interpreter

12-13/ \_\_\_\_\_

consultant teacher

14-15/ \_\_\_\_\_

speech therapy

16-17/ \_\_\_\_\_

audiology

18-19/ \_\_\_\_\_

psychological services

20-21/ \_\_\_\_\_

physical therapy

22-23/ \_\_\_\_\_

occupational therapy

24-25/ \_\_\_\_\_

counseling services

26-27/ \_\_\_\_\_

school health services

28-29/ \_\_\_\_\_

school social work

30-31/ \_\_\_\_\_

medical services

32-33/ \_\_\_\_\_

other (specify) \_\_\_\_\_

### PRESENTLY NOT PROVIDED

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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