

# Our Children's Voice

Retarded Children Can Be Helped

VOL. XXXIV NO. 3

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

SEPTEMBER 1982

## President's Column

### "The best of times; the worst of times"

by Eleanor Pattison

"It was the best of times, it was  
the worst of times —"

Charles Dickens: 1859

TALE OF TWO CITIES

Some classic quotes are a perfect and timeless description for both past and present. Dickens has provided us with just such a description for the last few months in the life of NYSARC.

The confirmation of Marc Brandt as the new Executive Director, and his subsequent arrival at State Office in July, indicates we are indeed in the "best times" once again. Even in a short period of involvement, Marc has exhibited the insight and leadership predicted by his unanimous endorsement. Gerry Sherwood, Don Westervelt and others on staff have labored to ease the transition, and have continued to be supportive above and beyond the call of duty.

Legislatively, we have weathered the trauma of highs and lows involving state budget that culminated in the majority of gubernatorial vetoes being overridden by the State Legislature. There is "no dancing on the tables", however, because the minimal victories we achieved have only lightened the load of fiscal problems, not eliminated them.

One of our biggest battles, that of achieving an extension of time for the finalization of HUD projects for the construction, by a number of our chapters, of barrier-free community residences for adults with special needs, was won through the efforts of many advocates. The chapters themselves responded admirably by sending documentation to State Office for our use, as well as working overtime at local levels with appropriate governmental officials. Of special note are the efforts of Congressman Stanley Lundine, who chairs the critical subcommittee in Washington, D.C. dealing with such issues. Members of his staff, in

concert with Joni Fritz, Executive Director of the National Association of Community Residence Administrators, were invaluable advocates on our behalf at the Federal level.

On the State Government level, one person is a shining star. That person is Helen Forman of the Facilities Development Corporation. Without her comprehensive understanding of issues and her bull-dog tenacity, implementation of steps necessary for completion never would have been accomplished! Thank goodness for good friends whose beliefs are in tune with ours when it comes to the mitty-gritty of human service. Although we have not completely finished with the mountain of red-tape this project has generated, it looks as if final success will be the well earned reward.

As usual, no sooner have we engaged in one battle, before another begins! Through our membership in the Legislative Coalition for the Disabled, it became evident that denial of Supplementary Security Income (SSI) that is the base of support for the majority of the adults who live in ARC sponsored community residences, and thusly a major part of the fiscal solvency of that program, was widespread throughout all levels of disability. Once again, our chapters responded to a request for documentation from State Office. The weight of evidence has been put to good use by Congressman Tom Towney at public hearings in the downstate area, with the intention of producing more responsiveness from regulatory agencies.

This report, more detailed than usual, serves a specific purpose. It is obvious we are in an era when we must select our causes carefully and broaden the circle of advocates who support those causes. Parochialism has no place in our future. There is too much at stake to stand alone.

## From your Executive Director

It is with a great deal of excitement and enthusiasm that I have officially begun to take on the responsibilities of the executive directorship of the NYSARC. I wish to personally thank all of you for your good wishes. I am eagerly looking forward to working with all of you, in what I envision as a close, honest relationship.

The staff of 175 Fifth Avenue have been most receptive and are making my transition easier than expected.

Since my appointment was confirmed at the May Board of Governors meeting in Albany, I have had the opportunity to visit with a number of chapters. I look upon these visitations as one of the most important priorities of my position and hope to be as visible and available to our chapters as my schedule permits and as you desire.

Although there are many problems chapters are having individually as well as a host of situations affecting us collectively, I am attempting to establish

realistic priorities and to set objectives that will be in the best interest of our state organization. In regard to this, I have had the opportunity to meet with the Executive Committee and have presented, for their review, a job description for the position of Executive Director of the NYSARC as well as a draft of short term priorities. With the guidance and input from our Executive Committee, I hope these priorities will become immediate goals and objectives for me and the staff of State ARC. When the Executive Committee reviews and finalizes these priorities, we will formalize them and request your comments so that, together, we will have a realistic understanding of our direction.

Obviously, advocating for the rights of mentally retarded shall be foremost and will take precedence over any individual problem or difficulty we may be facing. We are currently facing a number of situations which clearly call for our strong

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## Marc Brandt new State ARC Executive Director

The Board of Governors of the New York State Association for Retarded Children, Inc. unanimously appointed Marc N. Brandt, to serve as the Executive Director of the State association. Mr. Brandt began duties on July 1, 1982.

Mr. Brandt has served as the Executive Director of the Sullivan County Chapter of NYSARC since 1971. Prior to that, Mr. Brandt served as Headmaster and Director of Special Education at the Beaumont Residential School in Liberty. He holds a Master's Degree in Special Education and Industrial Psychology, and has worked in a variety of settings including the New York City Board of Education - Special Education Department.

By appointment of Governor Carey, Mr. Brandt serves on both the Fee-for-Service Provider Council (of which he is currently chairman) and the Day Training Program Provider Council. He has served as State Chairman, and as Mid-Hudson Regional Chair of the NYSARC Executive Directors Association.

Additional recognition of Mr. Brandt's professional expertise in the fields of mental retardation and mental health is evidenced in the many appointments he has received over the years, including service by appointment of Governor Carey on the Board of Visitors of Middletown Psychiatric Center, and his numerous voluntary contributions to social and civic projects.

Mr. Brandt's commitment to service and involvement in community affairs is

evident in his four-year tenure as Councilman for the Town of Liberty, and his various leadership roles on the Liberty Central School Board, Lions Club and Council of Arts where he has initiated and participated in numerous community and civic projects.

Currently, Mr. Brandt serves as a member of the Sullivan County Community Services Board, is chairman of the Sullivan Council Planning Committee on Mental Retardation and Developmental Disabilities, and Board Member of the New York State Association of Rehabilitation Facilities. In addition, he has served as Chairman of the Sullivan County Council of Social Agencies, as Advisor on Public Law 87-313 to the New York State Department of Education, and as Educational Consultant for the Sullivan County Full-Year Headstart and VISTA Program in Washington.

It is the intention of Mr. Brandt to provide technical assistance to each of the 63 chapters of NYSARC, and to continue Association efforts to provide advocacy and to strengthen legislation promoting the rights of those who are mentally retarded. His plans call for stronger utilization of professional staff employed at the chapter level, and broader training programs for local Board of Directors. Mr. Brandt will also be directing his efforts toward assisting parents assume a more active role in the Association, and hopes that through his leadership, the overall philosophy of the parent organization will be strengthened.



## Niagara Falls to be site of 1982 ARC Convention

We at the Niagara County Chapter ARC are very excited as we make plans for the New York State Association for Retarded Children 1982 Annual Convention October 7 through 10. We are certain all who come from out of town will be most impressed with the Niagara Falls and surrounding areas. The location for the Convention will be the Niagara Hilton Hotel. Special features and attractions located in the Niagara Hilton Hotel are:

- CAPTAIN JACKS — Entertainment, dancing, the place to be at night!
- SIDNEY'S — A most pleasant dining experience.
- PALM COURT — Indoor swimming, food and beverage service, in a tropical garden setting.
- EXERCISE ROOM AND SAUNAS — Shape up, slim down, relax and enjoy!
- DOCTOR HAIR SALON — The finest innovative hair cutting team for men and women.

In walking distance from the Niagara Hilton, enjoy these fabulous places!

- NIAGARA FALLS — A genuine awe inspiring Wonder!
- E. DENT LACKY PLAZA — Hub of downtown Niagara Falls.
- WINTER GARDEN MALL — Enclosed walkway from Plaza to Falls.
- WINTERGARDEN — Glass enclosed, year round tropical park. Just beautiful!
- RAINBOW MALL — Brand New! Enjoy the just recently constructed stores, a variety of restaurants (Greek, Italian, Japanese, Chinese, etc. . .), and pubs.
- THE TURTLE — Native American Art and history of the North American Indian.
- J.P. MORGANS — Excellent food and drinking emporium. Dancing and entertainment right across the street from the Hilton.

Just a five minute drive from the Hilton, you can visit these exciting places in Canada!

- RIPLEY'S BELIEVE IT OR NOT MUSEUM
- NIAGARA FALLS MUSEUM — North America's Oldest Museum!
- MAPLE LEAF VILLAGE — Right across the border. You can even walk! Enjoy the many stores, restaurants, pubs, and amusement rides!
- CLIFTON HILL — Take a walk down Clifton Hill and enjoy the bright lights of the Falls, the shops, restaurants, museums, and boutiques. And don't forget, Canada has beautiful English Bone China! You may even save money on the American - Canadian exchange in currency.
- SKYLON TOWER — Have a dinner or drink on the world famous Skylon Tower. Enjoy the revolving ballroom hundreds of feet above ground while viewing the Falls from every angle!

Additionally,

- You must visit the Gayboy Club, located at the Executive Inn in Buffalo right across from the Buffalo Airport.
- Did you know that Toronto is a one and one-half hour ride from the Hilton?
- Niagara Falls is well-known for fantastic Italian foods and don't forget to try the "Buffalo Chicken-Wings".
- Take a ride on the MAID OF THE MIST. The feel of the mist, the powerful roar, the breathtaking sight of the thundering water falling from above — the most exciting way to see Niagara Falls is aboard the world famous MAID OF THE MIST boat. . .

. . . And much, much more. We can go on writing forever. In summary, there are many things to see and do during your visit to Niagara Falls October 7-10 for the Convention. The Hilton Hotel offers many tours to the places mentioned. We look forward to an exciting Convention!

## Humanitarian Awards



Monsignor Cribbin and the Honorable Stanley Simon, each receiving the Humanitarian Award for Public Service are shown with (L to R) Michael Goldfarb, I. William Stone, Arnold Diaz, Eleanor Pattison and Walter C. Redfield.

### First award to Orange



Inga Travis

Inga Travis was honored and awarded the 1981-82 Residential Services award by the New York State Association of Community Residence Administrators (NYSARCA). NYSARCA is made up of directors of Residential programs for the mentally retarded from all over New York State. There are now about 700 community residences in New York State providing homes for approximately 7,000 people with Mental Retardation.

Inga Travis received her award at a dinner in Albany. The award is to be given annually to an outstanding direct care staff working with the mentally retarded in a community residence in New York State. Inga is the first person to receive this award.

Inga began her involvement with the Orange County Association for the Help of Retarded Children in 1971 as a volunteer in the summer program. She was honored at the Annual Conference of NYSARCA held in Albany attended by over 300 people. The award which was presented to Inga reads:

"New York State Association of Community Residence Administrators 1981-1982 Residential Services Award presented to Inga Travis, Orange County Chapter, New York State Association for Retarded Children, Inc., for outstanding dedication on behalf of the developmentally disabled living in community residences. 1982 Conference on Community Residence."

The Orange County Association for the Help of Retarded Children is grateful to Inga for her contributions to their program and for the lasting contribution she has made to the residents who have lived with her at the Newburgh Community Residence.

## Executive Director

Continued from Page 1

commitment to advocate for the mentally retarded. There are numerous issues challenging our role, and are striking even at the very heart of our philosophy and commitment. In this regard, I wish to report to you that your Executive and Institution Committees have recently met and are assuming a strong posture in response to the Governor's plan for the co-location of a medium - security prison on the grounds of Craig Developmental Center. We have, on behalf of the mentally retarded who reside at Craig, sent telegrams to the Governor and to the Commissioners of Corrections and Mental Retardation, stating our concern and assuring that further action will be taken by our association should the co-location occur.

I hope that, within the coming weeks as our state office redefines and reestablishes its role, we will be prepared to respond to our chapters and their needs. I am personally gratified by the excitement and cooperation I am receiving from our State ARC staff as well as from the many letters of support and constructive suggestions from the professional staff of our chapters. I look forward to establishing a Technical Assistance Team, employing the skills of our chapter staffs, to assist in those areas of agency functioning in which all of us experience difficulties from time to time. I believe we employ in our midst one of the most professional, dedicated groups of individuals, possessing competencies and abilities that are not being fully stimulated or challenged on behalf of the mentally retarded whom we serve. With your support, I look forward, in the coming

weeks, to develop this talent for our collective needs.

I recognize that our Chapter board members and Board of Governor Representatives have many different views concerning our State ARC and, on any given issue, have philosophical differences. I have aspired to this position, however, because the common thread that ties us together is our true commitment to serve the mentally retarded and to advocate with them so that they may have their rights secured today and for tomorrow. To this end, my strongest ongoing priority will be to carry out the initial intentions and purposes of those parents who, in the late 1940's-early 1950's, had the vision and courage to establish NYSARCA.

Let me take this opportunity to thank each of you for your words, feelings, and kind thoughts as I assume my new responsibilities. My one hope and main goal is that I may truly serve our association and be the effective Executive Director each one of you seeks, and to be a strong advocate for those whom we have chosen to serve. It's nice to be with you.

**NIAGARA FALLS,  
HERE WE COME.  
OCTOBER 7-10**

# Our Children's Voice

Retarded Children Can Be Helped

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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## Healthy mothers; healthy babies

Increasing awareness among pregnant women of the importance of good health for themselves and their unborn babies is the goal of "Healthy Mothers, Healthy Babies," a campaign launched by a coalition of national voluntary, professional and government organizations with a commitment to maternal and infant health.

Sponsored initially by six organizations — the American Academy of Pediatrics,

American College of Obstetricians and Gynecologists, American Nurses Association, March of Dimes, Parent Teachers Association and the U.S. Public Health Service, DHHS — the coalition now includes more than 40 national organizations. Among its members are the American Public Health Association, Child Welfare League of America, Future Homemakers of America, Planned Parenthood Federation of America, the Salvation Army and the U.S. Department of Agriculture.

The coalition publishes a quarterly newsletter and is preparing a directory of educational materials on prenatal and infant care for pregnant women and teenagers, parents and professionals. The Public Health Service and March of Dimes have produced radio spots, narrated by Surgeon General C. Everett Koop, giving advice on a variety of topics important to good health during pregnancy. Local March of Dimes affiliates delivered the spots to radio stations in April and May.

Organizations that have a special interest in maternal and infant health, and that have a structure of state and/or local affiliates or other types of networks to reach members at local, regional or state levels, are invited to participate in the coalition. Application forms and additional information may be obtained from Elaine Bratic, Office of Public Affairs, U.S. Public Health Service, DHHS, 200 Independence Avenue, S.W., Room 740-G, Washington, D.C. 20201.

## Federal agencies to withhold aid data

The Reagan Administration has decided to make it a little more difficult to find out where all that federal money is going around the country.

Deputy Budget Director Edwin L. Carpenter has ordered federal agencies to stop compiling and publishing information on how many federal dollars are going to which county under each program.

The compilation, which enabled members of Congress to gauge what they considered the fairness or unfairness of how federal money was ladled out, had been made by the now-defunct Community Services Administration.

It was first published in 1968.

It had formed the basis for Sen. Daniel P. Moynihan's annual report to New Yorkers on how they were faring on the distribution of federal funds compared with other states. The breakdowns, however, went farther and showed funding for each county, as well as for key communities, like Watertown, in many counties.

Senator Moynihan observed wryly, "If you don't have the information you can't complain about the income."

Thirteen Democratic senators, including Mr. Moynihan, and one Republican, Minnesota's David Durenberger, have introduced a bill establishing a system for collecting data on geographic distribution of federal funds.

Sen. James Sasser, D-Tenn., one of the main sponsors, says there "must be 'truth in packaging' for (President Reagan's) New Federalism."

Mr. Harper ordered the collection of data halted "immediately" on Dec. 14. The General Accounting Office (GAO), however, said on March 10 the information was needed continuously to help assess the impact of fund shifts "between and among federal program areas." The GAO said it could do the job for \$2.5 million over a three-year period.

Other reporting systems do not have the same scope, the GAO found, and scrapping the geographic funding plan would mean Congress, the executive branch and other agencies "will lose some ability in assessing the economic effect of congressional budgetary decisions in regions, states and localities over the next few years."

The GAO warned, however, against keeping overlapping report systems. The plan the administration has ordered shelved is the only one that includes salary and expense payments to federal employees.

Sen. Donald W. Riegle, D-Mich., says the Office of Management and Budget (OMB) has been "hostile" to collecting the data because they "disprove OMB's claims that the Reagan budget cuts are fair to all regions."

According to Mr. Riegle, federal agencies had prepared data for fiscal 1981 and were ready to submit it when they received Mr. Harper's memo telling them not to report the information. The Senator said the system should "not be subject to the changing whim of bureaucrats," its accuracy should be improved and it should be made widely available to the public.

## Joni Fritz receives award



Executive Director Joni Fritz of the National Association Private Rehabilitation Facilities for Mentally Retarded (NAPRFMR) enjoys sharing success with friends Karen Meyers, President NYSACRA; Eleanor Pattison, NYS ARC President and Duncan Whiteside, Director of One to One.



Terence Cardinal Cooke studies the bronze sculpture of a young mentally retarded man, Allan Ashkenas (right) of Manhattan, as the sculptress, Judith Weller of Manhattan, looks on. The bust, commissioned by the New York City Chapter of the Association for the Help of Retarded Children, was presented by Cardinal Cooke to Pope John Paul II for exhibit at the Vatican. Allan's mother, Esther Ashkenas, is co-chairperson of the AHRC Manhattan Division and a director of the New York City Chapter.

## Vatican receives Down's Syndrome sculpture

This is a story about a female sculptor, a young retarded boy, and the Pope.

It began 10 years ago on a sunny day in Fort Tryon Park in north Manhattan as sculptor Judith Weller sat on a bench with her 5-year-old son, Jonathan, who had just been expelled from nursery school by teachers who called him "lazy and dumb."

Jonathan was not lazy and dumb. He was severely retarded.

Soon Weller noticed someone else on the bench. He was Allan Ashkenas, then 18, and afflicted with Down's Syndrome, a form of mental retardation with distinct facial characteristics.

"He came over to Jonathan," Weller recalled, "and was gentle and sweet with him and showed so much understanding that I realized that here was a fantastic human being with a lot of dignity."

"It's hard to confront retardation — very painful and very sad. But when I saw Allan I realized there was also some hope."

It was then that Weller asked Allan's mother, Esther, who lives in Inwood, if she could make a sculpture of her son. Mother and son agreed.

"He came to my home for several weeks regularly, and we talked as we worked."

"He loved life and was funny and friendly and explained those intolerant of the handicapped by saying, 'They don't know any better. I feel sorry for them,'" Weller recalls.

Allan was proud of the finished product — a lifesize head, and he took it to show to his classmates. It was the only image they had ever seen that they could identify with, Weller recalls.

For 10 years, though, Weller was unable to find any public place willing to display this work, although her other sculptures have found wide acceptance in dozens of shows and galleries.

"One former teacher said that God had made a joke, and why did I have to make a joke on a joke," she recalls.

"I said it was serious, and people had to be shown it. The purpose of this head is to emphasize the dignity of all people."

Weller redoubled her efforts to display the sculpture of Allan Ashkenas last year, the International Year of the Disabled. She has just recently succeeded, beyond her greatest imaginings.

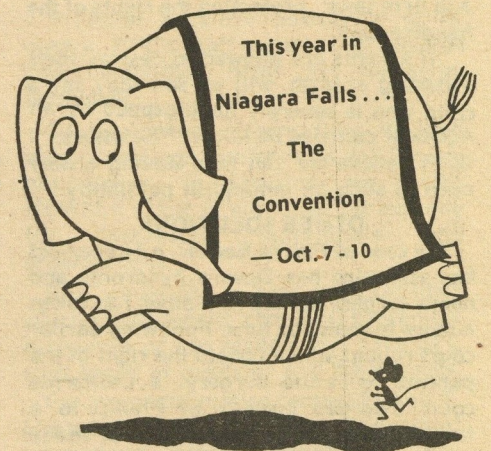
The Pope has promised to display a bronze casting of Weller's work in the Vatican, so the sculpture was flown to Rome this week.

And recently, Weller, Allan and his mother presented another casting to Cardinal Cooke in the parish house at St. Patrick's Cathedral.

The cardinal said, "This is a clear demonstration of the value and worth of every human being made to God's image and likeness."

The sculpture will be displayed in a building of the archdiocese, yet to be determined. At the presentation ceremony, Allan told the Cardinal, "This shows that we can make it."

Beneath the sculpture the artist has inscribed these words from Psalms: "How manifold are Thy works, O Lord. In Wisdom hast Thou made them all."





# Baby Doe dies and an issue is born

Responding to the death by starvation of a handicapped infant in Indiana, legislation strengthening the federal government's ability to intervene in such cases has been introduced in Congress.

Sponsored by Rep. John N. Erlenborn (R-III.), the bill would permit federal officials to save a handicapped infant's life if either the parents or the hospital or health facility refuse treatment.

It also would allow private individuals and organizations to intercede when such cases come to light.

Current law, according to Erlenborn, only permits the federal government to cut off financial assistance to hospitals after they refuse treatment. That, he said, would be too late to save the infant's life.

"A baby is more than a mere possession of his or her parents," said Erlenborn at a news conference May 26. "It is a life which society should protect."

## BILL DRAWS 10 CO-SPONSORS

Erlenborn's bill, introduced the same day, had 10 co-sponsors ranging from politically conservative Rep. Henry Hyde (R-III.) to liberals Rep. Paul Simon (D-III.) and Rep. Millicent Fenwick (R-N.J.).

"Basically, what this bill does is to insure equal treatment for handicapped and non-handicapped infants alike," said Erlenborn.

"It is not intended to require any extraordinary or prolonged medical care for infants, either handicapped or non-handicapped, whose physical conditions are untreatable or incurable or whose lives would not be prolonged beyond the immediate future," he added.

In the Indiana case, the parents of a newborn baby boy asked that their child, born with Down's syndrome and an abnormal esophagus which prevented food from reaching his stomach, not be fed intravenously and not be given corrective surgery that would permit the baby to take food normally.

The baby died six days after birth following a series of court decisions which refused to interfere with the parent's decision.

Later President Reagan said he considered denial of such treatment a violation of federal anti-discrimination regulations. He ordered government officials to cut off federal subsidies to hospitals which refused to treat such infants.

At the news conference, sponsors of the measure denied that it would amount to government interference in the private decisions of parents. "Society has always intervened when children are abused," said Rep. Dale E. Kildee (D-Mich.), another co-sponsor.

Simon compared Erlenborn's bill to existing requirements that handicapped individuals be given educational opportunities equal to those of non-handicapped individuals.

Erlenborn, whose bill would amend existing federal child abuse prevention and detection laws, said the death of the Indiana baby showed the need for "clear and firm laws" protecting the rights of the handicapped.

"If parents are allowed to destroy their offspring at birth, will we someday say a child who is severely handicapped by an accident can also be killed?" he asked. "I don't believe we can risk leaving a door open to such an outlandish possibility."

## OTHER SOLUTIONS

The case of Phillip Becker, a 14 year-old boy who also has Down's Syndrome and needs surgery to keep him alive, has taken a more humanistic turn. Following earlier court rulings which upheld the right of the parents to refuse surgery, a California court awarded custody of Phillip to a family which has cared for him for many years. Unless Phillip's biological parents have raised additional legal impediments, he may well have the needed

corrective heart surgery at this writing. There was some additional concern, however, that surgery had been delayed so long that permanent heart damage might have occurred.

In both of these cases, statements were made regarding the quality of life experienced by someone with Down's Syndrome. An editorial in the Washington Post declared, "All who have known Down's Syndrome children who read and write, participate in family life and beam with pride at each victory... know the joy these children can experience — and give. Life for them, with a missing chromosome and even with a repaired esophagus, can be a life very much worth living."

The family's lawyer said that "Infant Doe's" mother was with the baby almost all day the day the baby died. "It wasn't a case of abandonment," he stated, "It was a case of love."

## ARC members and others react

Dear Editor:

At the May 1, 1982 meeting of the Board of Governors of the NYSARC, a resolution was passed expressing its opposition to a court order refusing life support systems to a Mongoloid infant with severe medical problems to be kept alive by such life support systems. The resolution calls this "infanticide".

This was a most unfortunate resolution, if not arrogant and presumptuous.

Substituting its judgment for that of the Court and the parents, it condemns both as murderers.

Is the ARC qualified to judge the agony of the parents or the wisdom of the Court? Is the ARC prepared to assume the life-long terrible burden of the care of this child?

The Board of Governors of the ARC would do well to ponder the words of Chancellor Kibbe at the CUNY graduation.

"What I have learned by living is that there is too much arrogance (and) simple-mindedness in the world.

The antidotes to these destructive evils are humility, an appreciation of complexity, and compassion. These I would urge on you for your own sakes and that of society."

"Judge not, lest ye be judged."

Sincerely,  
Joseph T. Weingold

## HARD DECISION

I do hope this may be about the last word on the decision of a mother and father not to try to save their baby. I speak as one who also had to go through that decision, although in a dim past when one was allowed to make such a decision and not to have it news.

While still on a delivery table I was told to immediately assign a pediatrician to my infant. Never having had any contact with other than the obstetrician, I accepted the one they suggested. Forty years ago the term spina bifida was not as familiar, and they admitted they had another baby there with the same problem. The other parent agreed to try an operation and they never had time to do it.

Besides the spina bifida (and you could see nothing of the difficulty by looking at the curly-headed infant), the insides were all jumbled and the common problem of clubfeet was present. There was no way my infant could have taken nourishment, and thank goodness they did not use tubes and try. My David lived exactly one week, and they were so kind to me about it. As a practically new bride, although the shock for my husband and me was great, we were relieved that all had been done that could have been done without our going into permissions, publicity or court decisions.

## NYSARC STATE BOARD ACTION

In response to our deep concerns about the legal ruling that recently allowed an infant with Down's Syndrome to die because the child had medical problems, the Board of Governors of the State Association passed this resolution at its meeting on May 1, 1982:

Whereas,

This Association is an advocate for those who are retarded; and

Whereas,

This Association fully understands its essential responsibility to serve as a medium of communication for every "voiceless" being;

Be it resolved,

That this Association embark upon a formal aggressive community education program designed to combat perpetuation of fallacious implications related to mental retardation; and

Be it resolved,

That this Association communicate to court systems and medical personnel, its opposition to infanticide, while conveying accurate information concerning mental retardation;

Be it further resolved,

That this Association advocate against categories of developmentally disabled infants being deprived of the protection of laws available to other citizens.

Our child's immortality then was complete in that we gave permission for an autopsy and study. Out of such decisions have come the modern process for implanting a tube to drain the fluid from the brain of hydrocephalic infants, and our David helped that progress.

I suggest that any of the bleeding-heart letter writers read in its entirety the article in the April 6, 1982 *Family Circle* magazine titled "The Agonizing Decision of Debra Sorensen." It will help them know the agony better than any amount of sensational news accounts.

My experience ended in three positive actions: We had another child; we meantime took in a needy infant to assist the mother (recommended by our family doctor and the Children's Aid Society), since we had all the equipment for it until we did have our own child; and we became active in the Association for Retarded Children, which ours certainly would have been had he lived — and they projected at that time a life-span not beyond six years. There is more to the story than meets the eye.

Hermon

Mary H. Smallman  
Former President,  
St. Lawrence County ARC  
and member of directors  
of State ARC  
From Watertown Daily Times

## LETTERS FROM THE NEW YORK TIMES

To the Editor:

The writer of the editorial "Private Death" (April 27) is ignorant of the medical facts of Down's Syndrome and the editorial is in error and grossly misleading.

Contrary to the editorial, the consequences of Down's syndrome (mongolism) are reliably predictable at birth. Individuals suffering from this disorder are always significantly retarded. They may vary in the degree of retardation, but the variation is only from bad to worse. None of them are ever able to live independently and take care of themselves. Down's is the result of a genetic defect and can be documented by a well-established prenatal laboratory procedure as well as postnatal observation.

The editorial writer is noble in championing the rights of Down's individuals, but he is deficient in considering the well-being of the other members of the family. I have a daughter with Down's syndrome, now 23 years of age, so that I can speak of personal experience.

A family with low income and the misfortune to have an infant with Down's syndrome faces the prospect of infant care (diaper, hand feeding, carrying) for 7 to 10

years and perpetual small-child care (of the level of a normal child age 3 to 6) since the maturation of Down's individuals is very prolonged. They never progress beyond the stage of requiring constant supervision for their own safety.

A low-income family can also abandon the infant, in which case it becomes the ward of the state. A more prosperous family may elect to institutionalize the child or to provide 24-hour home nursing care.

Our family elected institutionalization, in the interest of our normal children, since the pressure of a Down's child in the home must necessarily subtract from care of and attention to normal siblings.

Cost to our family so far, \$85,000; current annual cost, \$7,000. Think what \$7,000 could do for an impoverished college student or a poverty-stricken family of four normal people. Home care would have cost more and would have precluded a normal family life for parents and siblings. This money and effort have produced absolutely nothing of any value to our family or to society.

Another long-term consideration is the plight of the parents as they approach retirement and old age. If they have elected to care for the Down's individual at home, they are faced with perpetual child care. With institutionalization, as income decreases the cost becomes relatively greater and may require a substantial part of available income.

Our child now receives approximately \$3,000 a year in Social Security supplemental income. This is Federal money, which comes from everyone's pocket, including yours, and which produces nothing at all except to the individual concerned and the institution in which she lives.

Wouldn't our family and society in general have been benefitted if our child had died of natural causes as a newborn, as did Infant Doe?

Adele K. Friedman, M.D.  
Philadelphia, April 28, 1982

To the Editor:

Eleven and a half years ago, my husband and I faced the same situation as the parents of Infant Doe, the Down's syndrome baby born in Indiana who was allowed to die.

When a Down's syndrome baby was born to us, it was suggested by medical personnel, in a positive way, that we could refuse permission for surgery which might be required to save our baby's life. After all, we had three other children, and this baby would put an enormous strain on the family.

Continued on Page 6



# State Legislature resolves PL 94-142 Support

In January of this year, a group of organizations concerned about the education of children with handicapping conditions gathered in Albany to form the New York State 94-142 Coalition. In unanimous agreement that Public Law 94-142 and its governing regulations should remain intact, coalition members shared information and ideas on how best to assure a free and appropriate education for all handicapped individuals. Member agencies, including NYALD, New York State ARC, NYS Council for Exceptional Children, UCP, Advocates for Children and the NYS Speech, Language and Hearing Association, established networks through which immediate action could be taken in response to federal proposals and decisions.

Impact on Federal government, however, was not enough. The coalition realized the necessity of impacting at the State level as well. A resolution was drafted and submitted to Assemblyman Alan G. Hevesi, Chairman of the Assembly Task Force on the Disabled, and Senator John E. Flynn, Chairman of the Senate Select Committee on the Handicapped. These two legislators were the lead sponsors of the following resolution, which was passed in both Houses during the week of May 17, 1982.

WHEREAS, Public Law 94-142, the Education for All Handicapped Children Act, made the provision of a free appropriate public education for children with handicapping conditions a matter of national interest; and

WHEREAS, Significant strides forward have been made since its passage in nineteen hundred seventy-five toward meeting the educational needs of this Nation's handicapped children; and

WHEREAS, P.L. 94-142 and its implementing regulations have established a vital planning mechanism to ensure that the unique educational needs of handicapped children are met through placement in the least restrictive setting along with the provision of essential related services; and

WHEREAS, P.L. 94-142 and its implementing regulations have established procedures to protect the rights of handicapped children to a free appropriate public education by providing for parental consent to a discriminatory testing, evaluation, and placement, and for procedural safeguards to resolve parental concerns; and

WHEREAS, It is the sense of this Legislative Body that promoting and securing the free appropriate public education of children with handicapping conditions must remain not only as a matter of national interest, but be recognized as an obligation of the highest priority so as to enable these citizens to enjoy as independent and productive a life as possible; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize the Honorable Ronald W. Reagan, President of the United States, and the Congress of the United States to maintain current statutory and regulatory provisions regarding the educational rights of children with handicapping conditions; and be it further

RESOLVED, That copies of this Resolution, suitably engrossed, be transmitted to the Honorable Ronald W. Reagan, President of the United States, to the President Pro Tem of the Senate, to the Speaker of the House of Representatives, to each Member of Congress from the State of New York, and to the United States Department of Education's Office of Special Education and Rehabilitative Services.

The New York Association for the Learning Disabled joins with other members of the 94-142 Coalition in commending the New York State Legislature for its public recognition of the essentialness of a free and appropriate public education for children with handicapping conditions and for its pledged commitment to assure handicapped education's place as a priority responsibility of the State through the preservation of current statutes and regulations mandating its provision.



Dr. George Jervis, past Director of the Institute of Basic Research, was presented a Chapter Award at the Conference on Aging and The Developmentally Disabled Person at Queens College in May. Anne Kraus, New York City Chapter's Director of Community Education presented the award on behalf of the chapter, which co-sponsored the event.

## Conference explores needs of aging

New York City Chapter sponsored a successful all day conference "Aging And the Developmentally Disabled Person" at Queens College on May 7th. Representatives of more than 250 agencies, consumers, and professionals attended. The conference presented important information about developmentally disabled elderly persons and explored ways of providing services for this neglected population.

The plenary session featured a key-note address by Monsignor Thomas Cribbin, Office of The Handicapped, Brooklyn Catholic Charities. Presentations were made by Matthew Janicki, Ph.D., Director Research and Planning, OMRDD, and George Merz, Ph.D., New York State Institute for Basic Research in Development Disabilities.

A surprise award was made by New

York City Chapter to Dr. George Jervis, past Director of the Institute for Basic Research, for his scientific contributions and his many years of service as a member of City Chapter's Professional Advisory Committee. Anne Kraus, Director of Community Education, presented the plaque to Dr. Jervis.

Co-sponsors of the conference were the Boro Developmental Service Office, New York State Institute Basic Research Developmental Disabilities and the Queens College Department of Health and Physical Education. Dr. Jack Gorelick, City Chapter Associate Executive Director and Ruth Bogarsky, Director of Education and Training, Queens Boro Developmental Service Office were coordinators for the conference.

Plans are being made to publish a summary of the conference proceedings.

## Recycling assistance for hazardous wastes

The New York State Environmental Facilities Corporation (EFC) has developed a wide range of services designed to help manufacturing and industrial operations reduce or recycle hazardous and other industrial wastes. EFC has recently provided assistance in this area to a NYSARF member contract manufacturing facility in Binghamton, New York. These services, initiated under the State's Industrial Materials Recycling Act (IMRA), are aimed at encouraging the exchange and reuse of such wastes wherever technically and economically feasible.

EFC's responsibility under the act includes:

- Preparing a list of industrial materials that can be technically and economically recycled or recovered.

- Promoting the use of recycling and recovery, as well as the exchange of wastes and reduction of sources.

- Assisting manufacturing facilities that produce, use, or recycle hazardous wastes, through preparing a handbook on recovery and recycling, and operating a technical reference center and information clearinghouse.

- Determining the scope of the hazardous waste problem in the State, as well as the market potential, and technical and economic feasibility of recovering and recycling such wastes.

Since the Act was signed last July by Governor Carey, EFC has:

- Partially funded the Northeast Industrial Waste Exchange. The Exchange has published three catalogs listing "waste wanted" by manufacturers and "waste available" by generators.

- Created an "information library" for use by manufacturing and contracting facilities. Individual sources of information about specific wastes and methods of recovery and recycling are available and continually updated.

- Provided technical assistance to industry. EFC's staff responds to requests from individual firms for waste information.

- Disseminated information through public meetings, conferences and outside publication. In addition, an IMRA NEWSLETTER is published periodically for interested individuals and organizations.

- EFC would like to hear from facilities which might benefit from EFC's technical assistance, or who would like to have EFC staff speak at meetings and conferences.

For more information contact Pickett T. Simpson, P.E., Director, Industrial Hazardous Waste Programs, Environmental Facilities Corporation, 50 Wolf Road, Albany, New York 12205. Phone (518) 457-4138.



When the police officers from the Nassau County Police Benevolent Association held their annual summer picnic for the Nassau AHRC, everyone had a fun time. The off duty policemen came with rides, games, refreshments and one of the cops even dressing up as a clown. The American Legion, always a good friend of AHRC, was on hand with their 40 & 8 locomotive, giving rides to the children.





Mrs. Frances Reville speaking to guests at the ceremony honoring her late husband, James Reville.

## Reville portrait dedicated

A reception honoring the memory of Mr. James F. Reville was recently held by the Board of Visitors and Letchworth director Edward Jennings.

Dedicating a great part of his life to bettering the lives of mentally retarded individuals, James Reville served as president of the Welfare League from 1963 to 1964, was a member of that organization's Board of Directors for several years, and served as the chairman of the Ways and Means Committee for the National Association for Retarded Children in 1970.

James Reville was presented with a citation for his notable contribution on behalf of the mentally retarded by Dr. Alan D. Miller, commissioner of the New York State Department of Mental Hygiene, in 1969. New York State Governor Nelson Rockefeller appointed Mr. Reville to the Advisory Council on Mental Retardation Facilities and to the Developmental Disabilities Council.

On December 7, 1975, the "old hospital" at Letchworth Village was renamed the James F. Reville Building as a result of his "unsurpassed devotion to the mentally retarded."

Jim, one of NYSARC's most respected presidents served the Association from 1965 to 1969. Through his wife, Frances, member of the NYSARC Board of Governors and former NYSARC

Treasurer for many years, the memory of Jim is kept alive as she continues in the same fine tradition of advocacy that distinguished his service to those who are retarded. NYSARC takes pride in the accomplishments of those two fine individuals who have contributed so much to the Association.

## Permanent State Advocate for disabled

The Assembly has sent the Senate a package of 16 bills designed to aid handicapped or disabled people.

The measures approved included a tax exemption on residential property improvements to accommodate handicapped people and creation of a permanent advocate for the disabled in the governor's office.

Another bill would prohibit discrimination on the basis of disability in employment, public housing, public accommodation, education and the sale of real estate.

The package also included measures providing for the establishment of independent living centers for the disabled and authorizing the Department of Motor Vehicle to issue "non-driver" identification cards to disabled and elderly people.

## Reactions to Baby Doe

Continued from Page 4

A little over a year later, The Times Magazine published an article by Dr. Anthony Shaw (Jan. 30, 1972), who expressed his belief that parents had the right to choose whether to accept or decline such surgery, since an "I.Q. of 30" was characteristic of those with Down's syndrome.

When I think of what we would have missed had we, in our ignorance, chosen to withhold needed surgery (as it turned out, we were spared such a decision) I feel compelled to tell anyone who will listen how much our Down's child has enriched our lives.

We take as much pleasure in his achievements as we do in those of our other children. The problems we have encountered in raising him are no more severe than those we have encountered in raising our other children, although of a different nature. He is home with us, flourishing in our family environment, attending a special education class in a public school in our district.

He is active and responsive, with a love of life hard to match. He reads, he writes, he even types. He adds, subtracts, carries and borrows, and he uses a calculator to check his results. He swims, bowls and

plays tennis. He is the favorite of his siblings. He has filled all of our lives with joy.

Prospective parents and the medical profession need to realize that Down's children are not necessarily severely limited or guaranteed to be a burden on their families. They are more like other children than not and can bring the same measure of happiness to their parents. If this were better understood by the public, tragedies such as that of Infant Doe would be avoided.

Elizabeth Villam  
Yonkers, April 28, 1982

### DOWN'S SYNDROME CONGRESS MOVES ON BABY DOE DEATH REQUEST FOR NATIONAL TV PROGRAM ON THE ISSUE

(Editor's note: Excerpted from letters)

... "We are all so fired up about this! In my anger and frustration and pain, I want to make sure those parents and those judges never get a decent night's sleep again!"

Emily Perl Kingsley  
Board of Directors  
Down's Syndrome  
Congress Chairperson

## What is Fragile X?

A team of researchers from the Institute for Basic Research, Willowbrook, has found a new test on fetuses can detect a genetic abnormality that most often affects male children, and may be the cause of 20 percent of all cases of mental retardation.

This group of New York State researchers say they have successfully tested the fetuses of at least two pregnant women for the second most common chromosomal cause of mental retardation in males.

If their work can be duplicated, it will eventually provide information and options to parents at risk of having babies with the so-called Fragile X chromosome, which is second only to Down's Syndrome as a chromosomal cause of retardation.

The scientists say that, on at least two occasions, they have isolated the Fragile X chromosome in the amniotic fluid of pregnant women known to be carriers of the defect.

Geneticists are calling the work "a major clinical advance" if it can be duplicated in other laboratories.

"From a point of view of pure science there's no breakthrough," said Dr. Frederick Hecht, director of research at the Genetics Center at the Southwest Biomedical Research Institute, in Tempe, Ariz. "But from a medical point of view, there is."

Edmund Jenkins and Drs. W. Ted Brown and Henry Wisniewski of the State Institute for Basic Research in Developmental Disabilities, have stressed that their work is still in an initial stage and must be replicated by other scientists.

Each female has two X chromosomes and every normal male has one X and one Y. In persons with the Fragile X, one of the X chromosomes has a thin, or fragile, leg. Scientists do not know whether the defective chromosome itself, or a gene for retardation associated with the fragile defect, causes the retardation.

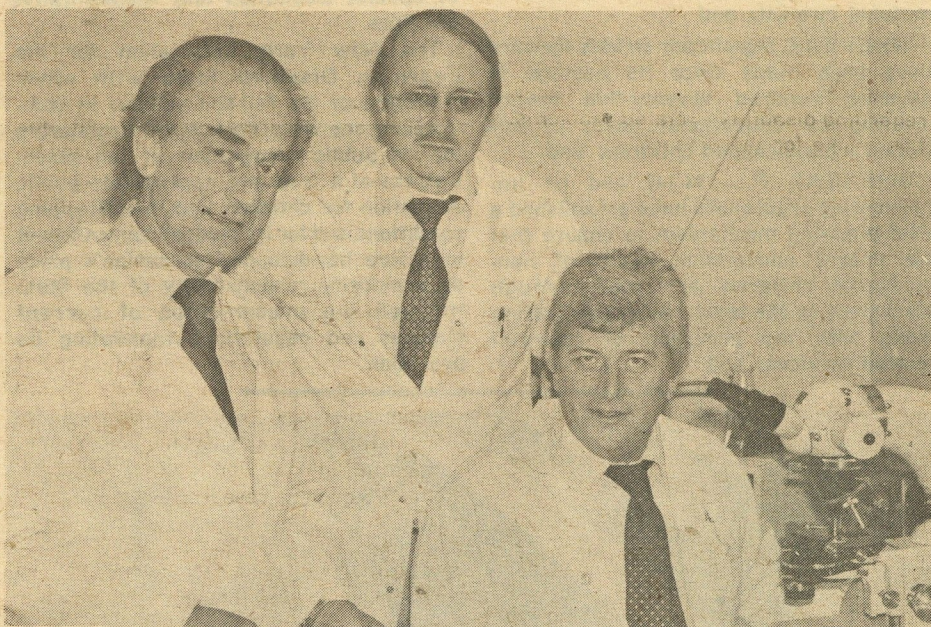
Females with the defect were once thought only to be carriers of the Fragile X, but recent research has indicated that the defect may cause retardation in a very small proportion of affected females. Almost all males with Fragile X are mentally retarded.

The new breakthrough will allow a woman carrier of the chromosome to learn the sex of her fetus and whether it has the tragic chromosome abnormality, which produces children with an I.Q. between 40 and 55. A test already has been developed to determine whether a woman is a carrier of the chromosome.

The Fragile X testing is a refinement of the more common genetic testing known as amniocentesis which can determine the sex of a fetus and the presence of other chromosomal abnormalities.

The Fragile X test should cost between \$100 and \$150, according to Jenkins, and should eventually be available at any medical facility doing amniocentesis. But it is not readily available yet, and may not be for two years, the scientists said.

However, Wisniewski suggested that families which have a history of two or more males who are mentally retarded should contact such agencies as the state Office of Mental Retardation and Developmental Disabilities for genetic counseling.



From left, Henry M. Wisniewski, M.D. Ph.D., director, State Institute for Basic Research in Developmental Disabilities; W. Ted Brown, Ph.D., M.D., chief, Department of Human Genetics (IBR); Edmund C. Jenkins, Ph.D., chief, Division of Cytogenetics (IBR), the principals in the Fragile X research.

## YAI receives 1982 Award for outstanding facility

The National Association of Rehabilitation Facilities (NARF) recently held their annual national conference in Indianapolis. Each year, NARF, a nationwide association of over 700 agencies which provides rehabilitation services to mentally retarded and developmentally disabled people, presents outstanding achievement awards to individuals and agencies alike.

This year's recipient of the Outstanding Rehabilitation Facilities Award is the Young Adult Institute and Workshop, Inc., (YAI) of New York. Chosen out of a field of over 700 agencies the award cited YAI's "leadership and service in advancing the quality of life for handicapped persons through the development of rehabilitation

facilities." Celebrating their 25th year of service, YAI was also cited as having a long and dedicated history of service to the disabled citizens of New York. YAI is one of New York State's leading private providers of Community Residences and Day Treatment Centers with 25 different programs throughout the New York metropolitan area.

In accepting the handsome plaque, Joel Levy, Executive Director, said "I am pleased and proud to accept this award on behalf of the Young Adult Institute — it honors the hard work and dedication of our staff, parents, Board of Trustees and clients who have helped YAI one of the best rehabilitation agencies in the country."



# Additions to ARC Legislative Program

## LEGISLATION

After studying legislation pertaining to mental retardation and developmental disabilities, the Sub-Committee on legislation, chaired by Irene Platt, Senior Vice-President, added the following bills to the NYSARC Legislative Program.

Several bills of interest require additional study before a NYSARC position can be taken and, as the Sub-Committee completes its review of these particular pieces of legislation, we will keep our readers informed.

### Senate Bills:

(in descending numerical order)

S-10033-A, FLYNN

repeals provisions relating to employment of mentally retarded persons, authorizes local Civil Service Commissions to specify 500 jobs (instead of 200) that can be performed by the mentally handicapped. It also includes persons physically handicapped by blindness as certified by the SDSS Commission for the Blind and Visually Handicapped.

**Action:** NYSARC cannot support without assurances that a minimum of 200 positions are retained for the retarded; otherwise this could lead to erosion of gains for which we have fought.

S-10027, FLYNN

requires an annual study by the Office of Advocate for the Disabled on the transportation, needs of the disabled, and the services available, and to make recommendations on upgrading present services and adding new ones.

**Action:** NYSARC supports.

S-10026, FLYNN

requires the Office of Advocate for the Disabled to make a toll-free telephone number available for disabled persons to obtain information and assistance regarding disability-related problems.

**Action:** None for the present.

S-9976, PADAVAN (A 12593, RULES COMMITTEE)

to direct Commissioner, within amounts appropriated therefore, to coordinate, promote and conduct summer therapeutic programs for developmentally disabled children, adolescents and adults, which programs shall be continuation of such person's ordinary school placement, training or treatment, and shall be primarily concerned with building factors, qualities and skills set forth herein.

**Action:** NYSARC supports.

S-9922, GASSARA

to make person guilty of promoting death of person when he intentionally denies nutrition or ordinary life sustaining medical procedures to any person in his care with intent of causing or hastening death of such person, with congenital or other physical defects of person denied care not to be defense in proceeding hereunder.

**Action:** NYSARC support, cognizant of distinction between life sustaining measures and life support systems.

S-9782, FLYNN (A 11921, WALSH)

requires the General Services Commissioner to determine the impact of a relocation by any State agency on persons with disabilities, with the agency to use his findings to maximize access by the disabled.

**Action:** NYSARC supports.

S-9749-A, MARCHI (A-4249-A, BRANCA)

to provide that definition of direct labor by blind persons which excludes work by blind persons consisting solely of packaging goods, wares and merchandise not manufactured by blind persons, shall not preclude preferred bid status for value added portion of any product that has been in part or solely packaged or assembled by blind or

other severely handicapped persons; extends powers and duties of General Services Commissioner relative to determining price of products manufactured by blind and other severely handicapped offered for sale to state, to include determining price of product produced or assembled by such persons.

**Action:** NYSARC supports.

S-9714-A, FLYNN

entitles a child with a handicapping condition to receive a minimum of 12 years of public school education.

**Action:** None.

S-9635-A ACKERMAN

to repeal provisions relating to equal right in places of public accommodation and amusement and rights of blind or deaf persons, and to enact new provisions relating to equal rights in places of public accommodation and in employment, and to prohibit discrimination because of disability as defined herein, in regard to jury duty, places of public accommodation, employment opportunities, housing and insurance coverage.

**Action:** None.

S-9367, PADAVAN (A 11326 CONNELLY) to direct the clinical information tending to identify patients or clients of facilities operated by certain offices within mental hygiene department, and clinical records maintained at facility not operated by such offices shall not be public records, and shall not be released to any person or agency outside such facility except pursuant to certain portions hereof, and that any disclosure made pursuant hereto be limited to necessary information in light for reason for disclosure, and shall not be further disclosed, and that, except for certain described disclosures, notations of disclosure shall be placed in clinical record of individual about whom information is disclosed, and such person shall be informed of all such disclosures upon request; strikes out certain provisions governing disclosure of contents of clinical records, and describes certain additional circumstances under which such confidential information may be disclosed.

**Action:** Requires research

S-9075, PADAVAN (A 11503, CONNELLY) to empower Commissioner of Office of Mental Retardation and Developmental Disabilities to regulate and assure consistent high quality of services provided in N.Y. to mentally retarded and developmentally disabled, provides that Commissioner ensure that all such services are periodically evaluated and requires that all providers of services described herein have operating certificate; makes provisions concerning issuance of such operating certificates, approving certain certificates of incorporation, approving new construction, visitation and inspection of facilities, duties of providers of services, fiscal year report, suspension or revocation of operating certificate, confinement, care and treatment of mentally retarded and developmentally disabled, family care homes and payment of service at intermediate care facilities for mentally retarded.

A July 2, 1982 AMD-RECOM 9075 A

**Action:** NYSARC opposed in present form, reviewing revised form.

S-8499, FLYNN

Establishes statutory basis for the Office.

**Action:** NYSARC approves.

S-8487, PADAVAN (A 10847, CONNELLY)

to authorize Commissioner to establish respite demonstration projects for purposes of establishing eligibility criteria for respite services, evaluating demand for respite services and means of effectively and economically meeting such demand, ascertaining respite services available and necessary to meet demand, evaluating relationship between respite and need for institutionalization, identifying costs of providing such services and effectiveness of continuing such projects, with Commissioner to make application forms for such demonstration projects available within 3 months and report to Governor, Budget Director and Chairmen of Senate Finance Committee and Assembly Ways and Means Committee on or before October 1, 1983, evaluating appropriateness of continuing respite projects; describes effective period of certain provision hereof and appropriates \$250,000.

**Action:** Requires further study in view of amended version.

S-7911, SMITH

to change and clarify various provisions relating to responsibility for regulation and quality control of services for mentally disabled, and local and unified services, by defining "commissioner" to mean Health Commissioner in reference to services provided mentally retarded or developmentally disabled, and Health Commissioner in reference to services provided to mentally ill, and "Department" as meaning Health Department in reference to such services provided to mentally retarded or developmentally disabled, and Office of Mental Health in reference to services provided to mentally ill; repeals provision that Office of Mental Retardation and Developmental Disabilities shall carry out provisions relating to regulation and control of services for mentally retarded and developmentally disabled; requires that Commissioner of Mental Retardation and Developmental Disabilities submit proposed fee schedules for inpatient and non-inpatient services annually to Health Commissioner for his approval; provides that Social Services Department shall be responsible for establishing and maintaining standards of medical care and services, reimbursement rates and fees in institutions operated by Office of Mental Retardation and Developmental Disabilities of Mental Hygiene Department, or subject to supervision of Health Department; defines terms "mental retardation", "developmental disability" and "school" for purpose of Public Health Law; makes various related changes.

**Action:** NYSARC withholds support pending further study.

S-7195, RULES COMMITTEE (A-9227, RULES COMMITTEE)

to limit applicability of powers of Family Court with regard to certain handicapped children by making same applicable to handicapped children over 5 determined to have handicapping conditions who require special educational services during July and August to maintain educational level attained during regular school year and who are not eligible for other educational services as currently provided, continues power of court concerning handicapped children under 5; describes such proceedings and makes provisions concerning review by Committee on Handicapped, program serving such children being subject to approval and regulation by Educational Commissioner, certain reim-

bursements by Commissioner and arrangements of transportation for such handicapped children ordered by Family Court; makes related provisions.

**Action:** NYSARC endorses concept of Early Education; however withholds support of this bill pending review of revised form.

### Assembly Bills:

(in descending numerical order)

A-11979, SCHIMMINGER (S-10289, MEGA)

creates temporary commission on prevention of developmental disabilities, composed as described herein, to examine, evaluate and make recommendations concerning prevention of infant death and disability, with commission to make study of statewide coordination of preventive and followup services among public and private agencies and monitor implementation of recommendations of Governor's conference for prevention of such disabilities and mortality, and initiate further appropriate efforts to improve health and well-being of infants, children and families; appropriate \$4000,000, with provisions hereof to remain in effect until March 31, 1983.

**Action:** NYSARC endorses the concept of Prevention; however feels that the language of this bill requires clarification.

A-11534, LEVY

creates within Office of Mental Retardation and Developmental Disabilities, demonstration program for care and treatment of autistic children in community based residences and drug treatment centers, which shall be conducted at up to 3 community based facilities other than in-patient institutions operated by such office; appropriate \$5,200,000.

**Action:** NYSARC supports.

A-11223, CONNELLY (S-9366, PADAVAN) authorizes the director or operator of a facility in which a retarded or developmentally disabled person resides to give effective consent for medical, dental, health and hospital services — if the person lacks the capacity to consent, and if a parent, guardian or committee is unavailable to consent, and the delay involved in seeking a court order will result in the "risk of harm." There are related provisions.

**Action:** NYSARC awaiting status report; requires further study.

A-11217, CONNELLY (S-8890, PADAVAN) permits the Commissioner of OMR-DD to commence a special proceeding for a short-term involuntary protective services order if he "reasonably believes" that a retarded adult lacks the substantial capacity to govern his own affairs and is at risk in his environment.

**Action:** Standards to be defined; amendment pending. Hold for further study.

A-11200, TALLON

provides that supervision and ratio requirements regarding physical therapist assistants shall not apply to RHCF's and facilities under OMH and OMR-DD jurisdiction, and requires that new standards be issued on or before next January 1, under regulations promulgated by the Commissioner of Education in consultation with the Commissioners of Health and Mental Health, to take effect April 1, 1983. There are related provisions.

**Action:** NYSARC requires further study; possible double standard.

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# CHAPTER NEWS

.... What our Chapters are doing  
for our children and adults

Our **ALLEGANY** County Chapter sponsored a Wine-tasting evening at Willsville Country Club. The evening included fine wines from Johnson Estates, Gold Seal, Great Western, Merritt Estates and others. There was music and dancing and a good time was had by all. The folks at **ALLEGANY** are enthusiastic about their second Annual Corn Roast scheduled for August 22nd. Their First Annual ARC Car Raffle is scheduled to be held at the roast. Students at Alfred State College raised \$750 for the **ALLEGANY** County Chapter with their misa-meal project. Students went without a meal once each semester to raise this money. We applaud these students and it encourages us to know that the coming generations do care enough to "put their money where their mouth is" . . .

Our **CHAUTAUQUA** County Chapter recently opened the doors of its new 60 bed ICF in Jamestown. This facility brings **CHAUTAUQUA'S** bed capacity to 188. . .

**WEST SENECA D.C.** held its 11th Annual Happytime Carnival in June. The event was sponsored by the West Seneca Kiwanis, Rotary and Lions Clubs and its \$30,000 cost was paid by private sources. The whole affair was a huge success thanks to the work of hundreds of volunteers. . .

**SULLIVAN** County Chapter is proud of its own, Gary Teitel. Gary serves with his wife Karen as a weekend resident counselor in one of the chapter's group homes. He has been awarded a full-tuition scholarship worth \$8,000 to the School of Visual Arts in New York City. He is a graduate of Sullivan County Community College. Gary's major is Commercial Art.

The **WAYNE** County Chapter has been busy this summer. Wayne held its Annual Banquet in June and then conducted a Trash or Treasures Drive in order to obtain merchandise to sell at the Flea Market booth in July. . .

A golf tournament for the benefit of the **ULSTER** County Chapter was held at the Granit Hotel in Kerharkson. An entry fee of \$50 included greens, balls, carts, and open bar buffet. That sounds like a good deal. . .

And speaking of good deals, **ONTARIO** County Chapter spends a good deal of its time providing recreational activities for its people. Recently they've sponsored an eight weeks summer bowling program, a canoe instruction program, a Softball Program and if that's not enough, they have now broken ground for a new 25,000 square foot building to house their programs. The construction costs are about \$1.4 million. And somewhere in all of this they found time to hold their Annual Chapter's Meeting and Client Dinner Dance. The evening included; cocktails, dinner, business meetings, and presentation of awards. Music for dancing was provided from 9:00 p.m. to midnight. . .

**STUBEN** County Chapter held its Annual Dinner at the Ramada in Bath. Speakers were Assemblyman John R. Kuhl, Jr. and our very own President, Ellie Pattison. . .

**NIAGARA** County Chapter held its Annual Banquet and honored two individuals, three firms and a sorority. The day treatment staff sponsored a fish and chicken dinner and baked goods sale to raise funds to send clients to the YWCA's summer day camp. **NIAGARA** County Chapter has received tentative approval from the U.S. Transportation Department for van service in rural areas. The vans would be owned and operated by the association, with federal funds applied toward operating expenses. . .

The **ONONDAGA** County Chapter's, Parkside School held a Trash and Treasure sale and raffled a Kawasaki dirt bike donated by Performance Harley Davidson of Syracuse in order to raise money for the school. . .

Our **NASSAU** County Chapter is \$709.84 richer, thanks to the 7-Eleven District Office. Eighteen employees of the **NASSAU** district made voluntary contributions during the year and elected to make the association recipient, to help pay for the Special Olympics. It's great to know that so many people from so many different walks of life, think of us. . .

**ORANGE** County Chapter presented its first Annual Musical "Once Upon a Mattress", a delightful musical spoof for the whole family, in June. The cast of some of **ORANGE** County's most gifted comedians and comedienues received rave reviews for their performances. . .

**LEWIS** County Chapter found a new way to help themselves. In cooperation with the Thousand Islands Region of the NYS Office of Parks, they sell firewood to supply campers and picnickers with their campfire needs. This helps both the chapter and the preservation of the environment in the parks. It makes one wonder just how many of our resources are we actually using to our own best interests. . .

Our **RENSSELAER** County Chapter was the recipient of the proceeds from the sale of food at Troy, New York's 15th Annual Flag Day Parade. About 45,000 people turned out to watch about 8,000 marchers. The local Anheiser Busch donated \$2,700 to the Italian Community Center to buy food which was cooked and sold, along with beer, at the parade. It sure was great team effort to make the most of **RENSSELAER** Chapter. . .

## This high school diploma says courage



Francis Young (center) receives his high school diploma and is congratulated by Bill Albertin, President of ARC Montgomery County and Ellie Pattison, State ARC President.

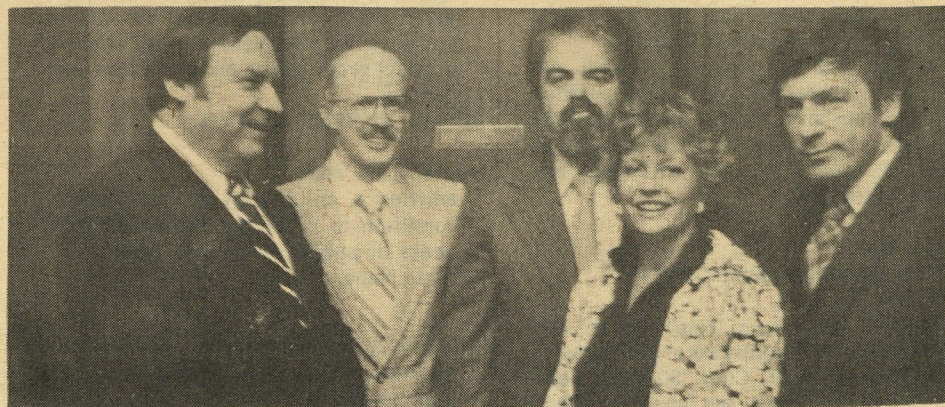
The **ROCKLAND** County Chapter held a Las Vegas Night. These are getting to be very popular fund raisers and the participants usually have a good time. . .

**BROOME-TIOGA** Counties Chapter is having a great summer. Who wouldn't with a schedule of Staff-Client Softball game, Outdoor Hot Dog Roast, Outdoor Rock Concert, and Old Fashioned Fun Day, to mention a few items. . .

Our **SUFFOLK** County Chapter, received the proceeds from the Babylon Tuna Club's 26th Annual Invitational Tournament that was held on July 24th and 25th. In this tournament, Anglers are awarded big game rods and reels for tuna, sharks and marlin. The fish are auctioned as soon as they come in and the proceeds go to our chapter. . .

**MONTGOMERY** County Chapter held an Annual Awards Banquet, June 29th. The affair was attended by 325 persons including 125 government officials and civic leaders. Many awards were given out. A G.E.D. diploma was earned by Francis Young. Francis now a 53 year old

## Celebrities at Chenango



Assemblyman Clarence D. Rappleyea of Norwich; Dr. Ray Dann, President; John McHale, Executive Director; Eleanor Pattison, N.Y.S. A.R.C. President with Marc Brandt, N.Y.S. A.R.C. Executive Director.

man, had contracted an illness accompanied by a high fever when he was an infant. He was left unable to sit up or walk and left with a permanent speech impairment. Since he is unable to hold a pencil he communicates with sign language or electric typewriter. Francis scored 31 percent higher than the average non-handicapped person on the G.E.D. test. Sixty other clients also received awards for individual accomplishment. Fiber Glass Industries was named "employer of the year" and Lorraine Lampkin received the Sollecito Scholarship.

Ellie Pattison led the ceremony for the newly elected officers of the Chapter. The principal speaker was Zygmund Sleazak, Commissioner of OMR-DD who stressed the benefits of Community placement. . .

In March of this year **LIVINGSTON-WYOMING** Chapter opened a Community Residence for geriatric clients. The nine residents attend a special geriatric group at their day program. The home is equipped with an intercom system to allow staff to hear what is happening anywhere in the building. The house is situated on three acres of rural land allowing for a vegetable garden and flower beds to tend as well. A unique staffing pattern provides care 24 hours a day. . .

In order to show its appreciation to selected area business and employers for their continued support, the **CLINTON** County Chapter held a Business Associates Recognition Day on July 28, 1982 at 4:00 p.m. A number of businesses in New York State, Canada and Vermont have been supplying the ARC Sheltered Workshop with a diverse range of subcontract opportunities which is used as a basis for their Rehabilitation Program. Additionally, several area employers have hired and continue to employ handicapped clients from ARC's program. Plaques were awarded and tours of the program were available. Senator Ronald B. Stafford and **CLINTON** County Legislative Chairperson Janet Duprey also participated in the ceremonies.

Also on the 28th, the Sheltered Workshop changed its name to "Champlain Valley Industries" in order to better reflect their services to the business community. The primary goal of Champlain Valley Industries is to develop in each of their handicapped clients a maximum potential for vocational success, while providing quality industrial subcontracting services to the business community. . .

Awards were presented at the annual dinner meeting of the **ROME DEVELOPMENTAL CENTER** Chapter in June. Barbara DeKay, the runner-up for the Employee of the year, was given a check and certificate.

Awarded certificates of appreciation were Mary DiAcunto, Lila Karam, Ed-

ward McCaffrey, Alan Ratzlaff, Michael Raha, Robert Wilbur, Howard Waddell, Margaret Sayko, and Keith Hoffman.

Dr. William Hartnagel, recent winner of the Rome DDSO W.T. Wheeler award, was the guests speaker. The Wheeler award is given each year to the outstanding DDSO professional employee in memory of Dr. W. Theodore Wheeler, former member of the medical staff at Rome Developmental Center. Dr. Hartnagel stated that the ARC should be the driving force to keep progress on-going, even though it is very slow, but steady.

Officers elected were: Nancy McCaffrey, recording secretary; Joseph Parzych, Dorothy Bingel, Stephanie Parzych, and Fred Hallock on the Board of Directors. . .

**THE ALBANY COUNTY** Chapter had a very successful general membership meeting on the topic of Guardianship in April. The Chapter's attorney, Mr. Stephen Waite, of the Albany law firm Cooper, Erving & Savage, and a local attorney, Mr. Barry Gold, worked with the Albany County Surrogate and Surrogate Court Clerk to prepare forms to be used to petition the Surrogate Court for guardianship of a mentally retarded person. Judge Marinelli presented the procedures for guardianship applications at the general membership meeting. Mr. Waite and Mr. Gold explained to parents what guardianship is all about and why they should consider becoming a guardian of their retarded relatives. Dr. Aletha Crowder, the Chapter's Executive Director, discussed the NYSARC guardianship program. . .

The **ORANGE** County Chapter hosted a lecture on the "Fragile X Syndrome". The presentation was made by Dr. Edmund C. Jenkins of the Institute for Basic Research in Mental Retardation and Developmental Disabilities. Dr. Jenkins is one of the principal research scientists who have made these discoveries. He is currently involved in studies attempting to develop a treatment which could present or ameliorate the "Fragile X Syndrome".

The "Fragile X Syndrome", a major cause of Mental Retardation, is an inherited genetic abnormality about as common as Down Syndrome (formerly referred to as Mongolism). "Fragile X" has also been discovered to be associated with Autism.

Important scientific breakthroughs in genetic research have opened the way to pre-natal detection of the "Fragile X Syndrome". Preventative research is now being conducted. . .

**CHEMUNG** County chapter honored David Keyser as its "worker of the year". David was chosen for demonstrating a high degree of personal growth. When it comes right down to it — shouldn't this be the bottom line!!!



# Order ARC Christmas Cards TODAY!

## 1982 AWARD WINNERS

These card designs were selected from an Art Contest of Christmas subjects created by the retarded especially for this program.

25 Cards for \$8.50  
Add \$3.75 for each 25 cards imprinted

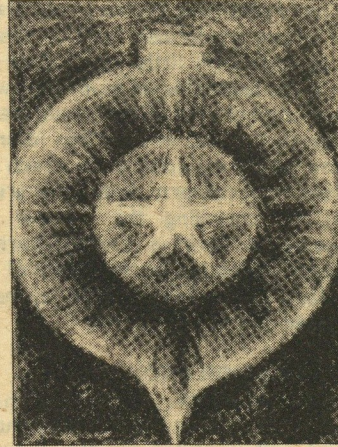


CARD NO. AG1-2392 "Good Friends". A charming dog and cat are portrayed in front of a gaily decorated Christmas tree within a red border. Created by Russell Velte of Brookville, New York. White envelope. Inside: Warmest thoughts and best wishes for a wonderful holiday and a very happy new year.



Card No. AG1-2393  
Snowscene to express the happiness of the season. Created by David A. Hoffman, Schoharie County, New York. Colorful printing with a blue border. White envelope. Inside: Best Wishes for the Holidays and Happiness throughout the New Year.

## PREVIOUS AWARD WINNERS



Card No. AG-837W3  
A glorious and beautiful multi-colored ornament by Thomas McComb, Wassaic, New York, reproduced in full brilliant colors against a blue background. White envelope. Inside: Wishing you all the Joys of the Season and Happiness in the Coming Year.  
25 Cards for \$5.00



Card No. AG-1881 W3  
A delightful snow family celebrates the holiday season, designed by Stanley Popielarz, Fulton, New York. Reproduced with bright color and a red border on a white background. White envelope. Inside: Warmest thoughts and Best Wishes for a Wonderful Holiday and a Very Happy New Year.  
25 cards for \$6.50

Add \$3.75 for each 25 cards imprinted

## SPECIAL ASSORTMENT

Our own Special Assortment Box of 25 cards featuring original award-winning and best selling designs by retarded persons.

Box of 25 cards and envelopes for \$6.00. Imprinting not available for this assortment.

### ORDER FORM

TO: NEW YORK STATE  
ASSOCIATION FOR  
RETARDED CHILDREN  
175 FIFTH AVENUE  
NEW YORK, NEW YORK 10010

Please send me the following  
cards by mentally retarded artists:

No. Boxes	Style, Price & Message	Amt. Enclosed
_____	AG1-2392: 25 cards at \$8.50. Warmest thoughts and best wishes for a wonderful holiday and a very happy New Year.	_____
_____	AG1-2393: 25 cards at \$8.50.  Best Wishes for the Holidays and Happiness throughout the New Year.	_____
_____	Add \$3.75 for each 25 of the above two cards imprinted.	_____

No. Boxes	Style, Price & Message	Amt. Enclosed
_____	AG-837W3: 25 cards at \$5.00. Wishing you all the Joys of the Season and Happiness in the Coming Year.	_____
_____	AG-1881 W3: 25 cards at \$6.50. Warmest thoughts and Best Wishes for a Wonderful Holiday and a Very Happy New Year.	_____
_____	Add \$3.75 for each 25 of the above two cards imprinted.	_____

No. Boxes	Style, Price & Message	Amt. Enclosed
_____	ARC: 25 cards at \$6.00  Special assortment featuring the best selling designs by mentally retarded persons. Imprinting not available for this assortment.	_____

Specify Imprint: \_\_\_\_\_  
(Add \$3.75 per each  
25 cards imprinted.) \_\_\_\_\_

TOTAL ENCLOSED \_\_\_\_\_

Your Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_ Zip \_\_\_\_\_



# "Handicapped Rights" guidelines reshaped

At this moment the "Handicapped Rights" Act is being reshaped, and the summary presented here was culled from "The Pacer" Advocate, a publication of Pacer Center, Minneapolis, Mn. 55407.

Since we are asking everyone to contact their Congressman and the President, we feel this background information is valuable.

Anyone involved with rights for handicapped persons is watching with some concern as not one, but two federal Cabinet departments work on proposals to revise the guidelines that shape Section 504's regulations, Section 504 being the statute often known as the Civil Rights Act for Disabled Americans.

Parents ordinarily more interested in Public Law 94-142 may find the proposed changes of concern even though in the past Section 504 (which is part of Public Law 93-112) has been thought to have more applicability for post-secondary students than for those in grades kindergarten through twelve.

The Department of Justice (DOJ) has primary responsibility for revision of the 504 guidelines. One of its proposed drafts (dated as of last January) has been released and reported upon by groups of both the state and national level. Two groups who monitor issues concerned with rights of the handicapped, the Minnesota State Council for the Handicapped and the Disability Rights Education and Defense Fund, Inc. (DREDF), contend the DOJ proposal would endanger the civil rights of the disabled.

A later draft has also been prepared by the DOJ; it is, presently being circulated among government agencies but was not available for review by PACER at the time this was written. A DREDF staff member who has seen the later draft said that it is an "improvement" over the version reviewed here but that critical gaps and deletions still exist.

The draft discussed here is the earlier version dated last January.

Parents of handicapped students in elementary and secondary programs may be interested in two facets of the DOJ proposal: (1) the deletion of sections that refer to education and (2) the philosophical impact of changes in guiding principles for all programs.

A second federal department, the Office of Management and Budget (OMB), in a departure from tradition, has also written a draft of guideline changes. Ordinarily, OMB would only review the proposal written by the cabinet department directly responsible for a specific area. However, in this case, OMB is the author of its own detailed proposal, unique in its introduction of a "cost effectiveness" measure as a test of whether or not services should be offered to handicapped individuals in certain cases.

A distinction must be made between changes in laws and changes in regulations. Only Congress can revise laws. However, the various administrative — or executive branch — departments and agencies have responsibility for drawing up and enforcing the regulations that put into action the laws passed by Congress.

Usually these regulations deal with "nitty gritty" details: for instance, the items that must be included in the application for a federal grant or the minimum standards for the length of an airport runway.

In this case, however, the DOJ and the OMB are working on "guidelines", not on ordinary "regulations". Here's why: Because Section 504 (which states that no handicapped person can be excluded — solely on the basis of his handicap — from any program receiving or benefiting from federal assistance) has such wide application, it was obvious upon passage that many of the Cabinet departments would have to write sets of their own regulations to enforce 504 in their departmental areas of concern.

To coordinate all the regulation writing and ensure that one department's rule writing didn't conflict with another's, what was then the Department of Health, Education and Welfare in 1978 wrote the "guidelines" that would bring unity to the process.

It is these guidelines that the DOJ has been instructed to revise as part of the administration's umbrella project to streamline regulations. Unlike on our state level — where guidelines tend to mean general policies with little legal effect or power — these federal level guidelines will have great impact in shaping the nature of the regulations which are written later.

Because they are guidelines to which all regulations must conform, they have great potential for changing the manner in which the nation views a disabled person and in determining the accessibility of all the services and rights enjoyed by non-handicapped peers.

## EDUCATION PROVISIONS

As mentioned earlier, parents of handicapped children may ordinarily be more concerned with maintaining the current strength of PL94-142 and its regulations, for Section 504 has received more attention as the protector of rights for the college students... the adult wage earners. However, as an April 15 memo from the Children's Defense Fund points out, neither 94-142 or Section 504 alone is "adequate to ensure that handicapped children will be entitled to an appropriate education. If Section 504 were not enforced through strong regulations, a state could avoid its obligation to provide a free, appropriate public education to handicapped children simply by turning down limited federal funds that are available under PL94-142.

"The State of New Mexico tried this. It turned down funds and then refused to provide appropriate education services to handicapped children. Parents in New Mexico went to court to try to get an education for their children. The federal court there found that the 504 regulations required the public schools to appropriately educate handicapped children, to prepare individual education plans, to provide related services and to provide due process procedures — in other words, to provide virtually all the PL94-142 services. Without the Section 504 regulations, handicapped children in New Mexico would have lost their right to a free appropriate public education."

In the past, federal officials have said that any weakening of PL94-142 should not be a concern since Section 504 contains all the needed protections.

Among the deleted provisions are: the guarantee of a free, public appropriate education... the right of all handicapped children to an education designed to meet their unique needs... the right of handicapped youngsters to be educated with non-handicapped classmates to the maximum extent appropriate... and due process safeguards.

Substituted in their place is a statement requiring a recipient of federal funds (in this case, a local school district) to provide an education to handicapped students at no greater cost than would ordinarily be charged for the service to non-handicapped youngsters. The Council fears that this statement could be interpreted to mean that a school need not provide any additional aids or services to a disabled child — even a special ed teacher.

## SERVICE PROVISION IN GENERAL

Besides the removal of provisions about education, another area of major concern comes in a section that deals with whether or not a recipient of federal funds is complying with the law's requirements and with the manner in which it's determined if the recipient is in compliance.

Here in several steps is what's involved:

First, the Section 504 statute (the original law) prohibits discrimination against "otherwise qualified handicapped individuals".

Second, the DOJ draft defines this "otherwise qualified handicapped individual" as someone who — with "reasonable accommodation" — can meet the "essential eligibility" requirements of a program and can achieve the program's purpose(s).

Finally, included in the DOJ's definitions of what the "reasonable accommodation" should be is a statement that the accommodation need not mean any changes in the "fundamental nature" of a program or any steps that would impose an "undue hardship" on a federal fund recipient or on "other beneficiaries of a program."

We are concerned with this section for several reasons:

- 1) There is no definition or standards against which to measure what could legitimately mean an "undue hardship" in most cases. Therefore, critics argue that recipients could resist making reasonable accommodations on the grounds that to do so would impose financial problems and, thus, "undue hardship".
- 2) The plan's opponents are worried about the statement that accommodations don't have to include any change that would cause "undue hardship" to the program's "other beneficiaries". They question whether this might be interpreted to mean, for example, that non-handicapped graduate students would have the right to forbid participation in a seminar by a person with a severe speech handicap on the grounds that his presence would impose an "undue hardship" on the rest of the group.
- 3) Compliance with the requirement would be entirely voluntary under the DOJ plan. All that a service provider who's receiving federal funds would need to do to be judged in compliance with having made reasonable accommodations is: provide an opportunity to interested parties of any objections; consider each or service; notify other interested parties of any objections; consider each objection in light of the DOJ standards; and make a written determination that accepts, rejects, or changes the objection or proposal made by an outside party.

Nowhere in the DOJ draft is there a provision for monitoring or enforcing the compliance of a recipient by a government department.

Nor is there any requirement that an offender be actually called to remedy any discrimination that's found; the recipient is allowed to serve as its own defender, prosecutor, and judge.

## "EFFECT" VS. "INTENT"

Language in the DOJ draft that would seem to require an alleged victim of discrimination to prove that a service provider and federal fund recipient had actually "intended" to discriminate is another major area of concern to the Council and DREDF.

The present HEW guidelines prohibit any action or behavior or practice that simply "results in" or "has the effect of" discrimination; the motivation or intention of the provider and fund recipient is irrelevant.

This change of direction to the need to prove "intent" is similar to that taken by other administrative departments; it has alarmed advocate groups because the "intent" to discriminate is extremely difficult to prove in court.

Finally, the present HEW guidelines — in a section called "general prohibitions" state several times (using various wordings) that handicapped persons must

have the opportunity to participate in and to receive benefits from programs that are "equal" to or "as effective as" those received by non-disabled persons.

The DOJ draft drops all parts that use the words "equal" or "as effective as".

In this same section, the draft neglects to define what is meant by the phrase "significant programs" even though it states that service providers receiving federal funds must give handicapped persons the opportunity to participate in integrated programs (even though separate or different programs may exist) ONLY if the program involved is a "significant" one. It's feared that a recipient could claim its program is not a significant one and, thus, handicapped person would be forced to receive the service in question in the segregated, separate program.

## THE OMB DRAFT

The changes proposed in the draft drawn up by the Office of Management and Budget (OMB) follow the path set by the Justice Department. For instance, OMB states that recipients must enable handicapped persons to take part in a program in the most integrated setting and can substitute a program in a different setting only to "avoid imposing unreasonable cost or other burdens on the recipient or other beneficiaries". The OMB doesn't define what standards might constitute unreasonable costs or other burdens.

However, the OMB draft goes even beyond the changes implied by the DOJ version: OMB would apply a "cost effectiveness" test to determine whether or not a handicapped person could take part in, or receive the benefits of, a service.

When outlining what recipients must do in order to provide "reasonable accommodations" for handicapped persons, the OMB says that the recipient can consider several factors to decide whether or not the accommodation would impose unreasonable costs or other burdens on the recipient (in which case, they would not have to be made). These considerations include:

- competing demands upon scarce resources,
- the value of the accommodation to the affected qualified handicapped person,
- the value to society.

We express dismay over the implications of this measure and believe that, for the first time in history, the government is applying the concept of cost to civil rights and protections.

In addition to disagreeing with the philosophy of measuring the financial expense of human rights, we are worried about the practical implications of one person or agency attempting to measure the dollar value of a benefit, either to the handicapped person receiving it or to society in general.

Following the review of the DOJ's draft by the OMB and a dialogue between them to resolve any conflicts in their desired versions, the revised guidelines will be published in the **Federal Register**. The public will have an official period provided them to offer input.

However, they may also correspond with their U.S. Congressmen and Senators and the respective Cabinet departments at any time.





## Family Care

# Gladys Ozga honored

Gladys Ozga

Provider from Rensselaer County

Mrs. Ozga has been a family care provider with the Rensselaer Team since October 6, 1972. Since the beginning, Mrs. Ozga and her home maintained compliance with the Standards for Operating a Family Care Home as well as meeting all the requirements of the Policy and Procedures Manual.

This provider has proven herself to be an exceptional Family Care Provider in a variety of ways over the years. She has always been a dependable resource to our team in providing respite to clients with many degrees of disabilities and behavioral problems. Additionally, she has been a most cooperative Family Care Provider in meeting the needs of the team during an emergency or crisis situation, without advance notice.

Her sensitivity to the clients' needs has been an asset in meeting these needs, and discussing them openly in an intelligent and knowledgeable manner. She has made it a habit to regularly attend the case reviews of all clients in her home, and to contribute to their service plans, despite the long distance she must travel. Her loyalty in carrying out individual treatment plans is above reproach.

Mrs. Ozga's ability to constructively cope with client problems whether behavioral or medical has been proven many times over. If the problem is medical, she unhesitatingly contacts the team nurse and discusses it with him. If a doctor is to be involved, she willingly transports that client to the doctor or hospital and follows directions implicitly. Behavioral problems are discussed with her case manager and, if a meeting of team members is deemed necessary, Mrs. Ozga willingly attends and provides input into the resolution of the problem. Having raised a family of four of her own, Mrs. Ozga rarely, if ever, has a client problem she is unable to solve. However, she always seeks the advice of her case manager prior to following her own intuition. As a rule, her suggestions around the resolution are acceptable and carried out. The few times a team decision has been made over a problem, she has willingly carried out those suggestions.

Two years ago, a client who had resided in her home for nearly seven years, met with an unfortunate accident. As he was leaving his work program, he was struck by a car and seriously injured. Upon notification of the accident, Mrs. Ozga immediately drove to the hospital where she remained at his bedside all night. She periodically phoned her daughter at home, who is a registered nurse, to report on his condition and to check on the other clients. Her daughter, in turn relayed messages to the Chief of Service to disperse. A constant vigil was maintained until the clients' family arrived from out of state. When he succumbed a few days later, Mrs. Ozga was cooperative, considerate and sympathetic with the family in spite of her own grieving. As she said "he was like my own." Later, she arranged to have a memorial service at the local church the client attended so his friends and co-workers would have an opportunity to pay their respects since his funeral was held out of state.

The Clients in the Ozga home have always been well received in the community and have been encouraged to function more independently through shopping in the local stores, being trained to use public transportation to and from their day programs, and the promoting of personal development through participation in activities in the home. They independently attend church services and frequently attend dinners held by various organizations in the community. Occasionally, Mrs. Ozga takes the whole group

of five to New York City to a stage play. They annually attend the county fair of a neighboring county and since Mrs. Ozga is a member of the Family Care Association of that near-by county, she frequently coordinates activities with them for her clients. One of these activities was an all day bus trip to a large zoo including a picnic — this involved three bus loads of clients and providers.

Following her husbands' sudden death six years ago, it was feared that Mrs. Ozga might retire from Family Care, but instead, she became more involved. She purchased a van large enough to accommodate all of her clients and frequently takes them out to dinner or on a trip she feels would be interesting to them. Her clients range in age from 21 to 56 and are of both sexes, and yet she manages to provide activities for all. A few years ago, when one of her daughters was married, the clients were all invited to attend the wedding. Presently one unmarried daughter (who works) and one unmarried son (who attends college) reside at home as well as Mrs. Ozga's mother, while a married daughter and a married son reside in the area, all of whom relate to the clients.

Theirs is a musical family and whenever her son's orchestra plays at a function that is appropriate for the clients to attend, they're invited. Music appreciation is an integral part of this family since her son has practice sessions and her daughter gives music lessons.

Animals are also a part of the family and the clients share the love and affection of the dogs and cats in the home. They also have the opportunity to observe the hatching and habits of Peacocks since Mrs. Ozga raises them.

Beyond all of her household duties, Mrs. Ozga is active in her church and is a member of the Altar Society of St. Mary's. Frequently she has been called by the pastor of the church to take in a youngster who has been "tossed out of his home". Other children and adolescents have come to her on their own when they have had problems or her children have brought them home — hers is an "open door policy to anyone in need". Her reputation as such, is well known in the community because of the help she has always provided to the less fortunate.

Mrs. Ozga is active in the Moose Lodge and whenever they have activities such as dinners or other appropriate events, she always includes her clients. She also is a member of the Free Citizens of Schodack. This group searches out community problems and brings these problems to the attention of the Town Board for resolution.

Whenever Mrs. Ozga knows or hears of an elderly or "housebound" person she contacts them to offer to take them shopping or to give them a ride to their doctor. She also frequently will send a home cooked meal to these people. Her musical family is well known for providing entertainment to Nursing Homes (Barnwell - Van Rensselaer Manor), the elderly (Veterans of Foreign Wars) and Senior Citizens Groups. This is all provided voluntarily by the family which indicates that her children are as caring as Mrs. Ozga.

This summer, when the Family Care Association from Hudson had a booth at the Columbia County Fair in Chatham, Mrs. Ozga "manned" that booth for a day to promote Family Care recruitment.

She relates well to the biological family members of her clients. She was instrumental in getting her youngest clients into a Boy Scout Group. Her clients are well cared for spiritually, nutritionally, emotionally and socially.

This is a true Family Care Provider in every sense of the word and truly deserving to be named Provider of the Year.



Gladys Ozga, Family Care Provider of the Year, stands between Ellie Pattison and Henrietta Messier.

## Legislative Summary

Continued from Page 7

### A-11146-A, TALLON

to enact provisions whereunder health care provider must provide access to patient information and mental health professional provide access to mental health information, upon written request of any subject, commission for incompetent, patient or guardian of infant, and qualified person; makes provisions as to disclosure to 3rd persons, waivers deemed void, correction of patient information, challenges to accuracy of information in clinical records as to mental health information, and limitations on access to mental health information; excepts certain proceedings and court orders.

Action: NYSARC requires further study.

### A-7847, SILVER (S-5632, SOLOMON)

to make it duty of Education Department to formulate rules and regulations pertaining to issuance of appropriate certificate to children with handicapping conditions who have achieved objectives of their individualized education plan as prescribed by Commission on Handicapped of school district of residence, and have been unable to successfully pass competency test required for graduation, and have satisfactorily participated in all of appropriate educational opportunities for pupils with handicapping conditions pursuant hereto and regulations of Commissioner, with such child to be entitled to receive educational services and programs until age 21, notwithstanding receipt of such certificate.

Action: NYSARC endorses concept, but withholds support until final review of two other related bills (S-3282, Harenburg and S-4682, Calandra).

### A-6244, KREMER (S-4377, LEVY)

to extend definition of operating costs of operation and maintenance of Community Mental Health, Mental Retardation and Alcoholism Services Board and local facilities to include interest on loans made to voluntary agency to obtain funds to operate community facilities for mentally disabled pursuant to contract with state or local governmental unit provided such loans were necessarily incurred; limits provisions excepting debt service on obligations from such operating costs, to debt service on obligations of local government; appropriate \$500,000.

Action: NYSARC supports.

### A-4971-B, KREMER, CONNELLY

requires the OMR-DD Commissioner to submit an annual plan to the Budget Director for his review and approval, defining the class of community residences deemed appropriate for fee-for-service funding, based on various criteria, with all residences so classified to be scheduled for conversion to such funding. There are related provisions.

Action: Hold for Status Report; No time frame for implementation.

### A-4774-A, GRABER (S-837-A, FLYNN)

permits the issuance of a non-operating driver's license for identification purposes to adults who do not drive.

Action: NYSARC supports.

### A-4266-A, BUSH (S-3374-A, LOMBARDI)

to require that upon request and when site has been selected for community residential facility by sponsoring agency, latter shall do feasibility study to determine whether it is less costly of agency to acquire and rehabilitate proposed site, lease it, or construct new facility thereon or on sites as may be proposed by sponsoring agency or municipal, with study to also consider possible architectural needs as they may be determined to affect nature of program at proposed facilities; makes related provisions.

Action: NYSARC opposed. (Extends unnecessary Site Selection process)

### A-2583-A, BUSH (S-2036-A, LOMBARDI)

to make certain changes in definition community residential facility for disabled in provisions relating to site selection thereof, to include supervised living facility subject to licensure by Office of Mental Health or Mental Retardation which provides residence for less than 9 instead of for up to 14, mentally disabled persons.

Action: Requires further study and tracking.

### A-1002-A, CONNELLY

requires the full amount of Medicaid spent at any Intermediate Care Facility - MR - DD, including transportation, to be paid to the local DSS, after deducting available Federal reimbursement.

Action: Requires further study.



## Study shows retarded ratio high in jails

Thousands of mentally and physically handicapped people are in the nation's prisons, but apparently no one knows exactly how many and few resources exist to meet their needs, according to a Federally financed survey.

The survey, "The Handicapped Offender," and its bibliography, citing 182 books and research works, concludes that there are proportionately more mentally retarded people in prisons and jails than in the general population.

A Missouri study cited by the survey found 3 percent of the state's general population mentally retarded, compared with 10 percent of the prison inmates and 6 to 7 percent of parolees and probationers. One of the few national studies, made in 1966, found similar data.

The survey, published by the National Criminal Justice Reference Service, was financed by two Justice Department agencies, the National Institute of Justice and the National Institute of Corrections.

James L. Underwood, acting director of the National Institute of Justice, said there was a major need to accelerate training so prison employees could recognize mental handicaps in offenders and develop programs for them.

Estimates by prison experts of the number of mentally retarded people in inmate populations range from 9 percent nationally to as high as 30 percent in some states, the researchers said. "Clearly, the number is unknown, but the lower estimates are probably closer to the mark," their report said.

The survey said even less was known about the numbers and needs of physically handicapped inmates.

In addition, it was reported that many retarded offenders were confined in state institutions other than prisons. A 1975 study of 141,000 institutionalized retarded people found that 5 percent, or 7,050, could be classified as offenders sent there instead of to prison.

The researchers cited these shortcomings of existing prison programs for the handicapped: lack of appropriate treatment facilities, inadequate diagnostic services, lack of trained personnel, infringements on legal rights and abuse of handicapped offenders in prisons.

"Naive or retarded and physically disabled incarcerated offenders are particularly vulnerable to exploitation by stronger and more aggressive inmates," the report said.

## WIC wins in NYS

Governor Hugh L. Carey signed a bill in July amending the Public Health Law to establish an emergency nutrition aid program for pregnant women and adolescents. Eligibility for the program is limited to low income, pregnant women and adolescents who, because of their dietary deficiencies, may be at high risk of endangering the health of their fetuses or delivering low birth weight infants.

The federal supplemental food program for women, infants and children has demonstrated that nutrition programs can result in a significant decline in the number of low birth weight babies delivered to participating women and in the incidence of infant morbidity.

The bill will provide the State with the necessary flexibility to allocate up to \$4.5 million in State funds to meet the nutritional needs of pregnant women and adolescents who are at risk but are not currently being served by the federal program or who may be affected by proposed reductions in federal funding.



## AHRC re-elects President Redfield

Manhattan attorney Walter C. Redfield (right), receives congratulations on his reelection as president of the New York City Chapter of the Association for the Help of Retarded Children from I. Joseph Harris, commissioner of the State Commission on Quality of Care for the Mentally Retarded, as Michael Goldfarb (left) looks on. The AHRC, with headquarters at 200 Park Avenue South, Manhattan, held its annual election meeting at the Sheraton Center, Manhattan.

## Handicap differences decide action

Suggesting that no law of the land can change attitudes, keynote speaker Dr. Elizabeth Boggs of the Association for Retarded Citizens told a New Jersey conference early this year that many important achievements for the developmentally disabled will depend on the efforts of deeply concerned individuals.

To provoke concern and to examine some of the "ethical dilemmas" involved in social policy for the handicapped were co-equal goals of the first conference sponsored jointly by the Association for Retarded Citizens — New Jersey and the National Conference of Christians and Jews. Focusing on the theme "Social Policy and the Handicapped," the one-day meeting was attended by approximately 65 persons at the Center for Health Affairs, Princeton.

Four issues that highlighted the paradoxical nature of some contemporary social problems concerning the handicapped were presented in a late morning session. . . They were Paternalism versus Autonomy, Integration versus Segregation, Competing Equities, and Family Life and Reproductive Rights.

In that sequence, the presenters were Harold Rubenstein, J.D. of the Administrative Office of the Courts; Frank Laski, J.D. of the Public Interest Law Center of Philadelphia; Ethan B. Ellis of the New Jersey Division of Advocacy for the Developmentally Disabled; and Linda Carelli, ACSW, a co-adjunct faculty member of the Graduate School of Social

work, Rutgers University. Following lunch, those guest authorities presided over afternoon discussion groups that examined the same subjects.

No pat solutions were expressed, or expected, at the conference. The point was rather to develop new ways of thinking about the issues and to give light to different points of view, a direction that was set by Dr. Boggs during her opening presentation.

**She declared that freedom of choice was important to mental health and, concomitantly, to a positive outlook on life. She said, too, that handicapped people are very different from one another and that those differences had to be taken into account when deciding, or trying to decide, what choice of action to favor.**

Throughout the day, another aspect of difference was frequently illustrated; it was the contemporary presence of nearly diametrically opposite points of view — in law, policy, and "social philosophy" — surrounding the principal themes of the conference. Discovering and exploring some of the spontaneous expressions of those differences was what developed, in fact, during the afternoon discussion groups.

If any answer emerged from the conference, perhaps it was that the most appropriate and useful solutions to the ethical dilemmas posed would come only from long and deliberate exchanges of opinions among all concerned people, particularly the handicapped themselves.

## Onondaga expands work opportunities

Monarch Industries, the Onondaga County Chapter's work division, has dramatically expanded its Work Stations in Industry project which employs retarded persons at community sites. Forty-five workers are now employed at job sites like a local hospital, warehouse and apartment complex.

In a work station arrangement, which is a transition between a sheltered workshop and competitive employment, Monarch Industries contracts with the company to provide a service at the company's place of business. The workers, who are still paid and supervised by Monarch Industries, have an opportunity to work in an integrated setting, to do more demanding

work and to better prepare themselves for a competitive job.

Work stations employees have performed tasks such as dishwashing, sorting of metals and lot beautification for local employers. Monarch Industries has also completed negotiations for two additional work stations at factory sites.

In addition, the work stations project received a boost when "Work Stations, The Employment Alternative," a 25 minute television program about Monarch Industries' efforts to employ more workers at community sites, premiered on a local cable channel. The TV program, one of the first about work stations, is a community educational tool.

## Amniocentesis

## defended as

## prevention method

Replying to a request from Geraldine Sherwood, Dr. Lawrence R. Shapiro, Director of Genetics at Letchworth Village, welcomed the opportunity to clarify the relationship between amniocentesis and abortion "because this is a much misunderstood subject."

Amniocentesis for prenatal diagnosis, in my opinion, wrote Dr. Shapiro, results in the birth of many more babies than pregnancy terminations since 98 percent — 98½ percent of prenatal diagnostic results are normal; thus, amniocentesis for prenatal diagnosis tends to be an exercise in reassurance.

The options related to the detection of an abnormal fetus include termination of the pregnancy as well as preparation, both psychologically and actual, for the birth of an abnormal baby.

In my experience, even if a couple is unable to consider termination as an option, amniocentesis for prenatal diagnosis offers considerable reassurance since the results are normal 98 percent of the time and enables preparation if the results are abnormal.

Many couples have indicated that they would not have planned a pregnancy if amniocentesis for prenatal diagnosis were not available and a small but significant percentage of couples have indicated that they would have terminated their pregnancy if amniocentesis for prenatal diagnosis could not have been done.

Thus, many more babies are born because of amniocentesis for prenatal diagnosis than are not.

The area of intro-uterine — prenatal therapy includes a number of metabolic diseases which can be detected by prenatal diagnosis and subsequently successfully treated with appropriate biochemical agents.

While the number of treatable disorders is small, research promises to expand the number. Intra-uterine surgery following prenatal detection, especially by ultrasound, has been reported and is now being developed on an experimental basis.

The final report of the Governor's Conference on the Prevention of Developmental Disabilities and Neonatal Mortality (New York State), of which I was a member, contains an excellent section regarding this entire subject, wrote Dr. Shapiro.

In June, Mrs. Sherwood queried the Director of Genetics on behalf of NYSARC: "It would be most appropriate if we could inform concerned individuals of the variety of ways in which a full range of prevention efforts can be made available on a continuum of service which do not in any way necessitate aborting a fetus."

The Association has recognized for years that by closing the gap between existing knowledge and the timely and effective dissemination of available knowledge, it is possible to reduce significantly the incidence of mental retardation and developmental disabilities.

Because we feel so strongly that the most effective treatment for such is prevention, we have, over the years, attempted to support legislation and research toward this end. Unfortunately, however, these efforts are sometimes misunderstood by those who perceive our support of prevention efforts as synonymous with pro-abortion activities," Mrs. Sherwood concluded.



# Rehab works together

By Yvonne Kristiansson  
Human Development News

Jane (not her real name) was placed in a small business firm as a file clerk after completing the Projects With Industry (PWI) skill-training program for young handicapped adults. After she had worked in the office for about a year, the company sent her back to the program and paid for her to upgrade her skills. A company spokesman explained, "We would do this for any of our other employees, so why not for Jane?"

John, another trainee, conducted a tour of the PWI program for its advisory board. A board member was so impressed with John's attitude and performance that they set up a job interview for him, and John got the job.

PWI is a growing concept in the field of rehabilitation. The program established under the Rehabilitation Act of 1973 (P.L. 93-112), contracts or jointly finances cooperative arrangements with local business and rehabilitation organizations for the establishment of projects designed to prepare handicapped individuals for gainful employment in the competitive labor market. This includes training and employment in realistic work settings and other such necessary services as job readiness skills.

The purpose of PWI is to develop partnerships with cooperative businesses that will lead to jobs for program graduates.

One PWI program in operation for the past five years at The Lieutenant Joseph P. Kennedy Institute in Washington, D.C. is helping developmentally disabled adults find jobs. The program is funded under the Rehabilitation Act, and the federal government pays for the cost of placement activities while the cost of training is covered by the State Vocational Rehabilitation Service or other sources.

Unlike most PWI programs that deal mainly with the physically handicapped, the program at the Joseph P. Kennedy Institute focuses primarily on persons with mental retardation.

All of the young people (the average age is 24-28) have some type of developmental disability and most are in the mild to borderline range of mental retardation. Many have multiple disabilities, such as emotional problems, and visual impairment as well. Most of the individuals either live at home with their families or in foster homes.

Usually referred by State Vocational Rehabilitation Service agencies or other types of community services, clients coming into the program have been through medical, vocational and psychological evaluations before being assessed to see if the program fits their individual needs.

The clients then rotate through a 3-week assessment period at the Institute where they visit three different training areas; food service, office skills and building maintenance.

After the assessment period, the participants will receive either skill training or on-the-job training, depending upon their individual needs.

The skill-training program, which involves about 25 young people, helps workers prepare for employment. They work on such skills as typing, building maintenance and food preparation until they finish their training or continue with on-the-job training. Usually, training is completed within one year, but the length of time varies according to individual needs and abilities.

In the on-the-job training component, which has 10 participants and is expanding, the client obtains skill training by working on-site at a company that has contracted with PWI. For example, several young workers are now learning food service skills at Howard University Hospital. When the current job training program ends in mid-July, the students will be ready to look for employment.

The program at the Kennedy Institute also offers training in developing skills in other areas, such as job seeking, which includes interviewing techniques, and other life skills, such as learning how to work with others in a business setting.

The young people are also encouraged to go out and find job leads on their own. For some of the workers, this may mean looking in the want ads; for others who are not as adept readers, it may mean going door-to-door or looking at building directories.

"This allows the clients to take on more responsibility and that is important, even if they only copy a company's name down from a building directory," said Judith Berland, director of Rehabilitation Services at the Kennedy Institute. "They get involved in the job-hunt process, and that is an important step in becoming independent."

Encouraging independence is an important aspect of PWI. For some of the young people, independence can mean they are able to take the bus by themselves — and that can be quite an accomplishment.

Peer counseling is another important part of the PWI program. Every week the institute offers a get-together with former trainees who have already found jobs. During this time, the workers talk about their jobs and encourage others who do not yet have jobs. Through the informal sessions, a network system develops.

"Healthy relationships often develop among the peer group members," said Berland. "There is more pressure for the clients to do well in their own peer group. Also, they will look out for one another, and help each other in finding job leads. This means that we are not always doing all the work, and that is great for the workers."

"The individuals in the PWI program at the Kennedy Institute have a better understanding and attitude toward business when they come to work because of their training," said David Walters of Vitro Labs in Silver Spring, MD. "They have gone through the program and the time the counselors spend with them is very important to their success. One important aspect is the flexibility the workers have. If a problem does occur, the counselor will come out to the job site and talk with the supervisor and the workers to try to solve the conflict. I hope to continue with this program. The people who come here are good workers and they have a good attitude."

Giant Foods — a local supermarket chain — the Woodward and Lothrop department store and Xerox, to name a few, are other firms involved with PWI.

PWI is working in the community. Placements have been fewer because of the economy, but this has not kept individuals from trying. They know jobs are available — but that a little more work and time will be required.

PWI is helping to bring independence to many mentally disabled individuals in the Washington area. As Kennedy Institute's Berland pointed out: "We all have the same goals, we want relationships, jobs and we all want to live on our own. The mentally retarded are no exception. They want these things, too, and PWI helps them to realize that they can achieve these goals, among others."

PWI is just one example of how the disabled can adjust and fit into our society as important and fully active members of the community.



Hail, Hail, the gang was all there as nearly six hundred children and adults attended Nassau AHRC's Camp Loyaltown. The residential camp is nestled below Hunter Mountain and includes a wide range of recreation and daily living activities.

## Suicide prompts proposal to train retarded adults

The arrest and subsequent suicide last December of a Hunterdon County retarded man led recently to an appeal by the Criminal Justice Education Project of ARC-NJ that the mentally retarded be taught how to deal with public officials, particularly the police.

For several years, law enforcement people have been learning about mental retardation and the mentally retarded in the various "classrooms" of Kevin Mays, CJE Project director. The time has come, it appears, that some of that instruction go the other way.

"There are times," Mays said recently, "when any citizen is likely to be approached by a police officer... individuals who have a handicapping condition might be approached even more frequently."

"Those contacts with law enforcement professionals do not have to be frightening, derogatory, or demeaning for people who have acquired some basic skills of conduct for such situations," Mays said.

Mays said he felt the suicide of James MacNamara, 40 year-old son of one of the founders of the Hunterdon County ARC, might have been avoided if MacNamara and authorities had greater understanding of the circumstances and acted accordingly.

The retarded man, an employee in the maintenance department of the Hunterdon Medical Center, was at the Center's Christmas tree sale on December 11 when he was taken into custody by Raritan Township Police and charged with having made an obscene remark to a 14 year-old boy. After being released by police, MacNamara returned home and took his own life, authorities reported.

Joan Crawford, Hunterdon ARC executive director, told a community group in January that somebody should have explained the offense to MacNamara and helped him to understand his rights.

"He saw it as such a terrible offense, such a terrible burden to his family, he

could not live with it," Crawford told the Community Services Council.

Mays, in a separate appeal for increased education and understanding, announced that he will make available a short workshop for any groups interested in trying to help the mentally retarded better deal with professional people.

"He said the workshop session would include a list of behavioral Do's and Don'ts, of which mentally retarded and other handicapped individuals should be aware. That and other workshop material, Mays indicated would "... maximize the maintenance of an individual's rights, while helping him to cooperate with the police or other criminal justice professionals to the greatest possible degree."

## Supermarket aids tots

A supermarket on Long Island has introduced what company officials say is unique in America — seat belts on the shopping carts. Their purpose, from the company's point of view, is to keep tots from tumbling out of the carts and bouncing back with injury lawsuits.

Thus, if the seat belts prove effective at King Kullen supermarket in Centereach, they will be used in all the chain's stores. Shoppers, at least those who have had to retrieve bloodied children from the frozen food section, seem to appreciate the innovation.

We can see a more universal application, since falls from shopping carts are probably fairly uncommon. It has to do with the parent's peace of mind rather than the youngster's safety.

If seat belts keep children strapped to the shopping carts, they may also restrict the range of juvenile fingers grabbing goodies from the shelves. And that may curb the checkout brawls over gum and candy bars and all the other little allurements that supermarkets dangle in the path to the parking lot.

## Proclamation

WHEREAS, Marc Brandt has been the Director of the Sullivan County Association for Retarded Children since June 1, 1971, and

WHEREAS, Marc Brandt has been the guiding light in the development of the many services rendered by the Sullivan County Association for Retarded Children which has served as a model agency demonstrating technical skills, compassion and service to the mentally retarded, and

WHEREAS, Marc Brandt's eleven years of dedication has served as an inspiration to all, and

WHEREAS, Marc Brandt will be leaving

the Sullivan County Association for Retarded Children to become Executive Director of the New York State Association for Retarded Children.

NOW, THEREFORE, BE IT RESOLVED, that I, Brian Ingber, Chairman of the Sullivan County Board of Supervisors, do hereby proclaim August 16-22, 1982, as MENTAL RETARDATION WEEK, in Sullivan County in honor of Mr. Marc Brandt's eleven years of employment with the Sullivan County Association for Retarded Children.

Dated: August 9, 1982  
Brian Ingber

Chairman

Complete registration on  
this OCV's back page today!



## No easy answers, says parent; Questions hard too, says daughter



Kate Klein and daughter Margaret Klein smile between sessions at Follow Up conference on Sexuality and Mental Retardation sponsored by Westchester Chapter in May.

By Kate Klein

Parents and professionals swapped facts and fears in an all-day conference on Sexuality and Mental Retardation in May at the old Tarrytown Road School, White Plains, N.Y.

After a warm welcome, Mary Kallet, Assistant Executive Director WARC and Coordinator Roy Strassman both promised that myths about sexuality and the mentally retarded would be explored and diminished during the workshops.

The conference dealt with Sex Education, its legal aspects in developmental centers and community residences, attitudes and values as expressed by professionals and parents, marriage and the mentally retarded, recreation in mixed company, and the complexities of sex education and sexuality education for the various levels of mental disability.

### WHERE TO START?

Professionals in dialogue with parents talked about the enormous responsibility they feel in guiding the people whom they serve in problems, recreation experiences and residence life — guiding them through the maze of establishing personal values. In doing so, they must move with care and understanding of the levels of comprehension of the person who is mentally retarded, professionals said. Sex education for an adult who is mentally retarded is closely tied into self-esteem. The evermore present problem for anyone, parent, teacher or counselor is the determination of — How Much is Enough?

Parents responded with duplicate fears about levels of understanding. In addition, parents said the same impediments to talking frankly about sexuality which deters proper sex education for children and adults who are not retarded are multiplied in conquering the embarrassment (due to cultural reluctance) and the uncertainty as to understanding of the person who is mentally disabled.

Parents expressed concern that the values in life relationships which were part of the family life at home might be lost in community residence life. Professionals responded with the explanation that they had a responsibility to act only with appropriate and functional information.

Both agreed it was necessary to explore solutions which avoided the premise of one-rule-for-every-complexity. Each person's education about sexuality ought to be as carefully prepared as is that of a school individual education program, one parent opined.

### WILL PEOPLE IN COMMUNITY RESIDENCES WANT TO GET MARRIED?

An undercurrent of emotion is always present in a conference on this subject because of the long cherished myth that people who are mentally retarded have little interest in the opposite sex.

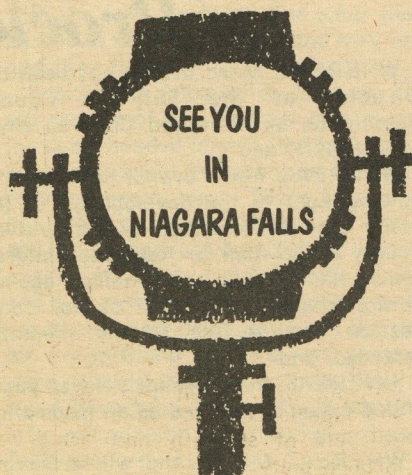
In developmental centers and in schools for the mentally retarded, separation of the sexes has been the tradition, except for highly supervised recreational opportunities. The conference, in highlighting the complexities of Marriage and the Mentally Retarded, was limited to consideration of marriage between persons who are disabled.

Parents fear exploitation and inability to meet marriage responsibilities. Professionals explain how appropriate supportive mechanisms have made marriage attractive but asked for input on dealing with the limitations of such marriages.

### HOW TO REMONSTRATE WITH PEOPLE WHO DON'T TALK

Spontaneous role playing by Margaret Klein of St. Lawrence Chapter resulted in clearing up one social problem for this interested young adult. "I didn't know how to handle it before" she said. "Now I know what to do." What impressed this 25-year-old former client of the Rehabilitation Center was that "so many nice people would come and talk with us!"

The need for this kind of conference was applauded. Ann McDonnell, WARC President summed it up. "We all need to know more. We need to talk more. This is only the beginning of the search for solutions."



# The Working Board

by Kate Klein

Fred McDonald, spokesman for McDonald Management Corporation, sparked debatable comments from members of the Board of Governors who attended his Management Training Session for board members and executive directors prior to Spring Board Meeting.

Not-For-Profit organizations are in jeopardy, McDonald told the group, because of lack of professionalism in conducting their affairs. He predicted that the number of not-for-profit organizations in current existence would be reduced by at least half because of improper accountability on the part of board members. He stressed the need for a "mission statement" for each organization which would clearly lay out both the philosophy of the organization and the framework for effective administration and delivery of service by the staff.

Responsibility for and establishment of funding mechanism to insure the needed support for the organization's programs is one of the chief responsibilities of the board of directors.

### EVALUATING EXECUTIVE DIRECTOR

Total administrative management accountability should be delegated to the executive director with appropriate techniques for measuring his efforts in place on a one-year basis and in a long-term goals written document, McDonald told the board members.

McDonald cautioned board members attending the conference that, in demanding accountability of its executive director, the board must not infringe on the authority of the executive director. The executive director must be allowed the authority to hire and fire staff, promote or demote staff and establish the internal evaluation system for personnel. The director must, however, utilize the talents of board of directors, their experience and resources as individuals or as a group in carrying out the management administrative role.

### ANNUAL BUDGET

Each year the Board of Directors will vote as a board on the annual budget submitted by the executive director, usually through the board's Finance Committee. The budget represents the cost of services, direct and indirect, that the Board authorizes for the year.

### HOW TO CHOOSE BOARD MEMBERS

In choosing new board members, McDonald advised that the Nominating Committee select people based upon criteria established by the board with recruitment focusing on committee needs.

Before being invited to join the board, a potential candidate should be fully briefed as to expectations the board has for that individual's tenure on the board and should be provided a preliminary orientation to the organization. The candidate should be given time to review the Board Manual for Policy and Operations prior to joining the board; the latest annual audit of the organization and official minutes of the last two board meetings.

### BOARD COMMITTEE

Management heads within the administrative structure who have been selected by the Executive Director may serve in an ex officio capacity with those board committees. Board committees recommend policy to the board of directors. They do not set policy. Each committee should have one board member on the committee as chairperson.

### BOARD MEETINGS

Board meetings are called to hear recommendations and motions of the various committees of the board where all of the preliminary investigative work and discussion of alternatives is conducted.

Meetings of the full board are decision meetings and are solution oriented. Committee meetings held between full board meetings identify problems and potentials and recommend to the full board what actions should be taken.

Board meetings should not be "problem" oriented. Problems are referred to committee for lengthy discussion.

In discussing how an executive director works with the board, McDonald cautioned board members not to allow the executive director to bring problems to the board for solution. When the executive director discusses a problem with the board it should be in terms of the solutions he recommends for their decision.

The agenda for the board meeting should indicate what decisions are needed at the meeting. Reports pertaining to the decision should be distributed before the meeting.

Discuss, react and solve are three separate steps, board members learned. Too often, reaction is considered the solution. Decision must fall under the framework of the goals and objectives of the association, and be free of personal content.

People attending the session agreed they had been given a lot to think about and detail to their chapter boards.

## Commission wraps up IYDP study

The final meeting of the state Commission on International Year of Disabled Persons was held in Albany in March to review committee recommendations for attaining the goal of full participation for all disabled persons in society.

In his remarks at the session, Lieutenant Governor Mario Cuomo, Commission Chairperson, stated, "This is the last meeting of the Commission on International year of Disabled Persons and it has been a very good effort. Indeed, I do not know if there has been in the last 20 to 50 years a challenge to progress like the one we face this year. There appears to be an instinct that looks for a reason not to be gentle, kind and outgoing or even fair."

This is not a time to be talking about persons with disabilities politically," he continued. "It is not a subject that is well-received and so all the more need for a group like this one to convene, to analyze, to conclude intelligently and then, most of all, to articulate. It has never been needed more."

New York State Advocate for the Disabled, Dr. Frances Berko, stressed the importance of the work that had been completed, vowing to make certain that the recommendations of the commission will be implemented so that citizens with disabilities in New York State will be fully integrated without bias into the quality and flow of community life.

**DON'T FORGET  
TO ORDER YOUR  
CHRISTMAS CARDS.**



## News and views

# Your Education Committee at Work

Betty Pendler, Chairperson

NEW... NEW... NEW REPRINTS WILL BE EXHIBITED AT OUR VERY BUSY BOOTH at the Convention, so be sure your chapter picks up all our reprints including our latest ones on "Instructional Objectives Checklist", "How and When to Observe Your Child", "Assessments", "Decreasing Problem Behavior", "In Praise of Teachers", 4-page critique of the State Education Department's "Parents' Handbook", and "Physical and Occupational Therapy."

MAKE YOUR OWN PARENTS HANDBOOK FROM OUR REPRINTS. Erie County Chapter did that and got a fabulous response — we heard about it from Rockland County which is pretty far away from Buffalo. It's a great idea and good for your chapter to assist your staff and help parents.

The theme of our workshop will be "SPECIAL EDUCATION UPDATE - CLARIFYING THE UNCERTAINTIES." We will have an open forum and dialogue on the most recent developments on education of the handicapped, with knowledgeable presenters, and plenty of time for questions and answers.

We feel strongly that, this coming year, chapters will have to become more knowledgeable about what is going on in the educational system in the light of all the changing rules and regulations. Also with many chapters moving into residential facilities for the under 21 population, they are going to be hit with such questions as which school district has the responsibility, can you represent a parent on the Committee of the Handicapped, how far is your authority in the due process procedure, etc. Therefore, we hope your agency will urge both staff and members attending the convention to come to our exciting workshop.

## EDULETTER

We are planning, this year, to put out three bang-up, packed full of information Eduletters, but the NEW THING WILL BE A SPECIAL PAGE FOR CHAPTER ACTIVITIES IN EDUCATION. We want to know all the things you are doing. So won't you get ready to send us items of what great things you are doing out there? We know they are being done because we hear about them — too often through the grapevine, and not directly. SO GET IN PRINT! TELL US WHAT YOU ARE DOING!

Our Eduletter travels far and wide, and while we don't want to sound like we are bragging, we want to announce that our publication has reached the shores of Frankfurt - Main, West Germany, where we received a communication from a member of the Associated Press inquiring about further information. So, our NYSARC gets international publicity as well!

Our Education Committee met during the hot July summer and had an in-depth self evaluation, and decided that this year, we were going to pay more attention to two new issues: early childhood education and education in the developmental centers. We would appreciate your comments, questions, concerns, etc. in both of these areas to assist us.

WRITE... WRITE... WRITE to your local politician, to your state officials and to your government officials. We quote from Senator Daniel Patrick Moynihan's response to Judy Shalvey, one of our committee members on the issue of 504: "I have taken the liberty of forwarding your

letter to the Justice Department revising its preliminary draft as it continues to develop new regulations, for inclusion in the public comment record on these regulations. I am assured that all comments are reviewed and taken into consideration before final regulations are issued."

Even if this is a form letter, if our representations do forward our correspondence to the accountable department, that is a significant action. SO, KEEP WRITING!

COMMISSION ON QUALITY OF CARE PROJECT ON HELPING PARENTS TO BECOME ADVOCATES will be winding up this project, and we hope to have materials available for all chapters. Look for further information on this in your next issue.

We hope all chapters will have an Education Column in their Newsletter, all chapters will list Educational Advocacy as a direct service, and that all chapters will consider having at least one membership meeting on Education. Our Committee stands ready, and willing to assist you if that is necessary, but we would like to attend if you do have such meetings, so we can learn from you. Therefore, please keep us informed of your plans. Please feel free to contact any of us:

Janet Calkins	Judy Shalvey
Joan Fiala	Georgia Sullivan
Mary Murphy	Marilyn Wessels
Shirley Reynolds	Barbar Pyle
Thomas Scholl	Shirley Valachovic
Betty Pendler, Chairperson	

## Dollars on the kids

The federal Education Department has run out of excuses for using 12 year-old census figures to distribute aid for teaching disadvantaged children. More current data are available and should be employed.

Education Secretary Terrel Bell has been enjoined preliminarily from basing the \$2.8 billion in federal money on the 1970 census. Federal District Court in Washington acted at the request of New York and nine other states which would receive less aid under the 1980 census figures than under 1970's because their poverty populations have grown.

The dispute means more than \$40 million to New York.

Mr. Bell said in May he would use the old information because the new census results would not be available until late summer or early fall. The state Education Department, however, says it has had the statewide total since May and county-by-county figures since early June. If the data are available in Albany, they ought to be available in Washington as well.

The Education Department is debating what its next step, possibly an appeal, will be. The proper answer seems clear enough.

The money will be given to the states. It should be distributed as fairly as possible. The information that would allow equity is available. There is not good reason not to use it.

Watertown Times  
Editorial

**DON'T FORGET  
TO ORDER  
YOUR CHRISTMAS CARDS.**

**Register today for Oct 7-10**



Bernard Carabello, a former 18 year resident of Willowbrook; Chairman John Johnson, and Founder Geraldo Rivera raising funds at the 1974 One to One Telethon.

## One to One to mark anniversary

Ten years of progress for the retarded will be celebrated by One to One members and friends.

A spectacular celebrity party will be televised "live" from New York's Studio 54, on the evening of October 12th honoring everyone who has helped make community services a reality.

John Johnson, One to One's new chairman, has invited many of the performers, musicians and show business personalities who have supported One to One's work over the past 10 years to reunite and help with this milestone anniversary party.

When One to One began, contributions hardly called for celebration. However, in 1972, following Geraldo Rivera's series of reports about the shocking conditions at Willowbrook, he joined forces with leading advocates for the retarded at a memorable festival in Central Park, matching thousands of volunteers with retarded individuals for a day of fun. That same night a concert at Madison Square Garden, starring John Lennon, Yoko Ono, and other musicians, raised over \$300,000 in start up money.

Since then, countless artists like Stevie Wonder, Chicago, Sammy Davis, John Denver, the Allman Brothers and Peter, Paul and Mary have performed at concerts that have helped to raise the over two-and-one half million dollars in grant money which has been given out to over eighty community residences in New York, New Jersey, and Connecticut. ARC chapters received over 1 million dollars to start residential programs.

This year's three hour television celebration will be hosted by John Johnson (WABC-TV Eyewitness News), with Geraldo Rivera (ABC-TV, 20-20), and will feature live performances by contemporary recording artists and Broadway stars. The program will be seen on WOR-TV, New York and via satellite to 2,000 cable systems coast-to-coast.

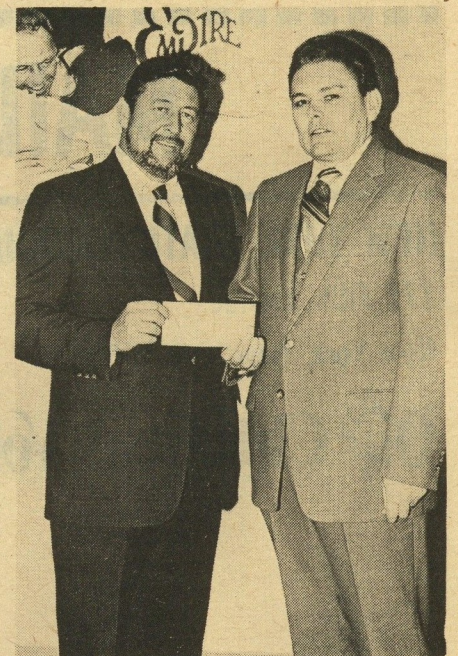
The committee working on the event includes Yoko Ono, Stevie Wonder, Tony Bennett, Art Garfunkel, the Harlem Globetrotters and many others.

## ARC wins in State Lottery Contest

Mr. James Nolan, Regional Director of the New York State Lottery, presented NYSARC representative Don Westervelt with a \$10,000 check for placing second in the State-wide Cashback Lottery Contest. The award ceremonies were held on April 28, 1982 at the Lottery Offices in the World Trade Center in New York City.

For the ARC, this program proved successful in several ways. It provided state-wide press coverage through the combined efforts of the Lottery Commission and the ARC participants. It also provided a united effort, allowing all of our chapters to become part of a joint fund raising program, while helping both large and small chapters equally. As a group, we received over twenty-three thousand dollars. This money was disbursed to the Chapters on a pro-rated basis according to the number of tickets each turned in. Chapters that could not collect vast number of tickets shared in the higher yield per ticket achieved through the group prize winnings.

In this way, we all helped one another and experienced once again a very basic example of strength and achievement through unity.



Mr. James Nolan, Regional Director of the New York State Lottery, presenting second place prize to NYSARC representative Don Westervelt.



# REGISTER HERE FOR N.Y.S. A.R.C. CONVENTION

October 7 - 10,  
1982

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Niagara Falls, New York

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CITY \_\_\_\_\_ STATE \_\_\_\_\_ ZIP \_\_\_\_\_  
PHONE NO. \_\_\_\_\_

IF SHARING ROOM  
PLEASE STATE NAME \_\_\_\_\_  
DATE OF ARRIVAL \_\_\_\_\_ TIME OF ARRIVAL \_\_\_\_\_  
DATE OF DEPARTURE \_\_\_\_\_ CHECK OUT 12 Noon

### PLEASE PRINT

NAME OF GROUP	CIRCLE RATE DESIRED
NYS ASSOC. FOR RETARDED CHILDREN, INC. Oct. 7-10, 1982	SINGLE \$45 \$49 \$53 \$57 \$61
	DOUBLE \$55 \$59 \$63 \$67 \$71
	IF NOT AVAILABLE, NEXT RATE WILL APPLY.

YOUR ORGANIZATION HAS RESERVED A BLOCK OF ROOMS  
TO BE HELD UNTIL 3 WEEKS PRIOR TO THE OPENING OF YOUR  
CONVENTION. WE WILL THEN ACCEPT RESERVATIONS  
ON A FIRST COME BASIS AT REGULAR RATES.  
PLEASE MAKE RESERVATIONS PROMPTLY.

ALL RESERVATIONS MUST BE MADE WITH THIS FORM.

PLEASE ENCLOSE YOUR CHECK  
FOR THE FIRST NIGHT'S LODGING  
IN THE ENVELOPE PROVIDED. A  
WRITTEN CONFIRMATION WILL BE  
SENT TO YOU UPON RECEIPT.

Thank You

## CONVENTION REGISTRATION FORM

TO: NIAGARA A.R.C.  
1555 Third Ave.  
Niagara Falls, N.Y. 14304  
Attn.: Convention Registration Chairperson

Please accept my reservation for the following Convention events:

Registration \$20.00  
Buffet Breakfast \$ 6.00  
Luncheon \$ 9.00  
Banquet \$20.00

Total

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

For reservations received before Sept. 20th special price  
of \$50.00 covers all.

# MAIL YOUR RESERVATIONS TODAY

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

175 Fifth Avenue

New York, New York 10010

**Our Children's Voice**  
Retarded Children Can Be Helped

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