

# Our Children's Voice

Retarded Children Can Be Helped

VOL. XXXIV NO. 2

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

MAY 1982



Helen Kaplan, Executive Director, Nassau Association for the Help of Retarded Children will be honored with AHRC's 1982 Humanitarian Award.

## Helen Kaplan to receive Award at June Rose Ball

The Board of Directors of the Nassau AHRC has announced the designation of Helen Kaplan as the recipient of the Humanitarian Award to be presented at the organization's annual Rose Ball, June 19th at the Hilton Hotel in New York City. Mrs. Kaplan becomes the twenty-third recipient of the Humanitarian Award, given in recognition of leadership and achievement for the mentally retarded.

Mrs. Kaplan, the executive director of the Nassau AHRC since 1961, was a founding member of the organization and served as the first president of the Nassau chapter when the Long Island chapter was divided into two groups. She assumed a staff position following the death of her husband and has played an important role

in the chapter's activities as well as in the development of the New York State ARC legislative program. As a member of the State ARC's legislative committee, she helped to bring about important legislation including laws which made possible the education of the mentally retarded.

Mrs. Kaplan, honored by the New York State Department of Mental Hygiene when it named its award for achievement for the mentally retarded, the Helen Award, received an honorary doctorate in law from the C.W. Post Center of Long Island University. Included in her long service as a member of various advisory groups was her membership in the 1970 White House Conference For Children.

### PRESIDENT'S MESSAGE

It is always a source of great frustration to know that publication deadlines call for writing a column long before the actual delivery date of OCV. The obvious difficulties of potentially out-dated material always looms over our heads.

Therefore, I am going to try to look into the "crystal ball" and foresee that hoped for lobbying efforts have paid off with a less devastating budget picture for NYSARC. Indeed, at this very moment, incredible efforts are in process by individual chapters, the Executive Directors

Association and all Regional Vice Presidents, as well as by me and the Acting Executive Director. In addition, the numerous coalitions with whom we have joined forces are adding to the outcry for fair fiscal allocations.

For some of us who are the "old-timers", it is a period of "deja-vu." Nevertheless, knowing we won these battles once before, should help breed optimism and energetic determination for this renewed effort.

Here's to accurate predictions!!!

Ellie Pattison

## NYS ARC reacts to Governor's Budget

"It is no secret that fiscal focus is now the name of the game," stated President Ellie Pattison as the new federalism, and the state of New York's response to it, mandates that our reactions as parents, friends and citizen advocates not be based solely upon the human element which we recognize as paramount.

Soon after the Governor's proposed budget was released to the public, the Subcommittee on legislation, a newly formed component of the NYSARC Legal and Legislative Committee, chaired by Irene Platt, Senior Vice President, met to study the implications of this Budget on our chapters.

It is eminently clear that if the proposed 1982-83 Governor's Budget as recommended for the Office of Mental Retardation and Developmental Disabilities is accepted, it will result in drastic reductions in services provided by the voluntary sector to the mentally retarded and developmentally disabled in New York State.

### COMMUNITY FUNDING INEQUITABLE

The proposed budget is grossly inadequate and misleading and continues the pattern of inequitable funding for community clients and the voluntary agencies which serve them. It provides start-up monies for new programs but insufficient funds for operating on-going programs. The proposed budget provides funds for new offices for the Office of Mental Retardation and Developmental Disabilities staff, but no increases for existing day treatment programs for clients. Funds are allocated for the unnecessary transfer of a special population to Creedmore and Pilgrim State facilities against the wishes of parents. Yet there is no provision for respite services so desperately needed by our clients and their families.

The appearance of containment is achieved by transferring certain budget items out of the State Purposes portion of the budget and by creating First Instance Funds. In reality, nearly all of the Local Assistance items have been frozen or reduced.

### DEFICIENCIES IDENTIFIED

The deficiencies in the Local Assistance Budget are identified in the following capsules:

#### 1. Local Services Budget

This figure is \$7,500,000 less than the documented need reflected in the (U.B.R.'s) and it is \$2,500,000 less than requested by Office of Mental Retardation and Developmental Disabilities (OMRDD) despite the fact there is an increase from 36,000 to 39,000 in the number of clients served.

In addition, the Governor's Budget makes no provision for inflationary increases in areas of Personal Services and Other Than Personal Services. Not only will the projected service level be unmet, but severe cutbacks in funding from 3rd party income sources will reduce the ability of Local Services funding to sustain current program levels. This will create a significant reduction in community-based day services for community clients.

We therefore recommend an increase of \$7,564,022 as requested by counties in their U.B.R.s.

#### 2. Subchapter A, Title XIX

We recommend full restoration of \$15,243,700 as requested by OMRDD for Subchapter A. The per diem rate for this program was reduced 3 years ago by 20 percent and frozen at a level of \$35. The Governor's recommendation of \$500,000 reduction from last year's adjusted appropriation, for a program which is already inadequately funded, is the first step toward total deliberate elimination of this important service.

In addition, funds for variable fees in day treatment are essential if this service is not to be reduced to one of mere custodial care.

#### 3. Voluntary - Operated Community Residences

The proposed budget represents a concerted effort by the state to curtail development of the voluntary sector community residence programs, while increasing dependency on state-operated programs, Voluntary-Operated Community Residences (VOCR) operating costs are reduced by nearly \$6,500,000. We recommend increasing the VOCR total to a level of \$29,330,000, as requested by OMRDD, which will allow approximately \$2,500,000 to cover inflationary costs, and a similar amount to for the development of new community residences. While adding \$8,500,000 to Fee-for-Service (FFS) support the budget reduces 41.33 funding (which supports the general operating costs of the VOCR) from \$20,700,000 to \$14,000,000.

A realistic appraisal indicates the state will not be able to meet its commitment to develop residential facilities. Therefore, resources for these new programs in the State Purposes Budget appropriately should be reallocated into the Local Assistance portion of the Budget.

Continued on Page 10

## Sticks and Stones, the story of a loving child

By Elizabeth Pieper

This book describes the unintentional and sometimes intentional ways society discriminates against disabled children. It is the story of how one parent raised her child who is disabled in the community, and the problems she encountered when she tried to obtain educational, medical, counselling and diagnostic services. An excellent book for professionals, as it gives practical ways of parents and professionals to relate to each other more effectively; it helps educators to understand what many parents expect of schools and how schools can respond to the needs of children who are disabled. It is a down-to-earth parent story with optimism about our essential humanness. Parents will cry and laugh with Mrs. Pieper as we relive our own experiences. In reading this book, we get to know Betty Pieper (as she is known) together with her son, Jeff, in an unforgettable way. She writes with warmth, determination, and even anger. When she first found out that her son was disabled, Betty Pieper knew little about disabilities. She knew even less about the depth to which our society discriminates against people who have disabilities. She quickly learned about both, and she learned one thing as well, **how to advocate for her child — for all people who have disabilities and for all people.** Betty admits the hurt that accompanies prejudice and discrimination; yet this is no account of hopelessness or pessimism. For Betty

Pieper possesses what all change agents must — optimism about our essential humanness. It is written in an easy conversational style and should inspire parents to continue their efforts to help change society and should inspire professionals to help educate their peers and join the parents to work for change. She says it better than anyone else, so we quote her closing paragraph:

"I am profoundly glad to know my son, Jeff. Once I heard Ramsey Clark, former Attorney General of the United States, say that his retarded daughter taught him greater truths than all of his travel and any of the great and famous people he had known, I understand that. Jeff is neither my burden nor my chastisement, although his care requires more than I want to give at times. He is not an angel sent for my personal growth or my future glory; he is not a punishment for my past sins. He is a son. Our needs do not always coincide so that I am not always a perfect mother or even a reliable advocate. We love each other. We enjoy each other. And we are friends to each other. That is why I have chosen not to sublimate my anger and my pain. The love and the friendship Jeff and I share is why I ask others to work for change, because we cannot do it alone". . .

(Additional copies may be obtained by writing to Human Policy Press, Box 127, Syracuse, New York 13210. Reference No. HPP — 8 — Price \$4.00).

## Inside Out Powerful Autobiography

This book may prove to be the most important ever published about the lives of those whom our society has chosen to label 'mentally retarded.' Its uniqueness and power come from the fact that it contains autobiographical accounts of two individuals — Ed Murphy and Pattie Burt (not their real names) — who grew up in institutions for the retarded. We learn at first hand what their lives have been like, how the stigma of 'retardation' has affected them both inside and outside the institution.

Robert Bogdan and Steven Taylor, both active in the teaching and treatment of the mentally handicapped (Division of Special Education, Syracuse University), tape-recorded the stories over an extended period of time and present them here, edited only for chronology, in Ed's and Pattie's own words. In their conclusion to the book they argue that, as a concept, mental retardation is a socially created categorization, having no objective existence outside the minds of people who created and continue to use the phrase. The concept, basking in an aura of scientific objectivism, conceals highly subjective moral and cultural value

judgments. In his story, Ed notes: 'We have to assume that the mind is working no matter what it looks like on the outside. We can't judge by appearance. . . If you take away the label they are human beings.'

Mickey Rooney, who recently starred in the television docu-drama, 'Bill', about a 44-year-old retarded man who re-enters society after a life of institutionalization, has read *Inside Out* and written to us to say: 'I find it very interesting, especially since making "Bill"'. The response all over the country really was overwhelming. Many, many letters were received from various individuals and schools regarding retardation. . . Your book. . . will help thousands of people all over the world.'

Thomas J. Cottle of the Department of Psychiatry, Harvard University, and host of his own National Public Radio show, has written that it is, 'one of the most touching, thoughtful, tender, and enlightening documents ever to be published in the social sciences. . . *Inside Out* is a proclamation of human dignity, strength, fortitude. It proffers a brand of truth so compelling, so human, that even as we feel anguish and utter shame, we are uplifted.'

## Speaking without Speech

HELFMAN, ELIZABETH.  
BLISSYMBOLICS: SPEAKING  
WITHOUT SPEECH  
NEW YORK: ELSEVIER

NELSON BOOKS, 1981. 1477 pp + INDEX  
Blissymbolics is a system of graphic (written) symbols logically designed to allow people to communicate across language barriers. This book describes the system, developed by Charles K. Bliss in the 1940's, as it applies to the teaching of non-speaking cerebral palsied children.

In a simple, easy-to-read style, the author begins with the history of pictographic and ideographic communication. She briefly describes the work of Charles Bliss and his cooperation with the Blissymbolics Communication Institute which was formed in 1975 to train teachers in the use of the symbols and to monitor symbol creation and design.

Two good-sized chapters are devoted to

the actual learning of the symbols and the various types of equipment that can be used in teaching the system.

The remaining 9 chapters are devoted to examples of the symbols in actual use: the work of the Ontario Crippled Children's Centre; how the symbols are used with adults; and several personal success stories about children whose lives have been enhanced through being given the means to communicate with the people around them.

Although the book is not intended as a text, it is an excellent resource for any teacher or educational administrator interested in teaching communication skills to the handicapped.

The appendix contains sample communication displays; a word-to-symbol glossary; and a list of supply and resource centers.

## NYS ARC visits legislators



Ellie Pattison knocking on Senate Chamber door accompanied by regional vice presidents Shirley Valachovic and David Lettman.

## Our Children's Voice<sup>®</sup>

Retarded Children Can Be Helped

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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

Editor: Geraldine Sherwood, Acting  
Executive Director

Assistant Editor:

Donald Westervelt

Contributing Editor: Joseph T. Weingold

Editorial Assistant: Adele Osinski

Subscription to *Our Children's Voice* is through membership in a local chapter of the New York State Association for Retarded Children, Inc. The publication is also available to the general public at \$1.50 per year.

Please address all inquiries to:

New York State Association for Retarded Children  
175 Fifth Avenue  
New York, New York 10010  
212-674-1520

# 103 confirmed in their faith

by George Swiers, Wilton D.C.

It was all that it was meant to be. The culmination of three years of extensive training and guidance tempered by patience, understanding, and sensitivity. In the end it was, above all, an act of love. For 103 clients of the Wilton Developmental Center, the training and guidance were of a nature that went well beyond programming. On a crisp November afternoon, these 103 were formally confirmed in the Catholic faith by Bishop Edward J. Hubbard of Albany.

"The act of confirmation is a sacrament of special grace," said Father Edward J. O'Connell, vice chancellor of the Albany Diocese.

"These (Wilton's clients) are obviously special recipients; having undertaken such an extraordinary effort in strengthening themselves for the Christian faith."

It is a principle of the Wilton DDSO that the mentally retarded are citizens of their respective communities and, as such, are afforded the same rights and privileges guaranteed to all. Accordingly, the wishes and needs of developmental center clients and their families concerning religious matters are, in every case, determined and addressed. The confirmations by Bishop Hubbard marked the fulfillment of those wishes as expressed by the clients themselves and their families.

"So much was done so unselfishly," said Cash Pagano, volunteer coordinator, said, commenting on the confirmation. "The operation from the Bishop's office was simply outstanding and more than 50

volunteers stepped forward to lend assistance."

According to Pagano, who was instrumental in arranging for the family-attended event, confirmations at Wilton had been initiated in 1978 by then Chaplain Father Dunne. Two subsequent Catholic Chaplains, Father Sieradski and Father Woempner, continued them. The two priests worked closely with Pagano's volunteers in providing presacrament instruction both at the developmental center and at Saratoga's St. Clement's church.

During the reception that followed, the Bishop spent considerable time in conversation with the newly confirmed, posing for pictures with proud family members and advocates.

Bishop Hubbard concluded his three-hour visit to Wilton by touring the facility and visiting each of the center's apartments. He spent time with all clients. He complimented Wilton's staff and his special tour guides Robert Hayes and Mary Jane Stern, deputy director. "Clearly, Wilton is not an institution," Bishop Hubbard said, "it is a home in the finest and truest sense of that word."

Wilton director Daniel T. Donohue expressed his hope that inspiring occasions such as the Bishop's visit could touch all retarded citizens.

"Just as 'normalization' embraces the rhythms and routines of day-to-day life, so should it somehow include that state of peace and inner-warmth that we experience on days like this."

Photos by Barry Lobdell



"I sign thee with the sign of the cross and confirm thee with the chrism of salvation."



Director Donohue: "normalization should somehow include the same state of peace and inner joy we experience on days like this..."

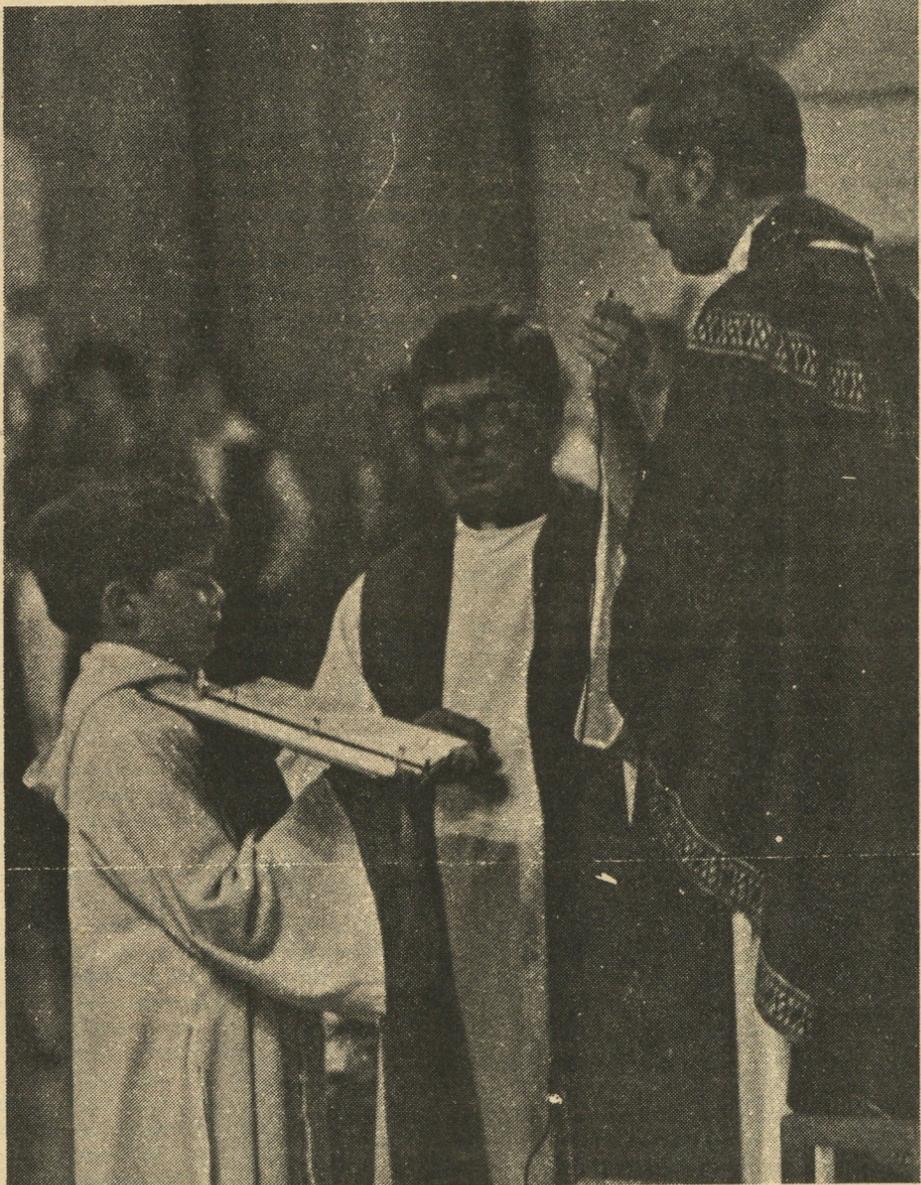
## Convention slated for Niagara Falls

The N.Y.S. A.R.C.'s 1982 Annual Conference is scheduled for Niagara Falls, New York, at the Niagara Hilton Hotel, October 7th through 10th, 1982. Plans are now being made and the Niagara County A.R.C. writes:

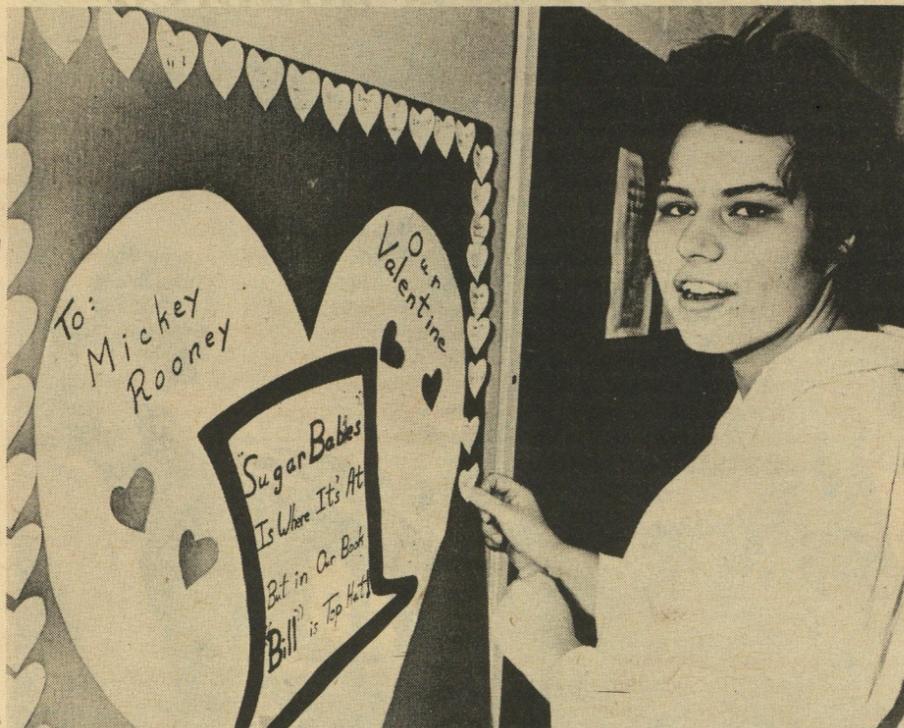
1. There will be tours of the Niagara County Association for Retarded Children, Inc.
2. There will be special tours of the sights at Niagara Falls by tour guides.
3. Wine and Cheese Tasting parties are planned.

4. The Niagara Hilton Hotel has a swimming pool, sauna, and even "indoor plumbing!"

5. The drinking water is safe.  
Ms. Marcia Buzzelli is General Chairperson. And, if any of the Standing Committees wish to be on the Program, please notify Ms. Buzzelli through the Niagara County A.R.C. If you have any questions, please contact Ms. Diane M. Runca, Executive Secretary, who will be doing most of the "leg work" for the Conference.



Many Wilton staff members joined clients and their families for Bishop Hubbard's opening Mass.



Valentine for Mickey — Sue Seguin, an ARC client at the Norwood Rehabilitation Center operated by St. Lawrence Chapter affixes her signature to a two and a half by three foot Valentine hand-fashioned there and sent to actor Mickey Rooney.

## Heartfelt response for ARC Valentine

Clients at St. Lawrence ARC signed each heart on a 2½ x 3 foot Valentine and sent it to the actor Mickey Rooney for his superb portrayal of an adult who is mentally retarded in the television production of "Bill."

Mickey Rooney won the coveted Golden Globe Award for playing the role of Bill Sackter, an adult who struggles to gain acceptance in the world outside an institution.

On the Tuesday before Valentine's Day, the huge love greeting was delivered to the Mark Hellinger Theater where Rooney currently stars in "Sugar Babies." Accompanying the valentine was a letter from Kate Klein, Chairperson of the Public Information Committee expressing the admiration of NYSARC for his artistic comprehension in playing this difficult role.

Actor Rooney called Mrs. Klein to express his delight with the Valentine and later sent a letter to the ARC in which he said, "I receive many mementos but this one made my work worthwhile. I was very

touched . . . I shall treasure it . . . Love! Love! Love!"

Emmy Award winner Alan Landsburg is executive producer for "Bill" which was directed by Anthony Page; produced by Mel Stuart and scripted by Corey Blechman for GE Theater.

The role played by Mickey Rooney was based on the real life story of Bill Sackter, an adult who is mentally retarded. Bill is befriended by a young film maker, Barry Morrow. Bill has spent 44 years in an institution but enters the community, thanks to a community placement program. Morrow, charmed by Bill's innocence and sense of humor plans to make a film about him. He gets involved in Bill's life and their friendship develops as Bill makes a successful re-entry into society.

In Mrs. Klein's letter to Rooney she stated "We feel that your sensitive character construction of "Bill" never once moved away from the gentle shining personhood of human dignity set in the limitations of mental retardation.

## Recycling. Is it worth it?

The city and town of Batavia, New York think so. This community of 20,000 started a recycling program in late 1979. Its purpose, backed by State approval and aid, was to increase the longevity of its landfill site plus provide the economical energy advantages of recycling paper, cardboard, glass and metal and the re-use of valuable raw materials.

Costs of operation were unknown or estimated in the initial stages but it was felt that the advantages in tax savings to the community by increasing the life of the landfill more than outweighed the estimated costs. Nineteen-eighty costs resulted in a \$9,000 deficit over revenues. This figure has been reduced to \$900 for 1981 with the recycling of 487 tons of paper and cardboard, 155 tons of glass and 123

tons of metal. The corner has been turned with expectations for a profit in calendar 1982.

Operation of the recycling center was awarded to the Genesee County Association for Retarded Children, a non-profit sheltered workshop for retarded adults. Such a contract provides normalizing work and income for these handicapped citizens in a useful and beneficial community effort.

So — recycling for the Town of Batavia is paying off in three ways: 1. Extension of life for their landfill; 2. Cost efficient to the point of being no cost to operate; 3. Productive and normalizing type work and income for the handicapped individuals who might otherwise be unemployed or in institutions.

# Growing up with Down's

The Westchester Chapter's Parent Assistance Committee on Down's Syndrome observed its tenth anniversary on March 28 with a celebration whose theme was "Growing Up With Down's."

PACDS was launched in May 1972 by a small group of parents in Northern Westchester, and since its inception hundreds of parents in the County have benefitted from its knowledgeable guidance and support. Today it is a resource center for professionals, parents and relatives around the world, who look to it for information on Down's Syndrome and for assistance in starting a similar parent-to-parent self-help program.

Board Member Barbara Levitz pioneered the movement and has led PACDS throughout its ten year expansion. When her son Mitchell was nearly a year old, Barbara felt other parents could be helped in their struggle with the obstacles that must be overcome, and the adjustments that must be made, in rearing their developmentally disabled child. Most importantly, she recognized the strength and hope that parents who have experienced the early struggle can bring to others by sharing their experience, stressing the joy these children can give, and assuring parents they need not be alone in their initial anxiety and bewilderment. She was convinced that parents who were veterans of the struggle could reach out with information on Down's Syndrome, the variation in potential of Down's Syndrome children and what these children may be capable of achieving.

Monthly education programs, with speakers on subjects covering medical concerns, education and psychology, guardianship, legal rights, sibling attitudes and every aspect of health and development, are open to the public. A newsletter keeps members informed of new information and events, and the Marjorie Gibbs Memorial Library, established by the group in the Westchester Library System, has contributed to the availability of current literature on Down's Syndrome and other developmental disabilities.

The anniversary program began with hors d'oeuvres, champagne and punch and included presentation of the award winning film, "A Different Kind of Beginning" by Fredda Stimell, Executive Director of Long Island's Association for Children with Down's Syndrome; and a panel discussion, "Growing Up With Down's Syndrome," in which original PACDS families discussed their experiences. Mrs. Levitz and Committee Member Emily Kingsley related follow-up anecdotes about some of the children in PACDS, and the afternoon closed with cake and coffee.

Certificates of appreciation for outstanding contributions to the welfare of Down's Syndrome children were presented to Dr. Mary Coleman of Washington, D.C.; Mary Kallet, Assistant Executive Director of WARC; Janet Marchese, PACDS Committee Member; Sylvia Slatzman, Reference Librarian for the Gibbs Memorial Collection and Dr. Lawrence Shapiro, Director of the Medical Genetics Unit at Westchester Medical Center.



Barbara Levitz, founder of PAC.

Barbara contacted parents of children she had taught in the Keon School. Some of these parents, in turn, referred her to parents of children in WARC's pre-school, and PACDS was organized under WARC's auspices. The following year, PACDS became a committee of WARC, with Barbara as its chairperson. Ten years later, she is still chairing the committee, and continues to spearhead its progress.

Among PACDS' achievements are the development of early intervention and model programs, research projects, adoption advocacy, public addresses to professionals in medicine and health at conferences and symposiums and representation and leadership on County, State and National councils and organizations. In-service training for a parent outreach program, a referral system from hospitals, physicians and social services agencies, and a brochure for public dissemination have been developed.

## Parents as PEERS

The Parents as PEERS Program has been operational since September, 1981. During the month of October 1981, four Regional Coordinators, the Statewide Project Coordinator and the Program Consultant, revised the curriculum for the Program. The end result was a 24 week Parent Training Program which provided enough structure to guide the facilitators, yet remained flexible enough for use with any parent group, regardless of the handicapping condition of the child, or the socio-economic situation of the family.

The orientation of the Regional Coordinators also included an introduction to the agency (Wayne County Association for Retarded Children), as well as an administrative component.

In November of 1981, the Regional Coordinators began their meetings with the agencies who had been awarded a grant to conduct a Parents as PEERS Unit. At that time, 111 agencies had been awarded grants. Since that time, ten agencies have decided not to pursue the grant. Currently we still have 101 agencies who are planning to conduct the units, with an additional 13 agencies interested in second-round funding for the Program.

To date, three training sessions have been held with 40 people being trained as facilitators for the Parents as PEERS Program. The training sessions were held in Genesee, Syracuse, and Tarrytown. Additional training sessions are planned during the months of February and March for Albany, New York City and Long Island.

It is anticipated that, by the end of the training, over 100 facilitators will have been trained and that between 1,000 - 2,000 parents will be enrolled in the program.

## Marilyn Wessels honored

The NYSARC Education Committee has known all along that its Albany representative has been doing great work helping parents get through the educational system, but we are thrilled to see her entire community appreciates her. TV Station WTEN in Albany, has an award called "Jefferson Award" for contributions to the community. She will be receiving a bronze Jefferson Medallion for her contribution to public service, and it will be aired on "WTEN ACTION NEWS".

Marilyn Wessels is a member of the Board of Directors in her Schenectady

Chapter, an active member of the Education Committee, a member of the advisory council for Assemblyman Alan Hevisi's Task Force on the Handicapped, a moving force in the Schenectady Advisory Council to the Special Education Division of the Board of Education. She reaches out to all groups to get her message across to church groups, pediatricians, social workers, school board members, nurses, and educators. She has assisted countless nervous mothers by accompanying them to the Committee on the Handicapped meetings and Due Process Hearings, so we are sure she deserves this award!

## Hearing Week in Newburgh

To ALERT you to the Importance of Hearing and to ASSURE you that there is HOPE. . . because most people with Hearing and Speech disorders CAN BE HELPED — medically, surgically, through hearing aids and other mechanical devices, or through hearing rehabilitation.

HEARING is a precious gift. Be thankful if you can hear. Use every means of prevention to conserve your hearing. Guard your ears from infections. LOUD NOISES, and other hazards. Your ears are live parts of your body; nourish them with good nutritional habits.

22 million people in the U.S., one out of ten, may be suffering from a hearing or speech disorder. 16 million of these, or one out of fifteen, are affected with a hearing loss. Can this be you, your child, a relative, or a friend?

If you suspect or sense a loss of your hearing or that of your child, have it checked without delay. Urge relatives and friends in similar circumstances to do so also. Find out how you can be helped; act quickly and follow through. A doctor and/or otologist (a doctor who specializes in hearing disorders) is in the best position to

determine if medical or surgical measures can help the hearing impairment and refer the person, when advisable, for further hearing evaluation, fitting of hearing aids, and rehabilitation.

Communication disorders can be helped through speech training, lip reading, or sign language. Become familiar with the resources near you — in the schools, in a speech and hearing clinic, and through private practitioners. National organizations and special programs elsewhere which deal with hearing and speech problems can be brought to your fingertips also.

Knowledge is gold in your hands. It paves the way to action and follow through. Become knowledgeable of preventative measures and research available for hearing and speech problems.

**Remember. . . people with speech and hearing disorders can be helped, one is never too young or too old. You can help yourself. . . and others too!**

For further information or assistance, contact Art Dadazzlo, c-p The City of Newburgh Optimist Club, Box 3154, Newburgh, N.Y. 12550.

## Cross country skiing for "special" pre schoolers

Wayne County A.R.C.'s Roosevelt Center for Educational Activities is offering a special cross country ski program for pre-schoolers. Each Tuesday and Thursday morning from 9:30 to 10:30 a.m., you may find children ages 3-5 years receiving individualized cross country ski instruction behind the Center. The program was designed by Patricia McCready, Adaptive Physical Education Teacher and assistant Diane Woodward.

The purpose of this program is to make available to children with various handicapping conditions the winter snow experience of cross country skiing, giving them the opportunity to ski within their capabilities, and encouraging independence. The children develop skills in the areas of balance, coordination, directionality and socialization through this program. Specific skills the children

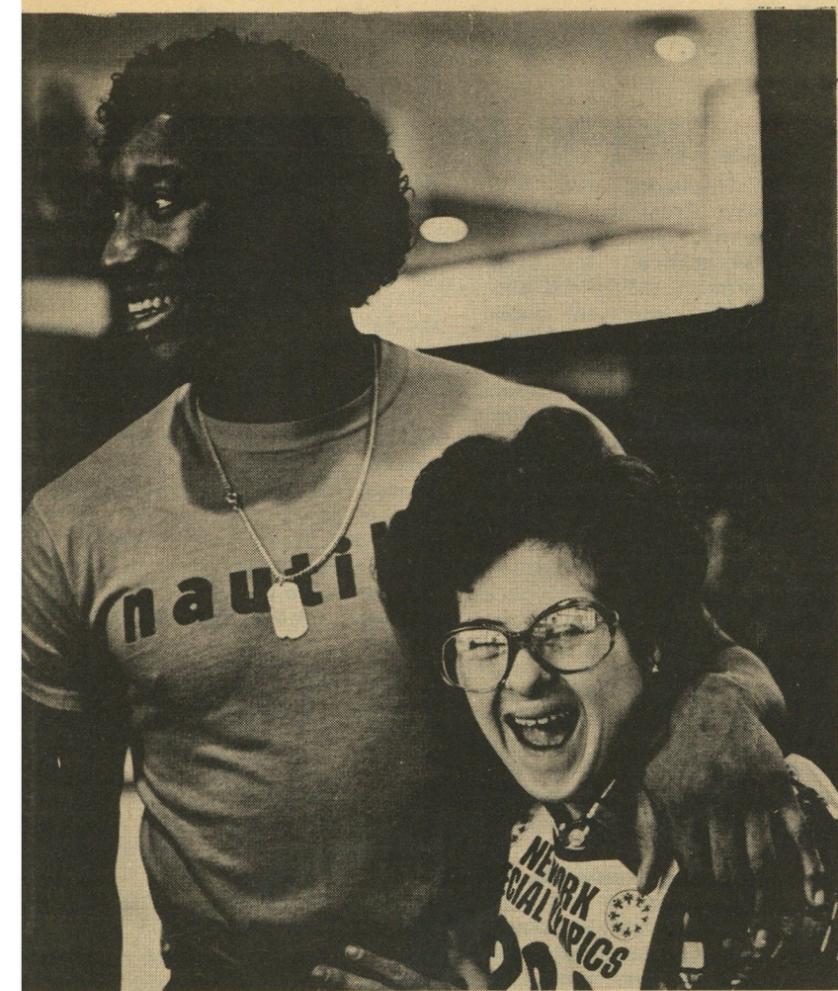
are learning include: recognizing and labeling various ski equipment, standing, walking shuffling on skis, turning and stopping and walking up, then skiing down a small hill. In order for all children to participate to their fullest potential, Diane Woodward created a special cross country chair-ski. This is used by children with orthopedic limitations, utilizing their upper body movements. The special junior ski packages were purchased by the Wayne County A.R.C. at the Sports Garden in Newark.

The program has been so well received by the children, that the Family Life Education Parent Groups have become involved in their own cross country ski program. And the children's reaction? By their smiles and laughter, anticipation and excitement, who knows . . . Special Olympics, Here We Come!!!

## Housing loan and grant information

The Farmers Home Administration has published a proposed rule regarding its Section 504 loans and grants to low-income rural homeowners for home repairs which will result in removal of health or safety hazards. The proposed rule establishes

uniform standards of eligibility, especially with regard to income and specific guidelines for processing Section 504 loans and grants. For information: Nancy Monesson, Farmers Home Administration (FMHA), (202) 382-1481.



Shafer Suggs and Tracey Grell, Special Olympian from Staten Island, New York.

## New York Special Olympics undampened by weather

Schenectady, New York. . . February 1, 1982 — Over 300 N.Y. Special Olympians attended the Seventh Annual Winter Games February 2-4, 1982 at the Concord Court Hotel, Kiamesha Lake, N.Y.

Although freezing rain covered the skies with a sheet of ice and forced all door events to be cancelled, the spirits of the athletes and coaches never dampened.

The Opening Ceremonies were held in a huge indoor tennis court where the Olympians paraded to the beat of the New York Wild Cat Marching Band. The day's festivities commenced with the traditional lighting of the torch by a Sullivan County representative, N.Y. Jet Donald Dykes and former Special Olympics Coach, Shafer Suggs. After words of encouragement from heavyweight challenger, Gerry Cooney, who reminded the Olympians that they were all "winners", Werner Roth, former Cosmos and Special Olympics Honorary Coach, led the Special Olympic oath. The Concord's walls resounded with the voices of our N.Y. Olympians. "Let me win. But if I cannot win, let me be brave in the attempt." Miss J.A. World, Brooke Alexander, and Special Olympic Skier, Karl Anderson, then released the balloons which filled the room with color and excitement and announced, "The games begin!"

All skaters then proceeded to the indoor skating rink to begin their competition. All snowshoe entrants donned their snowshoes and the races took place in the indoor tennis court. Although the conditions were as the athletes expected, the competition maintained all the challenges of an outdoor event.

The skiers, who handled the disappointment the weather imposed, like true athletes formed a strong cheering section. After they participated in a soccer game organized by our sports celebrities, played tennis, "worked out" in the weight room and swam in the hotel's pool. The Concord Court can certainly accommodate any activity!

At the awards ceremony and banquet, Gold, silver, and bronze medals were distributed. In addition, each Special Olympian received a participation medal and sincere congratulations from their coaches, friends and all who witnessed their efforts and accomplishments at the 1982 Winter Games.

New York Special Olympics is part of an international program organized and created by the Joseph P. Kennedy, Jr. Foundation providing year round sports training and athletic competition for mentally handicapped children and adults.

## Bill of Rights for Handicapped

The Handicapped Child Has a Right:

1. To as vigorous a body as human skill can give him.
2. To an education so adapted to his handicap that he can be economically independent and have the chance for the fullest life of which he is capable.
3. To be brought up and educated by those who understand the nature of the burden he has to bear and who consider it a privilege to help him bear it.
4. To grow up in a world which does not set him apart, which looks at him, not with scorn or pity or ridicule — but which welcomes him, exactly as it welcomes every child, which offers him identical privileges and identical responsibilities.
5. To a life on which his handicap casts no shadow, but which is full day by day with those things which make it worthwhile, with comradeship, love, work, play, laughter, and tears — a life in which these things bring continually increasing growth, richness, release of energies, joy in achievement.

Developed at a White House Conference on Children



An after hours raid caught Betty Pender with her fingers in the mailroom again, feverishly working on one of her Education Committee projects.

## The Kid From Nowhere

By Marilyn R. Wessels

Recently many of us had the opportunity to view not only a very entertaining program, but more importantly, an educational one. "The Kid From Nowhere" starred, among others, Beau Bridges, Susan St. James and Loretta Swit. However, the real star was Ricky Wittman, a child with Down's Syndrome (which used to be called, inappropriately, mongolism).

An important point that the film brought out was that persons who have developmental disabilities can do many things. The most important lesson, however, was not the story of Special Olympics, or of the supposed struggles many families face in rearing a youngster who is disabled, but the fact that a person who actually had Down's syndrome has played a major role in a national television production, thereby exhibiting his real skills and abilities in spite of his disability. Just a few short years ago anyone born with Down's syndrome would have been automatically recommended to a life in an institution.

The birth of a baby with Down's syndrome is always viewed as a very devastating occurrence. More often than not, physicians who usually have the job of breaking the news to the family do a less than adequate job; other medical personnel reinforce the negative environment, and families and friends add to the dismal outlook. Unfortunately, much of this negative outlook is based upon myths and lack of real knowledge.

I am certainly not suggesting having a baby with a developmental disability is a thrilling experience, but I believe we usually overreact and fail to consider the positive aspects. No one can predict the eventual potential of a baby with Down's syndrome, any more than they can predict the so-called normal baby will become a Rhodes scholar or a drug addict. Most individuals who have Down's syndrome are, given the right kind of opportunities, only mildly retarded. Some are reported to have normal intelligence.

Society has done a terrible wrong to persons with Down's syndrome. They have been, and often continue to be treated as less than human beings. Parents of persons who have Down's syndrome who are now adults had to walk door-to-door fund raising to provide schooling for their children. They had to work day and night bringing political pressure to bear on legislators to pass laws insuring that their children could go to school like any other child. Fortunately their efforts worked.

Now parents of newborns and toddlers are fighting to insure the programs that their children are placed in are stimulating and exciting and not segregated from typical children. They are fighting to change the image of per-

sons with Down's and are demanding that their children are looked at as individuals rather than as a category or a label.

I see much hope on the horizon. Members of our communities in general are realizing that persons with Down's have something to offer and that their presence in a neighborhood is not something to be shunned but to be valued. It is a slow acceptance but it is happening.

We must all stop making up our minds about people based upon a label or a diagnosis. We are all individuals and want desperately to be treated that way. Persons with Down's syndrome are not any different. They too are citizens of this land and deserve nothing less.

"The Kid From Nowhere" was a sensitive and accurate portrayal and gave us the opportunity to learn a little bit about Down's syndrome. Accolades and thanks to NBC and WNYT for giving all of us this wonderful presentation.

## Advocacy defined

The New York State Commission on International Year of Disabled Persons has developed a working definition of advocacy:

"Advocacy has been defined as the formal roles by which any social system — public, community - based and private — is made more responsive to all the needs of each individual served by that system. Basic to this definition is the concept that the role of the advocate is a specifically assigned, structured responsibility which carries the obligation of manifesting change for the betterment of that individual. It is, therefore, a clearly distinct, autonomous or semi - autonomous role from others who function within the services systems, even though performance of the job functions of others inherently make the service delivery system more responsive to the individual needs of those for whom they are responsible.

There are three major types of advocacy: legal, systems and citizen (client). Legal advocacy is concerned with laws, statutes, government regulation, independent intervention in lawsuits, appeal processes on governmental regulations and other legal system changes.

Systems advocacy may be defined as deliberate approaches to changing organizational structures through which goods and services are delivered in order to make these structures more responsive to individual needs.

Citizen (client) advocacy is designed to teach and/or assist the individual in making the existing system more responsive to his-her needs."

## Ed Dept. proposes last minute Special Ed changes

ALBANY — Displaying what NYS United Teachers President Thomas Hobart has termed an "attitude of bureaucratic arrogance," the State Education Department (SED) has once again attempted to convince the Regents to pass revisions to the Commissioner's Regulations governing special education.

Weeks after public hearings were set for March 10 around the state (see box), NYSUT learned that the Department had unexpectedly recommended to the Regents numerous major changes in the revisions which had been presented to the public — which teachers, parents and other special education professionals have been studying and preparing to comment on.

One example of these unilaterally suggested, unpublicized changes is a recommendation that the current requirement that special education students receive five hours of resource room work per week be reduced to three hours.

While officially available upon request and listed in the February 17 New York State Register — along with numerous other legalistic state agency postings — the recommended changes were not disseminated or announced to the public, despite widespread intense interest in these revisions expressed repeatedly throughout the state of the past year.

A year ago protests heard statewide from parents, from NYSUT and from the Coalition of Concerned Organizations for the Education of Children with Handicapping Conditions had specifically focused upon the fact that the SED had released the complex, highly technical revisions to those working directly with the children and their parents only days before the actual public hearings began. This allowed virtually no time for these interested parties to properly study the revisions or to document a thorough response.

As a result of these vociferous protests, the Regents had directed the Department to allow adequate time for public input.

President Hobart noted that the SED's actions make the March 10 hearings "a cruel hoax and a mockery of so-called public involvement in education."

He charged that the Department has proceeded with implementing the new regulations "with an attitude of 'we're going to do what we damn well please regardless of what anybody says,' and with 'clouding and confusing both the proposals and the adoption process to discourage public understanding and involvement.'"

The controversial revisions, initially proposed a year ago by the State Education Department, encourage the mixing of pupils with different handicapping conditions, increase special class size at the elementary level, increase the case load for resource room teachers, increase the chronological age span within a special class and provide highly subjective criteria for the evaluation and placement of special students.

The Department says a goal of the revisions is to allow greater administrative flexibility.

NYSUT has repeatedly noted that while the revisions are presented as "educational decisions" they are, in reality, steps towards cutting costs and cutting services to the state's 240,000 special education students.

The strong protests last year on the part of NYSUT, the Coalition, and other groups around the state led to the revisions having

been passed on a provisional basis for 1981-82 in a somewhat modified form.

School districts have been given the choice during the 1981-82 school year of continuing to work under the previous regulations, using the new regulations or coming up with a plan, subject to prior state approval, combining the two.

Many districts in the state are using the revised regulations. NYSUT is in the process of tabulating — and expects to release shortly — the results of an extensive survey of special education teachers in these districts. Several of the organizations belonging to the Coalition have surveyed parents in these districts and are applying these results to their testimony.

The Regents are to decide at their March 25-26 meeting whether these new revisions are to be made permanent policy, based on SED's report to them.

SED's newest recommendations, while incorporating some of the suggestions which have been made, generally continue in the original direction of allowing districts the greater "flexibility" that could allow for decreased services.

For instance, the current requirement that special education students spend at least 50 percent of their schoolday in a special class would be removed with no minimum time requirement specified.

"These latest changes keep things so vague that verifying compliance will be nearly impossible," says Patrick Flynn, NYSUT associate in educational services with responsibility for special education. "As we've grown more sophisticated in seeking compliance when abuses arise, as they do frequently throughout the state, the Department is making the rules more and more nebulous.

"We would like to see more objective criteria for student placement, for instance, and plan to propose such criteria."

Flynn notes that the Regents had specifically requested that hard facts and statistics back up any assertions regarding the revisions.

"NYSUT and the Coalition have done extensive surveys and will present many detailed facts but these latest SED recommendations are without such documented basis. The report is full of phrases such as 'districts report' with few, if any statistics."

Hobart agreed, emphasizing that SED is employing "the charade of involvement and study while rejecting the use of objective evaluation criteria and the sound advice and alternatives offered by more than 15 organizations representing and working with children with handicapping conditions."

Hobart rejected the SED's claim that the proposals would allow for a more humane treatment of special students by removing the "handicapped" label. "The trust is that these regulatory changes will result in larger classes and layoffs of teachers, all to save money and not necessarily to help students," Hobart said. He also rejected SED claims that the proposals would provide more flexibility in student placement. "The truth is that these proposals would give school districts license to cut education services to special students, again with the idea of saving money the main goal."

The NYSUT leader said that teachers agree with the philosophy and intent behind some of the regulatory changes. "What we strongly object to is the unsound method being used to test and evaluate the proposals prior to adoption and the mockery of the public involvement process."

# Education Committee News and Views

by Betty Pendler, Chairperson

NYSARC was heard loud and clear at all six Public Hearings by **Board of Regents** and **State Education Department** on the revised regulations part 200. All of our members testified at the various public hearings, and the members of the Board of Regents got to know us. Regent Emlyn Griffith and Tom Scholl entered into a lively debate, and requested that we mail him personally our specific recommendations: Regent Mimi Lieber (newly appointed) assured Betty Pendler in New York City she reads every word of the testimony and has an understanding of parent needs. Our reports indicate that the attendance at all six locations was very high — so we hope that our chapter bulletin urging you to attend did the trick.

**DIPLOMA VS. CERTIFICATE** — two bills coming up in Albany No. 7848, introduced by Silver, Hevesi and Stavisky pertaining to the issuance of an appropriate CERTIFICATE for children with handicapping conditions — the other No. S3575, introduced in Assembly by A. Harenberg, in Senate by Senator Lack, to make provision by regulation of the commissioner to provide for the receipt of local high school diplomas by handicapped children based upon achievement of the objectives of their IEP. The pros and cons continue. Obtain copies of the bills — send us your comments so we can establish a position if and when the bills really start moving.

**504 OF THE REHABILITATION ACT OF 1973 IS NOT DEAD** — The Education Committee received a letter from Dr. Frank Dolan, Director of Regional Technical Assistance Staff of U.S. Department of Education, Region II, New York, N.Y. which says: "There have been no changes in our section 504 regulation since it was recodified from the older DHEW version. Subpart D of the regulations specifically addresses concerns in the elementary and secondary school environments, which, I presume, would be of primary concern to your organization. . . we would be most pleased to assist your organization in any way we can in assuring that children receive the full protection afforded them by Section 504. We would be most pleased to answer any specific questions you have, or to present a workshop on the subject to your group. We would certainly be willing to speak to individual parents who feel they might have a Section 504 complaint. . . we would encourage parent members to speak with us concerning recourses in section 504 for the specific problems of their children. Dr. Dolan was our guest speaker in April of 1981 when our committee had its annual statewide Education Workshop in Binghamton. See our Eduletter Volume III No. 1, Winter 1981 for further information and our reprints on this subject, also Federal Register, dated Wednesday, March 21, 1979 for "Vocational Education Programs Guidelines for Eliminating Discrimination and Denial of Services on the Basis of Race, Color, National Origin, Sex and Handicap. Frank Dolan can be reached at: U.S. Department of Education, Region II, Federal Building, Office for Civil Rights, 26 Federal Plaza, New York, N.Y. 10278, telephone (212)264-2906.

Accolades to those newsletters who are including items on education in their newsletter — latest addition is "Parchment of Livingston Wyoming ARC which listed the names of the persons on the Committee on the Handicapped in that area; Westchester ARC reprinted our recent questionnaire in their newsletter, and accolades also to Saratoga ARC for reproducing our questionnaire from the chapter bulletin. We're happy to see some chapters are listening to us.

**ALL CHAPTERS** — Please set up an Education Column in your newsletter (send us copies). **What do you do with all those reprints education committee displays at the workshop? ERIE COUNTY CHAPTER** put them to excellent use by combining them into an excellent 'Handbook for Parents'. Quote from Westchester ARC's Education Committee Reprint (a model to follow) "Education Committee prepared position paper on the new Commissioner's Regulations. . . working to put together a countrywide parent network which will act in an advocacy role for parents of school-age children having problems with their children's educational placement — planning to have an **Information Night** this spring for parents of school-age children. . . we are also working on getting together a list of churches, synagogues and other religious organizations offering religious instruction to handicapped children and we are planning a monthly column in WARC news on matters pertaining to the education of school-age children who are handicapped. **It is hope that if through these activities we have something concrete to offer parents of school-age children, WARC will be able to draw substantial numbers of new members from their ranks.**" (That's what we of the State Education Committee have been saying all along!!)

**COMMISSION ON quality of care helps unravel the special Education Maze** — at their second great workshop on January 29 for 12 local ARC chapters in Capitol District Area, covering such subjects as "Observing Your Child" Guidelines for Parents, presented by Catherine McHugh, Advocacy Training Coordinator of Commission on Quality Care, Seeking Help from Specialists; Parents Role in the Evaluation Process, Legal Definitions in the C.O.H. and IEP, presented by Nancy Maurer, Staff Attorney for Protection and Advocacy Bureau of the Commission. A presentation as interesting and enjoyable as a New York City Broadway play was presented by Commission staff simulating a real C.O.H. meeting. Every audience participant contributed in the small group sessions on how to monitor the IEP so one can readily see that it was a packed full on information day. The Commission staff is already hard at work on their workshop on impartial hearings. Our committee will be reviewing their draft copy of the Handbook which should be completed early fall and available to ALL chapters. **The Education Committee is spreading out** — from local school district to state education department, and now to United States Department of Education; letter was received from Mr. Thomas B. Irvin, Acting Director, Division of Assistance to States Special Education Program, in United States Department of Education in Washington asking our committee to assist them in planning for the current year. . . and we quote. . . "we consider the participation of your association to be a vital part of the planning of our monitoring and assistance effort". By that time we had a substantial response from our questionnaire and forwarded the results to him, as well as furnishing him with the last three Eduletter issues, including our critique of the regulations. It's nice to know some bureaucrats want to hear from the parents point of view—let's hope they're listening!

**JANET CALKINS** — Plattsburgh ARC is busy with mini workshops — working with Onondaga Neighborhood Legal Services, and keeps very busy accompanying parents to C.O.H. meetings. **SUNY AT GENESEE**, whose Special Education Department is headed by Dr. Lyle Lehman (member of our Board of Governors) has by far the liveliest, most enthusiastic student body in special education.

Recently Betty Pendler had the pleasure of participating in their annual workshop sponsored by the student division of Council for Exceptional Children. Parents — our hope is in these new, idealistic, hardworking teachers-to-be, they are great!

Shirley Reynolds and Mary Murphy, our upstate Committee members, coordinated a most successful spring workshop held on March 26 in Buffalo. More to follow at a later date.

**EXCEPTIONAL PARENT MAGAZINE** — still the most valuable information packed magazine for parents and professionals — discovering articles written by parents and professionals providing practical guidance for children with a variety of disabilities, covering such subjects as psychological testing,

curriculum, sex information, school conferences and other material for parents and professionals. Send your subscription in to the State Office and help the Education Committee get a commission! Rates one year \$15.00 (6 issues).

**PARENTS HANDBOOK** critiqued in depth with concrete examples of what we feel are serious omissions. We sent our critique to Mr. Lou Grumet, Assistant Commissioner of Education of Children with Handicapping Conditions and look forward to his response, which we will publish upon receipt.

Below we list the up-to-date member list of the **New York Board of Regents**. Keep sending THEM your concerns in education, as they are the ones who make the decisions. . .

THE UNIVERSITY OF THE STATE OF NEW YORK			
Year Term expires	REGENTS MAILING ADDRESSES		
1988	<b>GENRICH, WILLARD A.,</b> Chancellor, LL.B., L.H.D., LL.D. Litt. D., D.C.S., D.C.L. 4287 Main Street, Buffalo 14226	716: 832-7484	
1988	<b>MEYER, J. EDWARD,</b> Vice Chancellor, B.A., LL.B. 280 Park Avenue, New York 10017	212: 682-4444	
1986	<b>CLARK, KENNETH B.,</b> A.B., M.S., Ph.D., LL.D., L.H.D., D. Sc. 60 E. 86th Street, New York 10028	212: 772-1000	
1983	<b>NEWCAMB, HAROLD E.,</b> B.A., LL.D. 234 Main Street, Owego 13827	607: 687-3033	
1982	<b>GRIFFITH, EMLYN, I.,</b> A.B., J.D. 225 N. Washington Street, Rome 13440	315: 336-6500	
1983	<b>KENDALL, MARY ALICE,</b> B.S. 242 Belmeade Road, Rochester 14617	716: 266-8993	
1984	<b>BATISTA, JORGE L.,</b> B.A., J.D., LL.D. 600 East 233rd Street, Bronx 10466	212: 920-9575	
1986	<b>CHODOS, LAURA BRADLEY,</b> B.A., M.A. Box 320, R.D. 2, Rexford 12148	518: 371-9243	
1987	<b>BARELL, MARTIN C.,</b> B.A., I.A., LL.B. 645 Fifth Avenue, New York 10022	212: 935-9800	
1984	<b>MATTEONI, LOUISE H.,</b> B.A., M.A., Ph.D. 214-16 16th Avenue, Bayside 11360	212: 780-5892	
1987	<b>CARBALLADA, R. CARLOS,</b> B.S., L.H.D. 44 Exchange Street, Rochester 14603	716: 546-4500	
1988	<b>LINTON, FLOYD, S.,</b> A.B., M.A., M.P.A., D.C.L. P.O. Box 447, Port Jefferson Station, New York 11776	516: 928-7338	
1988	<b>SCALFANI, SALVATORE J.,</b> B.S., M.D. 435 Bay Ridge Parkway, Brooklyn 11209	212: 833-1808	
1982	<b>LIEBER, MIMI,</b> B.A., M.A. Suite 600, 1841 Broadway, New York 10023	212: 586-2118	
1985	<b>BROWN, SHIRLEY, C.,</b> B.A., M.A., Ph. D. Psychology Department, Social Sciences 217, 1400 Washington Avenue, Albany, New York 12222	518: 457-8482	
	<b>AMBACH, GORDON M.,</b> President of The University and Commissioner of Education, State Education Bldg., Rm. 111, Albany 12234	518: 474-5844	
	<b>CARR, WILLIAM J.,</b> Secretary, Board of Regents, State Education Building, Rm. 102, Albany 12234	518: 474-5889	

**TO ALL CHAPTERS** — send us your suggestions — your problems — your successes in dealing with the school system — let us share them with other chapters — the Eduletter continues to include specific items of interest to parents, teachers, administrators and other professionals. If you or anyone else you know would like to receive a free copy, please fill out coupon below:

Return to:

Betty Pendler, Chairperson  
Education Committee  
N.Y. State Association for  
Retarded Children  
175 Fifth Avenue, N.Y., N.Y. 10010

I wish to receive the Newsletter of the Education Committee of the N.Y. State Association for Retarded Children.

NAME

ADDRESS

Telephone ( )

CHAPTER AFFILIATION



Ice skating star Dorothy Hamill, honored at the Thurman Munson Awards Dinner sponsored by the Association for the Help of Retarded Children, receives congratulations from Michael Goldfarb of Port Washington, Executive Director of AHRC New York City Chapter. Jimmy Cagney, Rocky Blier, Tommy John, Earl Monroe and Denis Potvin were also honored at the dinner.

## Sports stars honored at Munson Awards Dinner

Some of the nation's outstanding sports personalities were honored at the second annual Thurman Munson Awards Dinner held at the Grand Hyatt Hotel in Manhattan to benefit the Association for the Help of Retarded Children.

Dorothy Hamill, Rocky Blier, Tommy John, Earl Monroe, Denis Potvin, David "Sonny" Werblin and Capt. Otto Graham will be among those who will receive Thurman Munson Awards at the dinner. Billy Martin, Cliff Robertson and Lou Saban presented the awards.

Jim Jensen, WCBS-TV anchorman, served as master of ceremonies. Mel Allen introduced the dais guests.

The awards were named in memory of Thurman Munson, late famed catcher of the New York Yankees, in recognition of his support in behalf of the mentally retarded.

Dean R. O'Hare, board chairman and chief executive officer of Chubb Life Insurance Company served as dinner chairman.

## Proposed act gives tax aid

Senators Roger Jepsen (R-Iowa) and Paul Laxalt (R-Nev.) have introduced the Family Protection Act (S.1378) whose purpose is "to strengthen the American family and promote the virtues of family life through education, tax assistance and related measures." The bill, now before the Senate Finance Committee, outlines a number of provisions ranging from rights of parents, proposed restrictions for the Legal Services Corporation, and a number of tax assistance provisions.

Under the tax provisions, parents could claim an itemized deduction up to \$2,500 per year for funds placed into trust account for future educational expenses of their children. When needed, the trust fund would cover the cost of tuition, fees, books and supplies as well as meals and lodging.

The trust provision would not be limited to college and university fees, but could also cover the cost of vocational schools and public or private elementary or secondary facilities which provide "education for individuals who are physically or mentally handicapped as a substitute for regular public elementary or secondary education."

Another provision of the bill would establish a trust fund for the care of a handicapped and/or elderly relative. Under the plan, a family could deduct up to \$3,000 per year with respect to payments under a trust established to provide care for a relative who "is unable to engage in any substantial gainful activity because of a medically determined mental or physical impairment which can be expected to be of long-continued and indefinite duration."

In an expansion of a tax deduction for each dependent, the Jepsen-Laxalt bill would provide a \$3,000 one-time deduction for a handicapped child born to the taxpayer. Parents would also receive this benefit if they adopted a handicapped child, a child whose parents were not members of the same race or a child over six years of age. Parents of other children born or adopted would receive a one-time \$1,000 tax deduction. Other provisions would also provide deductions for charitable contributions to day care centers and up to \$3,500 for expenses in adopting a child.

(Reprinted from *Rehabilitation Review*, Vol. 11, No. 10.)

## Carey asks EPA release of Love Canal study

Governor Hugh L. Carey has repeated his appeal that the federal Environmental Protection Agency release its study of the Love Canal area which was conducted to determine the extent of contamination of the area.

In a letter to EPA officials, Governor Carey cited the increased incidence of arson and vandalism in the neighborhood, and deplored EPA's failure to make public the study for which property owners still living in the area have waited for more than one year.

"No definitive program for the area's rehabilitation can be made by the Love Canal Area Revitalization Agency until the final report is forthcoming," the Governor said.

EPA originally promised to release the study by the end of 1980, and, since then, announcements of new release dates have been followed by as many postponements — the most recent statement asserting that it would be released in December 1981.

The Governor cited several problems in the area which result from the continued absence of EPA's findings. Since positive steps toward renewal and recovery have not commenced, physical deterioration of the Love Canal area has accelerated. Eleven instances of deliberately set fires have taken place and continue to occur even though the Love Canal Area

Revitalization Agency has engaged a private security force to augment City police and fire departments. The 170 still-occupied houses are scattered throughout the one-square-mile area, hampering area residents in detecting criminal activity and virtually eliminating the likelihood of discovery as a deterrent to these crimes.

In addition to the 400 private homes standing empty, two businesses have shut down and the three that remain are struggling to survive. A modern public housing development — one of the best in Niagara Falls — has only 56 of its 250 apartments still in use and the loss of rent revenues adds to the local tax burden. A garden style 54-unit senior citizen housing complex is at 50 percent occupancy rate with no new tenants being accepted. Even a neighborhood church had to be closed because of dwindling membership.

Governor Carey pointed out that until the EPA report is made public, not only is the Revitalization Agency unable to make restoration plans, it is obliged to continue costly fire and liability insurance coverage until the area's future is clarified.

"It is tragic that such a disaster occurred in the first place, but while prompt action by state and local agencies on every level blunted its initial impact, the unjustifiably long time spent to complete the EPA study following collection of the data, coupled with the sluggish review of the study results by other federal agencies is vastly increasing the severity of the tragedy by delaying the delivery of the basic information needed by affected individuals, organizations and government to chart a course of recovery," the Governor said.

## Be a volunteer

(from *The Star* Spring 1982)

— Volunteers! Who needs 'em? **WE DO!** Several years ago, Erma Bombeck wrote a column describing a dream she had about the departure of every volunteer in this land. As the boat sailed for distant shores, Mrs. Bombeck tells of standing on the pier shouting, "Good-bye phone committee, good-bye disease-of-the-month, no more getting out the vote, no more playground duty, bake sales and three hour meetings."

As the boat got smaller, she reflected: "Serves them right, that bunch of 'yes' people. All they had to do was put their tongues firmly against the roofs of their mouths and make an "o" sound. . . no. It would certainly have spared them a lot of grief. Oh, well, who needs them?"

Mrs. Bombeck does go on to tell who needs them, and what it would be like in their absence. "The home for the aged was like a tomb. The blind listened for a voice that never came. The hospital was quiet as I passed it. The reception desk was vacant. Rooms devoid of books, flowers and voices. The children's wing held no clowns, or laughter."

The social agencies had closed their doors unable to implement their programs of scouting, recreation, drug control; unable to help the retarded, crippled, lonely and abandoned. Health agencies had signs in their windows: "Cures for cancer, arthritis, birth defects, heart diseases, etc., have all been canceled for lack of interest."

Flowers on church altars withered and died. Children in day nurseries lifted their arms but no one was there to hold them in love. Alcoholics cried in despair but no one answered. The poor had no recourse for health care or legal aid."

"I fought in my sleep to regain a glimpse of the ship of volunteers just one more time. It was to be the last glimpse of a decent civilization."

Need I say more?

## United Together

United Together — that's the name of a new national coalition of mentally retarded people. Late last fall, members of the group planned and conducted their own national conference in Arlington, VA — to come to grips with just what mentally retarded people in this country need.

The conference stressed independence and self-advocacy for mentally retarded citizens. Like all fledgling "consumer" organizations, this one wants a minimum of interference from the "bureaucrats" but welcomes support of those interested in the problems of mentally retarded people. As one mentally retarded member of United Together said: "You know how a handicapped person acts, but you don't know how he feels. We do."

Here are some of the goals this new organization set for itself:

- Helping ourselves and choosing our spokespeople;
- Encouraging others to help themselves;
- Serving on boards of directors and committees everywhere so we can better help handicapped people;
- Becoming involved in politics and working to change legislation;
- Getting more jobs for handicapped people;
- Designing more community living situations;
- Making United Together a strong national organization.

Worthy goals for any organization. After the conference was over, members went back to their states, enthusiastic and ready to begin achieving these goals, each in his-her own way. For additional information contact the President's Committee on Employment of the Handicapped, Washington, D.C. 20210.

## Social Security eligibility redetermination stepped up

The Social Security Administration has significantly stepped up its redetermination of the continuing disability of SSI and Disability Insurance (DI) recipients. We understand that a number of people are being removed from the rolls.

Under 1980 amendments to the Social Security Act, SSA is required to review most disability cases at least once every three years, beginning in 1982. About 350,000 cases were reviewed during the 1981 fiscal year and more than 500,000 cases will be reviewed during FY 82. Cases selected to receive most immediate attention have been those of the individuals with disabilities that have shown the greatest likelihood for recovery. People with mental illness — one of the disabilities which SSA says shows a high recovery level — and those who are working have been among first cases reviewed. Some redeterminations have indicated that a person's work history demonstrates that he or she can engage in substantial gainful activity (SGA) and should therefore be removed from the rolls. At least eight suicides have been tied to SSA determinations that the disabled recipient should be removed from the rolls.

The more strict determinations are not all the product of the Reagan administration. Criticism of program laxity in the sixties led to increasing strictness in eligibility determinations as well as in redeterminations. A GAO report released on March 3, 1981, indicated that, "As much as \$2 billion annually in Social Security disability insurance payments may go to individuals who are no longer disabled." The report was critical of the small number of SSA redeterminations and suggested that, "As many as 584,000 persons may not currently be disabled, but they may still be receiving disability benefits." This represents 20 percent of the 2.9 million primary beneficiaries on the DI rolls. GAO pointed out that in 1978, SSA conducted Continuing Disability Investigations (CDIs) on about 141,256 of the 2.9 million on DI rolls and terminated benefits in 72,606 (51.4 percent) of the cases reviewed.

There has been little investigation over the years of what happens to those people who are removed from the rolls. While speaking to members of the CCDD Task

### Pattison letter protests article

Letter to Editor  
Newsweek

444 Madison Avenue  
New York, New York 10002

An open letter to Harry Schwartz, writer-in-residence at the College of Physicians and Surgeons of Columbia University.

As president of the New York State Association for Retarded Children, Inc. and on behalf of hundreds of thousands of children and adults who have the condition of mental retardation, I vehemently take issue with the appalling thought proposed by Mr. Schwartz in his article, WE NEED TO RATION MEDICINE, published February 8, 1982 in Newsweek.

To suggest that expensive medical treatment be denied to babies born with this condition as a cost containment process indicates an abysmal ignorance of documented facts that reinforce both the capability and productivity of over 97 percent of this population.

It makes one wonder WHO is retarded — Mr. Schwartz or those he would so cruelly write off as members of the human race!

Force on Social Security, an ex-employee of SSA stated that the bulk of individuals denied benefits never return to active employment.

**NAPRFMR and other members of the CCDD are anxious to identify individuals who are being removed from SSI and DI rolls. Please notify NAPRFMR of cases that come to your attention. We would like copies of termination notices and any additional information that can be provided which will describe the individual being denied benefits and his or her personal circumstances.**

It is important for Congress to know if denial of future benefits is creating difficulty for people. Both CBS and ABC TV are preparing special reports about denial of disability benefits. We would also like to identify cases which can be used in these reports.

**A high percentage of those whose benefits are terminated are successful in reversing the decision through the SSA appeals process, particularly at the Administrative Law Judge Level. We strongly advise all individuals who receive termination notices to appeal the decision!**

## Sexuality and disability

New York University is sponsoring the 4th annual national symposium on Sexuality and Disability. The theme "New Challenges" allows opportunities for us not only to look at where we have been in the field of Sexuality and Disability, but at where we want to direct our energies in the next few years. This year's conference will include consideration of the challenges we face in education, counseling and therapy, legislation, program planning and media.

The Symposium Planning Committee has incorporated the suggestions and recommendations of last year's participants to develop another stimulating, multi-dimensional conference. Expanded paper sessions, entertainment, and networking programs offer many opportunities for increased learning and resource development. For the first time, all-day workshops on general, introductory and advanced levels provide challenging material for the first-time participant as well as the experienced professional.

They symposium will begin Friday, June 18th at 7 p.m. and conclude on Sunday, June 20th at 5 p.m. For program and registration information, contact New York University, 51 West Fourth Street, Fifth Floor, New York, Nw York 10003.

### Malpractice award granted

A \$2.7 million medical malpractice award was granted early this month to a Metuchen couple and their moderately retarded daughter, after a jury ruled that an obstetrics and gynecology specialist had failed to diagnose and treat a problem during prenatal care of the child, who is now eight years old. The case went to trial last October 19. The plaintiff's lawyers had argued that the child, in utero, had been deprived of adequate oxygen supply and suffered brain damage as a result. A panel returned a verdict to Superior Court Judge John E. Keefe in New Brunswick that Dr. Lawrence A. Seitzman and the Seitzman Professional Association of Edison had been negligent in the medical treatment of the girl.



From left NYS Cashback Coordinator Jack F. Ranieri looks on as NYS Lottery Regional Director James A. Nolan presents award check to Don Westervelt for ARC's efforts in Phase III of the Cashback Program.

## ARC wins Cashback Lottery

The ARC won SECOND PLACE in the third quarterly awards and received a check for \$5,000. The awards ceremony was held at the World's Trade Center in New York City on February 9th. The Lottery Commissions Regional Director, James A. Nolan presented the check to Don Westervelt, who received it on behalf of the participating chapters in the ARC.

With the third Phase of the Program completed and only one more phase left, the chapters can be proud of their steady growth. We won the Fifth Place prize worth \$500 in Phase I, the Third Place Prize of \$3,000 in Phase II and now the Second Place Prize of \$5,000 in Phase III. So far we have turned in 293,587 tickets, which earned \$2,935.87 and this coupled

with winnings to \$8,500 means that we have already received \$11,435.87 in this fund raiser. The chapters that participated in Phase III of the program and received shares in the winnings are; Cattaraugus, Community League - Wassaic, Cortland, Dutchess, Erie, Genesee, Lewis, Montgomery, Niagara, New York City, Orange, Rensselaer, Rome D.C., Suffolk, Welfare League - Letchworth, Westchester.

Phase III of the New York State Cashback Lottery Program ended on December 31st. The program encouraged groups to collect non-winning lottery tickets for which the New York Lottery paid one cent each. In addition, quarterly cash prizes were given to the leading groups.

## Conference studies staffing

**New York** — The Young Adult Institute & Workshop, Inc. sponsored CONFERENCE II, at the United Engineering Center, 345 East 47th Street, New York City, April 15th and 16th, 1982.

In renewing its commitment to improve overall delivery of service in the field of mental retardation and developmental disabilities, YAI identified staffing recruitment and retention as the areas most problematic to professionals and consumers in the health services. In a series of lectures and workshops the YAI Conference examined staffing issues from every side.

Speakers were invited to discuss topics including the philosophy of work in the health professions, attitudes of academia towards the field of social work, recruitment of staff, training for service approaches, utilization and integration of different levels of staff, staff retention, and the labor pool for direct care staff.

April 15th was designed as a day for speakers from allied disciplines, academia, and government to give an overview of the service system. April 16th was comprised of small workshops led by panels of practitioners who shared their expertise in areas including time management, burnout, peer review and job satisfaction.

Speakers included Harold Demone, Dean, Graduate School of Social Work,

Rutgers University; Valerie Bradley, President, Human Resources Research Institute; James Muyskens, Professor of Philosophy, Hunter College; and K. Charlie Lakin, Professor, Department of Psycho-educational Studies, University of Minnesota.

### A wealth of ideas

Closer Look has available for distribution a limited number of copies of the Partners' Workshop Report published by the U.S. Council for the International Year of Disabled Persons (IYDP). Based on a series of workshops to promote community participation during IYDP, the Report contains project ideas and outlines a step-by-step approach for setting goals and implementing projects.

The 40-page booklet focuses on eight broad areas: accident and disease prevention, improved access to housing and buildings, greater opportunity for employment, expanded international exchange, expanded educational opportunity, access to transportation, greater participation in cultural activities and greater participation in recreational and social activities.

A single free copy may be obtained (while they last) by writing to: Partners' Workshop Report, Closer Look, Box 1492, Washington, D.C. 20013.



From left Eleanor Pattison, President N.Y.S.A.R.C.; Shirley Valachovic, Regional Vice President N.Y.S.A.R.C.; Joe Mahay, Program Director, Essex County ARC; Michael Mascari, Associate Commissioner O.M.R.D.D.; Gerald B. Edwards, President, Essex County ARC and Charles Hayes, Executive Director, Essex County ARC.

## Essex Ribbon Cutting

Essex County A.R.C. officially opened its new Intermediate Care Facility in Crown Point and Day Treatment Program in Port Henry on March 13. Among the many state and local officials present were: Associate Commissioner Michael Mascari of the Central County Services Group, O.M.R.D.D. and Ms. Eleanor Pattison, President N.Y.S.A.R.C.

The festivities began in Crown Point at the newly constructed intermediate care facility to be known as "Champlain House". This facility is replacing the former St. Frederick's Hotel which was totally destroyed by fire in April, 1980. Essex County A.R.C. had been operating the residence since 1978 as a community residence for twelve geriatric developmentally disabled citizens ranging in age from 65 to 82. These individuals have been temporarily housed in a residence in Port Henry, but are now returning to their newly constructed home.

Additionally, Essex County A.R.C. officially opened its new Day Treatment Program for 45 severely mentally handicapped adults at the new training center in Port Henry. Essex County A.R.C. acquired the former St. Patrick's School on December, 1981 and have been doing major renovating in the building to be ready to open the program in March.

Additional space in the new building is also being used for the community residence offices, business office and administrative offices of the A.R.C. The two new programs offer the severely developmentally disabled individual intensive care which could not previously be provided by A.R.C. These new services now make it possible to provide a range of services within the agency to offer the handicapped individual the opportunity to live and work in the least restrictive community setting possible.

## Herkimer sponsors Symposium

The third in a series of symposia on developmental disabilities, sponsored by the Herkimer Chapter was held recently at Herkimer County Community College. The symposium presented 18 workshops with speakers from across New York State. A variety of topics were offered to enable parents and staff to increase their knowledge of and skill in dealing with persons who are developmentally disabled.

Of special interest to parents was the workshop chaired by Mrs. Joan Edwards, Chairman of the NYSARC Prevention Committee, who spoke on the topic of "Parents Helping Parents." Mrs. Edwards has been instrumental in developing parent support groups across New York State and will speak on the parent as a central resource in a service delivery system. Dr. Frances G. Berko, State Advocate, New York Office Of Advocate For The Disabled, focused on the client as an individual and presented strategies to deal with the total person's needs. Dr. Ann Willey, the director of cytogenetics laboratory of the birth defects institute in

Albany, New York, discussed birth defects with an explanation of "Teratogenic" or environmentally induced birth defects. Her workshop included information on when parental diagnosis is indicated and the procedures involved. David Malone, Esq. and Richard Aust, Coordinator of Utilization Review, spoke on legal procedures for the establishment of guardianship and its implications for the individual. A workshop focusing on recreational opportunities and activities therapy for people who have handicaps was presented by Ms. Christine Reese, Assistant Professor and Director of Therapeutic Recreation, Utica College of Syracuse University.

In addition, workshops were offered as a follow-up to the January Workshop on Planning held in Rome including sessions to expand and disseminate information on staff involvement in the Planning Process. Dr. William Scanlon, New York State Director of Utilization Review, presented "Accountability In Programs," and Duncan Whiteside of One-to-One spoke on the inclusion of staff in the Planning Process.

# Governor's Budget Continued from Page 1

## 4. 620 FUNDING

Experience and estimates of costs involved in this area of service tell us the Executive Recommendation, as well as OMRDD's request, fall far short of what is needed.

Allowance must be made for inflation and annualization. Collective Bargaining Agreements, in particular, have produced a spiraling impact on our operating costs. We, therefore, urge funding at the \$24,779,701 level as requested by counties in their U.B.R.s., reflecting true costs.

The extent of fiscal constraints imposed by this Executive Recommendation places many of our chapters in the impossible position of having to operate with funding levels substantially below 1981, and others below even their 1980 levels.

## 5. Direct Contract — Sheltered Workshops

The Executive Recommendation reduces, by approximately \$4,000,000, the OMRDD request for \$7,287,900 in funds for Sheltered Workshops involved in direct contract arrangements with OMRDD. This shortage results in the exclusion of funds for five Sheltered Workshops, which at the urging of OMRDD, relinquished their local share which normally would have been received through their county contract. Threatened now with closing down, these workshops will have to terminate hundreds of clients from service.

## 5. Variable Fee for Day Treatment

The development of a variable fee structure, which will allow providers serving more disabled clients to be funded on a cost-related basis is essential for the continuation of existing programs. We recommend the \$1,361,000, requested by OMRDD, be restored to the budget so day treatment rates may move from \$37.50 to \$44 per day, depending on client need. The agencies involved are not able to absorb deficits in these programs.

## III OTHER AREAS OF CONCERN

### 1. Respite Program

We strongly urge the restoration of \$1,524,600 requested by OMRDD to establish a network of vitally-needed respite services which will actually serve to reduce institutional costs and improve cost-effectiveness in the long run.

### 2. Summer Programs

In conjunction with the respite program, it is most important that substantial attention be paid to funding for summer programs in the Local Assistance Budget. This program in the Executive Budget is inadequately funded at \$300,000. We strongly recommend addition of \$1,063,900 to bring the total funding for summer programs to \$1,363,900.

### 3. Interest As a Re-imbursable Item

The Governor's Budget includes \$750,000 for interest payments which relate exclusively to mortgages on property acquired for program use. We support the inclusion of these funds, but strongly recommend that the concept be expanded to include not only reimbursing interest payments, but include also interest on loans required for on-going expenses of chapters. This is necessary to compensate them in the area of cash-flow problems created by late payments from the state of New York. We estimate this would require an additional \$500,000 and requires a recommendation in Policy and in Regulation that this is a reimbursable item.

### 4. Camp Harriman

This facility, intended to replace Camp Catskill, will serve 450 retarded and developmentally disabled individuals who are both institutional and community clients. More than \$700,000 was appropriated in the 1981-82 budget and the request by OMRDD for an additional \$708,000 will allow the state to completely renovate the Harriman site. Failure to

approve these funds will unhappily eliminate any camp programs since the original site in Liberty is inadequate, and the Harriman site, by this omission, would be rendered inadequate as well.

## 5. Prevention - Research

New York State Association for Retarded Children, Inc. is committed to the development of an established program of prevention and research in significant areas. We therefore urge you to fund the program recommended by the Governor's Task Force on Prevention of Developmentally Disabled and Infant Mortality, including the creation of a Legislative Committee on Prevention, to the extent of \$500,000, so the important work of this task force is continued.

We also draw your attention to the revolutionary breakthrough in diagnosing Fragile X, and strongly urge you to increase funds for research for Institute for Basic Research. We are convinced research of this type offers significant opportunity for reducing the incidence of genetically-related disorders.

## 6. Court-Related Services

We strongly urge the legislature to support funding at a level of \$853,300 for the Willowbrook Review Panel, related committees and services identified in the budget as court-ordered and related services. However, our support for this funding, particularly with regard to the Willowbrook Review Panel (WRP) is conditioned on significant modification of the composition of the panel. It is our position the panel must be composed of New York State residents, both parents and professionals, whose knowledge of the field and valuable contribution is required if the Review Panel is to function successfully.

## 7. Special Population — Capital

The Executive Budget would provide \$4,819,000 for renovating two units at Creedmore and Pilgrim Psychiatric centers to serve autistic children currently residing at Queen's Psychiatric center. We urge you to revert the currently used space to OMRDD, reduce the Special Population Capital on State Purposes by \$4,819,000, and increase Local Assistance by \$1,000,000 so voluntary agencies serving the autistic may develop community-based alternatives to institutionalized care.

## 8. NYALD Demonstration Project

Recent attempts to develop programs for this "new" population must not be eliminated in mid-stream. This valuable program deserves support at the level of \$360,000 requested by OMRDD.

The Sub-Committee addressed critical areas of concern in the proposed budget, contrasting Executive Recommendations with NYSARC recommendations, showing net exchanges and rationales for suggested increases, transfers and reallocations.

It is important to note recommended transfers of certain funds from State Purposes to Local Assistance, in no way erodes NYSARC's support for quality institutionalized - based programs which we continue to enthusiastically support.

Rather, we have identified State Purpose Funding for Capital Purposes, and for operation of programs which, in our opinion, the state will not be able to open during the coming year.

An efficient cost-containment program is a noble goal for an administration. However, in this budget presentation, only the illusion of cost-containment is achieved. The end result is the denying of much-needed services to fragile populations. NYSARC vigorously opposes all such efforts to press the voluntary sector into a posture inconsistent with its tradition of advocacy. The subtle and pervasive design of planned attrition in this budget attempts to force us to disregard or to reject those individuals who need our services most.

# Therapist overcomes disability

## Aids patients from experience

by Denise Stary  
Gazette Staff Writer

Marcia M. Buzzelli has a reputation for being hard on her patients.

She knows how to maneuver minds as well as manipulate muscles. But that's just one of the reasons the physical therapist has enjoyed a successful private practice for 10 years.

"Physican, heal thyself," St. Luke advised in the Bible. Miss Buzzelli's credo must be close to that ideal, because she first had to overcome the same problem she helps to solve.

Struck at age four with polio severe enough to paralyze both of her arms and legs, Miss Buzzelli spent two years of her childhood at the Children's Rehabilitation Center in Buffalo, now part of children's Hospital.

"I'd see my parents twice a week and no one else," recalled the therapist, now 41. "That was my whole life."

After one and a half years of physical therapy, Miss Buzzelli was able to walk with a leg brace and could go home. One year later, she was back in the hospital for six months for surgery which eliminated the need for a brace.

A daily exercise regimen until she was 18 and additional corrective surgery in 1975 left the energetic woman with full use of all four limbs and a limp on the left side. And the experience left an impressionable young girl with gratitude and the desire to help others.

"When I was in the hospital, I didn't like the nurses feeling bad for me," she said. "I thought the physical therapists had the neatest job."

Although Miss Buzzelli remembers being "the worst patient they had—I cried constantly," a hard inner core was building in side her. It would carry her through times when other kids might point, and through recess when she couldn't jump rope.

"When I started school, the board of education offered to put me in a special class, but my mother said 'No,'" Miss Buzzelli recalled. She attended 24th Street School, Gaskill Junior High and Niagara Falls High School, graduating in 1958.

"I grew up with everyone else, thinking I was like them," she said. That feeling, probably more than anything else, is what erased any pangs of self-pity, enabling her to go on with the business of living.

"It's taken me many years to grow into a happy, self-confident person, into the position where I can accept my handicap," says Miss Buzzelli, who now works 50 to 60 hours a week rehabilitating patients and teaching others to do the same.

"I'm a little tougher on the patients than someone who hasn't gone through it," she said. "I know that nothing is more important than being independent and being able to take care of yourself."

Miss Buzzelli received a bachelor of science degree in physical therapy from the State University College at Buffalo in 1962 and a master's degree in education from Niagara University in 1971. Currently, she is voluntary president of the Association for Retarded Children, and assistant professor of physical therapy at Daemen College in Buffalo.

"She's a practicing therapist so she can bring in a clinical view as well as a theoretical one," said Daemen student John Pitarresi. "And out of all the teachers, she's probably the most friendly."

The woman's warmth is infectious. In her office on a recent weekday afternoon, she buzzed about, alternating between the interview, a teaching session with Pitarresi and an appointment with a young patient.

In a treatment room, 9-year-old Tammy was holding out her crippled hand. Three years ago, she fell through a glass door and bits of glass lodged in her wrist, putting pressure on the nerves. Just a few weeks ago, Tammy's mother noticed a dark spot on the hand and surgery revealed a hidden piece of glass.

Now Miss Buzzelli is "bringing the hand back to life" with an electric muscle stimulator probe. The little girl is smiling as she watches her fingers move with the impulses. She wants to be a gymnast when she grows up.

"When you're famous like Olga Korbut, can I say I knew you when?" the therapist asks, her eyes grinning. Tammy giggles.

Physical therapists work to rehabilitate people with injuries, diseases, birth defects, burns and many other kinds of discomforts. When it involves the movement of patients such as adult quadriplegics, the work can be physically as well as mentally exhausting.

Although Miss Buzzelli's feet are not proportionate, the left taking a size two-and-a-half shoe, the right a size five-and-a-half, she said her handicap has never really interfered with her work.

"My balance isn't so good on my left side, so what might be good technique for a physical therapist is not good technique for me," she explained. "I have adapted, for example, by approaching from the other side."

The five-foot-one therapist lifts patients in and out of wheelchairs without trouble.

"If you use good body mechanics, you don't have to be tall or big. It's just knowing how to move correctly."

On the office door is a poster of the coy Miss Piggy, a figure whose bold independence Miss Buzzelli greatly admires. It states, "Behind every good woman, there's a great left hook." "She's a tough lady, she's not going to let anyone step on her," the therapist said.

Marcia Buzzelli could teach Miss Piggy a thing or two.

## Genesee presents media awards

The W.N.Y. Public Education Coordinating Council recently sponsored a media appreciation breakfast at the Park Lane Restaurant in Buffalo. The breakfast was designed to show appreciation to those in the print and audio-visual industry who have given time and coverage to the Developmentally Disabled population. Honorable mention was awarded to Genesee Video Corporation (Mr. Frank Cappiello) for producing and airing a nineteen minute tape on the history and programs of the Genesee ARC. Clients were highlighted at work and in the community residence. Mr. Cappiello also provided a free print which has been used extensively with local civic and service groups, to the A.R.C.

The Batavia Daily News (Mr. John H. Connor, Editor) also received an honorable mention. One of the newspaper's photographers (Ms. Sue Armison) did a full picture page presentation of Workshop Clients capably handling their work assignments. Other articles included generous coverage of the NYSARC Inc. Employer of the Year Award to P.W. Minor, a local shoe manufacturer.



Ruth Bennett accepting building dedication. Looking on is Marc Brandt, Executive Director; Peter Roidt, President; Ida Frankel, Mayor of Liberty and Acting OMR Commissioner Zyg Slezak.

## Sullivan achieves goal with Bennett residence

With a great deal of excitement and pride, the Sullivan County Chapter of the New York State Association for Retarded Children completed one of its most ambitious goals and objectives: returning to Sullivan County the mentally retarded of Sullivan County who lived in State facilities throughout New York State. Since its formation in January of 1949, the Sullivan County ARC has attempted to provide necessary programming for the mentally retarded of Sullivan County in order to offer parents an alternative to the State Institution and Developmental Centers of New York State. The goal of the Sullivan County ARC over the past several years was to build in the community every necessary program in order to maintain the mentally retarded of Sullivan County so they would not have to enter into a State facility as well as to bring back to Sullivan County the more than 60 mentally retarded and developmentally disabled individuals that had to be placed in State facilities because no programs existed in Sullivan County.

On March 25, 1981, the Sullivan County ARC welcomed the first group of residents to their newly developed Intermediate Care Facility for the Mentally Retarded (ICF-MR).

At a Board meeting of the Board of Directors of the Sullivan County Chapter of the New York State Association for Retarded Children held on March 31, 1981, the Board unanimously adopted a resolution to name the building after Ruth and the late Martin H. Bennett. The building, located in the former Maimonides Hospital on Lake and Carrier Streets in Liberty, was dedicated on November 1, 1981, as the Ruth and Martin H. Bennett Residence for the Developmentally Disabled.

The Bennett Residence is a 35 bed Intermediate Care Facility for severely and profoundly retarded or developmentally disabled adolescents and adults who may be physically handicapped, and/or exhibit severe behavior problems, have limited activities of daily living skills and are unable to live in a less restrictive setting and attend day program. The opening of this facility not only realized the Sullivan County ARC goal of returning to Sullivan County the mentally retarded who were residing in the State Developmental Centers throughout New York State, but now also provides community mentally retarded and the developmentally

disabled persons in need of such a program with an alternative to institutionalization.

The Bennett Residence provides 24 hour supervision, nursing, and medical care as well as evaluation, program planning, and training in areas of ADL, Speech Therapy, Occupational Therapy, Physical Therapy, Educational - Pre-Vocational Assessment, Social Services, Psychological Services, Dental, Audiological, Optometric and Recreation. All residents receive training in hygiene and grooming, eating, communication, recreation and socialization towards the goal for each to become as independent as he-she is capable of being. Typically, work is done in small clusters of six or eight residents grouped according to skill level, working with staff who have received training in methods and appropriate to an activity.

In 1979, the Office of Mental Retardation increased the use of the ICF-MRDD Program as a major source to provide community residential living for severely and profoundly retarded individuals. One of the major reasons for the establishment of the ICF-MR program in the community was to enable severely disabled individuals to return to a community based program and, where possible, be returned to their County of Origin. There has been much controversy in the ICF-MRDD program throughout New York State. Initially, a move toward conversion of community residences (hostels) to the ICF model was suggested and encouraged by the State. In addition, a number of ICF's were developed for mentally retarded individuals that did not meet the structured environment the ICF model calls for. The Sullivan County ARC Chapter is proud of this accomplishment in the development of the ICF-MR program that is operated in Liberty, New York. They feel they truly have met the commitment of the Federal regulations for the ICF-MRDD Program and that the population that are being served is truly of the ICF-MRDD model.

With the opening of the Ruth and Martin H. Bennett Residence, parents are now able to visit their sons and daughters within the community in which they live. Visitation by parents to the Bennett Residence is most gratifying especially after years of having to travel great distances and often times finding their sons and daughters in conditions that were less than humane.

# CHAPTER NEWS

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

What better way to start off our Chapter News than with a success story — and the success is all the result of a hard working team at our **STEBEN COUNTY** Chapter. Instead of talking about their financial needs, they went out and raised the funds they needed through an intensive fund raising campaign. Their team effort brought in over \$21,000 and a feeling of "esprit de corps" that could be contagious.

**ESSEX COUNTY** Chapter is in the midst of its greatest expansion since it started operating in 1974, by opening two new locations. One, a new day-treatment center in Port Henry and the other, an intermediate care facility at Crown Point. A ribbon-cutting ceremony heralded the grand-opening.

"Best Boy" winner of the 1980 Academy Award for Best Feature Documentary and "Board and Care" the 1980 Academy Award winner for Best Live Action Short Film were featured by our **ROCKLAND COUNTY** Chapter in February. The show was free and all who saw it gained from the experience.

A different from of education came to **WESTCHESTER COUNTY** Chapter when their second placed Special Olympics Basketball team, the Bano Warriors, played against non-other than the New York Giants. About 800 spectators came to see the Warriors take on football greats like Turner, Jackson, Friede, Perkins, Shirk and Kelley. The Warriors are sponsored by Bano Buick of Mount Kisco, who provides the team with uniforms. The team has its own cheerleaders and most importantly, some very supportive fans.

And speaking of supportive fans, our **LIVINGSTON - WYOMING COUNTY** Chapter, knows what can be accomplished with the support of sports fans. Nearly 300 bowlers and 26 bowling teams took part in a Bowl-A-Rama that raised \$7,000 for the chapter. **LIVINGSTON - WYOMING** Chapter hopes to make the Bowl-A-Rama an annual event.

A different, but equally necessary, kind of support came to us from Mickey Rooney in his portrayal of just plain "Bill", a television production about a retarded adult struggling to gain acceptance in the world outside an institution. And our **ST. LAWRENCE COUNTY** Chapter let Mickey know just what it meant to them, through a huge Valentine card made by the clients and signed by each. Rooney was thrilled with the tribute and called Kate Klein, our Public Information Committee's Chairperson, personally, to let her know.

Speaking of celebrities, Jimmy Cagney was honored with some of the nation's leading sports stars including Dorothy Hamill, Tommy John, Earl Monroe and Denis Potvin at the second annual Thurman Munson Awards Dinner, the proceeds of which went to benefit our **NEW YORK CITY CHAPTER**.

The **SCHOHARIE COUNTY** Chapter received its thirteenth \$500 donation from the Knights of Columbus. What many may not realize is this money was raised by the K of C by collecting Lottery Tickets in the Cashback Program. Our hats off to the Knights of Columbia for their fine work.

Now that we've mentioned cashback lottery, let us not forget our very own **SUFFOLK COUNTY** Chapter, who received over \$2,700 for the 66,812 tickets they collected during the third quarter. This effort on **SUFFOLK** Chapter's part helped us to win the second place prize in Phase III of the program. Three cheers for **SUFFOLK COUNTY** Chapter.

The **WELFARE LEAGUE — LETCHWORTH VILLAGE** Chapter held their 42nd annual luncheon at the New York Hilton and named Norman P. Szymanski, Deputy Director of Letchworth Village Developmental Center as recipient of their annual award. Mr. Szymanski called the award "... the highest tribute..." because it came from the people who he was dedicated to serve.

The elements were not too kind to our people in **SENECA COUNTY** Chapter this year. We are told that the Collectible and Bike Sale fell "Flat" together with those who tried to weather the sleet, ice, winds and cold to patronize the event. But the effort was appreciated and so was the \$90 profit. On a positive note — plans for a Day-Treatment Center have been approved and the goal for this year's membership drive is a 50 percent increase. Good luck **SENECA**.

**FULTON COUNTY** Chapter's membership was pleased to have Attorney David F. Jung address their Parent Club on topics including guardianship and the legal rights of parents of children with handicapping conditions.

Surrogate Court Judge F. Warren Travers was the principal speaker at our **O.D.HECK** Chapter meeting. He spoke about adult guardianship for Mentally Retarded Persons.

Our **ONTARIO COUNTY** Chapter is trying to get everyone in better shape by offering Exercise Classes. One for youth, under 18 years old and another for adults. **ONTARIO** Chapter sure comes up with a variety of activities.

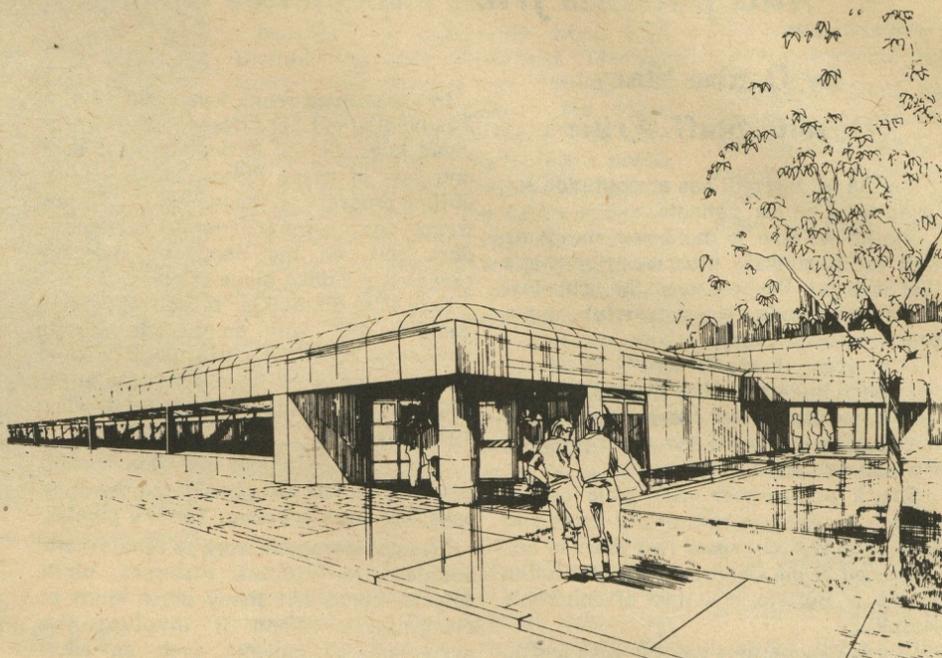
Mentioning improving our shape, brings us to our **OTSEGO COUNTY** Chapter who is not trying to slim down by any means. What **OTSEGO** is doing is called expansion. And it's a find job their doing The modernization and enlarging of plant facilities, including the addition of a cafeteria will enable them to employ an additional 79 people in the sheltered workshop. This is one place we don't mind adding on a few more inches.

A little further to the west, and under the persistent supervision of Hank Valerych (Board Treasurer and Fund Raising Chairman), the **GENESEE COUNTY** Chapter collected over \$6,200 with their Bowl-a-Thon. This is an annual event and the prizes awarded vary each year depending on the dollar amount of pledges collected. This year revenues exceeded 110 percent of pledges. That's what I call a success story! Participants from the work activities program assisted in raising nearly \$1,300 of the total amount collected.

Our **CHAUTAUQUA COUNTY** Chapter continues its construction. The second floor of its Allied Industries building has been completely renovated allowing all work programs to be located in one location. Now the main building is undergoing a major renovation.

Construction is also a main topic for conversation at our **ERIE COUNTY** Chapter where a \$2,200,000 building project is underway. Everyone in **ERIE** is behind the project as was evidenced by the Staff pledges of \$14,591 to support the new construction and this is in addition to Staff pledges of \$9,880 to the 1982 United Way Campaign. We must all applaud a staff who's willing to give its financial instead of just verbal response to a project.

**FRANKLIN COUNTY** Chapter has received a \$1,200 grant from the "Disabled Childrens Program" to provide education and support in training 10 families. They also intend to provide Early Intervention Services for children between 0-2 years of age.



Erie County Chapter's new facility.

## Erie construction drive in full swing

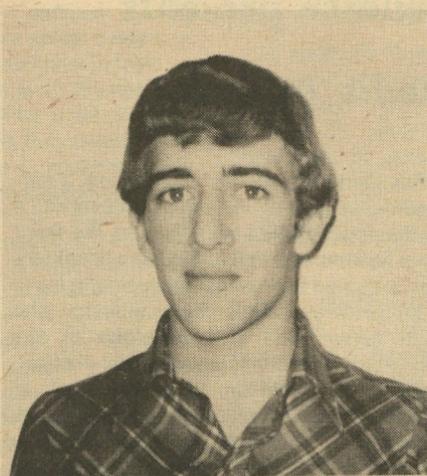
The Erie Chapter Association for Retarded Children Construction Fund held its Kick-off Luncheon to announce their new facility to be built at 101 Oak Street will be a barrier-free, one-floor building covering 65,000 square feet. It will house the agency administrative offices, the Community Planning - Neighborhood Services Unit, and the main work center of Allentown Industries. When the site is completed, there will be adequate space to employ 300 mentally retarded adults.

Erie ARC will raise funds for the approximately \$2,200,000 necessary for the new building. \$500,000 will be solicited from the community and the remainder will come from City of Buffalo Block Grant

Funds, New York State Office of Mental Retardation - Developmental Disabilities monies, and the Office of Vocational Rehabilitation funds.

Louis J. Billittier has been named General Chairman of the Construction Fund. Mr. Billittier, President of Chef's Restaurant of Buffalo, Inc., is active in many local volunteer efforts in the field of Mental Health - Mental Retardation. He serves on the Board of Visitors of West Seneca Developmental Center, Board of Directors of Sheehan Memorial Hospital, and as a member of the New York State Mental Hygiene Planning Council. In 1976, he received the Beatrice Edelman Award from the Erie County Mental Health Association.

## State writing winner from Schuyler Chapter



Glenn Miley, Journalism Contest Winner.

Glenn Miley, a 17-year old senior at Watkins Glen High School, was chosen by NYSARC judges as New York State winner in the National Journalism contest sponsored by the President's Committee on Employment of the Handicapped.

The contest promoted investigative journalism on behalf of the disabled and features \$6,500 in cash prizes to be donated by the Disabled American Veterans for five national winners. A free trip to Washington, D.C. for each State's first-place winner is in store for Glenn Miley of Burdett, N.Y.

In his article, Glenn Miley interviewed a handicapped person in a sheltered workshop, talked with three employers in the area and used references to the Rehabilitation Act of 1973.

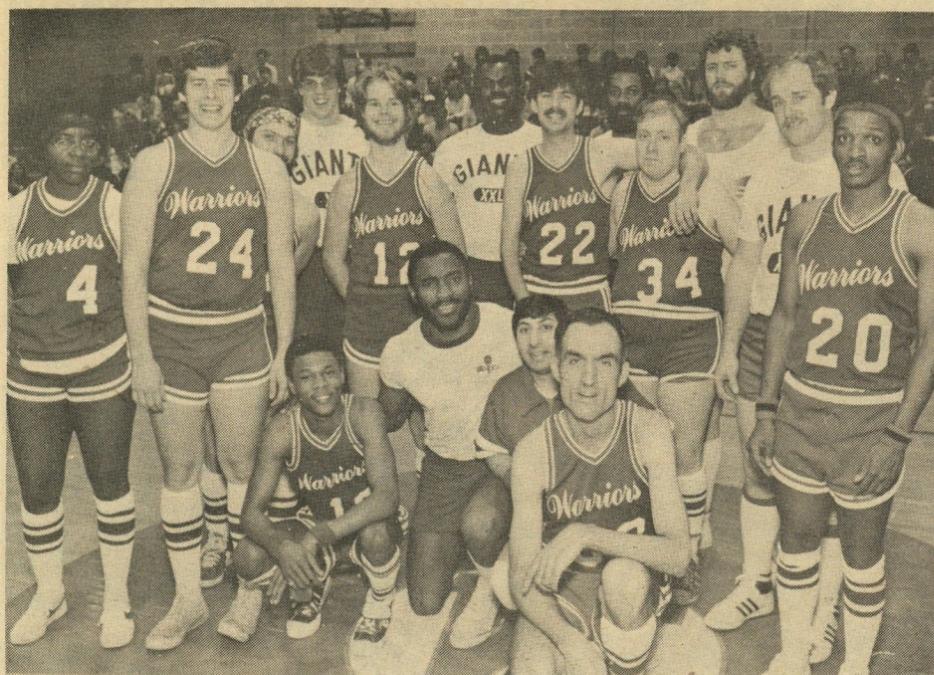
"Throughout the course of American history, we, as a people, have overcome discrimination in many areas. We have integrated ethnic groups into the mainstream of American life, but the era of awareness of the disabled is still in its infancy" Miley states.

The New York State Association for Retarded Children acted as the coordinator for this contest. Chairperson Kate Klein of the Public Information Committee said the judges had a difficult time choosing a winner from the excellent advocacy articles entered into the contest.

## Long term care report

The Long Term Care System Development project was designed to advance New York State to a new level of planning for the improvement and coordination of long term care resources. For a copy of the **Summary Report on Community Alternatives: Changing Directions for Long Term Care**, write to:

Marilyn Pickett  
N.Y.S. Health Planning Commission  
Tower Building, Room 1683  
Empire State Plaza  
Albany, N.Y. 12237



WARC — BANO Warriors

## WARC Warriors are Special Olympic Champs

There wasn't space for one extra body in the packed stands of the 800 seat gym at Woodlands High School in Greenburgh, when the New York Football Giants played an exhibition basketball game against the Westchester Chapter's WARC-Bano Warriors. The Warriors have been Area No. 3 Special Olympic Champions for the past two years, and competed fiercely and well against the professional super athletes. In a fast game which saw the lead seesaw continually, the pros won by 46 to 42. But the real story wasn't in the score; there were no losers. The Warriors and their cheerleaders, all clients of WARC, gained pride and a sense of accomplishment from being viewed by the public and their fellow clients as individuals with a talent who can make a contribution. The Giants expanded their understanding and respect for people with a disability, and benefitted from the knowledge that they had made a significant contribution. And gate receipts, sale of refreshments and raffle tickets for prizes of an autographed football helmet and footballs contributed

by the National Football League, netted over \$2,800 to benefit WARC programs.

The meeting between the two teams was the result of a special relationship that began last summer, while groups of WARC clients were attending the agency's residential camp. Campers visited the Giants' training camp in nearby Pleasantville on numerous occasions and were befriended by team members. The Giants then reciprocated by attending the camp's closing banquet and joining the campers at dinner. From then on, the Giants had an army of ardent fans among WARC clients and their families, who closely followed the fortunes of "their team" through a successful season. This special bond between the super athletes and WARC clients gave the event an emotional impact that no one could fail to experience.

### Handicapped children achieve

The foundation for Exceptional Children has initiated a special award program to recognize the skills, talents and aspirations of disabled young people. You can nominate a disabled child or youth through the age of 21 for a Handicapped Children Achieve! (HCA!) award in any of the following categories: academics, employment, arts, athletics, extracurricular activities, community service and independent living skills.

All nominees for whom completed forms are submitted by two persons will receive a personalized HCA! Certificate of Achievement, and an announcement which can be used to publicize their achievements in the local community.

To receive nomination forms, send a self-addressed stamped envelope to: HCA!, Foundation for Exceptional Children, 1920 Association Drive, Reston, Va. 22091. All requests must state the achievement category for which nomination forms are requested.

### Staten Island secretary's poem

It's a long walk through childhood  
The years go slowly by,  
We're trying our best to learn what we could  
It's a difficult task, but we try.  
You see, we're slow at learning  
Through no choice of our own,  
We're retarded children  
We can't make it on our own.

It's a long walk through childhood  
We may need some help from you,  
It's a long walk through childhood  
God gave us feelings, too.

Terry Gregorio  
Secretary  
Staten Island  
Aid for Retarded  
Children, Inc.

## 94-142 in jeopardy

The apparent commitment of the Reagan Administration to remove any federal role in education has manifested itself in a four-pronged attack on the educational rights of handicapped children. It is imperative that parents, professionals and all others concerned with the rights of our children take positive action to maintain existing rights which we have struggled so long and so hard to obtain.

The following is an Action Alert prepared by the Mental Health Law Project for the Education Advocates Coalition. Advocates for handicapped children can prepare now for the effort that will be needed to defend education rights. The following steps are suggested:

1. Gather information about the importance of PL 94-142 and section 504. This can be either anecdotal or quantitative data showing how the various protections are critical and are helping handicapped children, and what happens without them.
2. Hold factual briefings for newspaper editorial boards and electronic media to explain why services for handicapped children are so important to society as a whole, even in these days of belt-tightening.
3. Begin meeting with representatives and senators to explain the importance of PL 94-142 in its present form. Take them to a program to show how it is working.
4. Organize lists (telephone trees, mailing networks) to facilitate prompt communication as soon as precise issues and timetables become clear.

### THE PLAN TO ELIMINATE FEDERAL EDUCATION RIGHTS FOR HANDICAPPED CHILDREN

#### 1. Repeal of PL 94-142 or of Its Crucial Protections

The administration and its supporters in Congress will propose legislation to delete entirely crucial protections in the Education for All Handicapped Children Act (PL 94-142), including individualized education programs (IEPs), procedural safeguards (hearings and appeals to courts), least-restrictive environment (the mandate for programming in the most "normal" setting) and related services (services such as transportation, that allow handicapped children to participate in regular schools). In the last session of Congress, the administration's bill to repeal and block grant PL 94-142 was thwarted because parents and children's advocates made themselves heard by Congress. The administration may again try to repeal the law and give the funds to states in a multi-purpose block grant. More likely, the administration will try to repeal key provisions and thus claim that the program has not, technically, been repealed.

**TIMING:** Legislation to amend, partially delete or repeal PL 94-142 will begin surfacing between late January and April.

Congress could act very swiftly by including it in the new fast-track budget process, to be played out between April and June. Many important programs for poor people, children and the handicapped were lost this way last year, when the immense, single-vote Omnibus Budget Reconciliation Act made Reaganomics, not substance, the issue. Congressional hearings on PL 94-142 could come in February.

#### 2. Elimination of PL 94-142 Funds and Resulting State Withdrawal

The administration tried unsuccessfully to de-fund PL 94-142 last year. This year it plans to cut the program significantly (25-50 percent). The states are now receiving only about \$200 per handicapped child served. If the dollars get low enough, other states may follow New Mexico's lead and avoid all of the law's requirements by not taking any PL 94-142 funds. And with diminished federal funding, states that remain in the program will be pressured to cut back on services.

**TIMING:** The president's budget will be out in the third week of January. Congress will act on it in early spring. President Reagan will also have another chance to cut FY 81 funding when the current continuing resolution expires on March 31, 1982.

#### 3. Weakening the Regulations for PL 94-142 and Section 504

The administration is now redrafting all the regulations implementing PL 94-142 and section 504 of the Rehabilitation Act of 1973 (the Civil Rights Act for the Disabled). While no drafts have yet been made public, administration briefing papers make it clear that parental involvement, timelines for school district actions, related services and least-restrictive environment are major targets for "deregulation." Loss of these regulations will give states and school districts significant discretion in implementing both laws.

**TIMING:** The administration states that the proposed regulatory changes will be published in the Federal Register in early April. There will follow a period (perhaps 60 days) for public comment before the administration issues final new regulations.

#### 4. Dispersal of Education Enforcement

The administration proposes to eliminate the Department of Education and disperse all of its functions among a number of other agencies. Section 504 and other civil rights laws might go to the Justice Department; whatever remains of PL 94-142 might go to the Department of Health and Human Services. Coordination of enforcement of these two intimately related laws will become very difficult and the public will have to monitor the actions of not one but a number of agencies.

**TIMING:** The president is firmly committed to this and the administration bill is expected in January or February. It is not clear how soon Congress would act, although it could use the spring budget cycle.



Bernice Volaski, James Flanigan, Irene Platt, Chairperson and Eleanor Pattison at meeting of Sub Committee on Legislation.

## "Your Child's Right to an Education"

### Is it really a parent guide?

NYSARC Education Committee offers specific examples of how "Your Child's Rights to an Education" offers parents vague instructions by omission of essential facts which they believe essential and necessary in the pursuit of a free appropriate education.

1. Page 7 "Home-Hospital Instruction" — states that parents should contact their local districts for details on minimum requirements for home-hospital instruction. . . Omitted is the information needed to assure the child's rights to an "appropriate" education. A real guide for parents would include those minimum requirements which are: 5 hours per week at the elementary level and 10 hours per week at the secondary level.

2. Page 8 "Summer Programs" — Omitted is the information needed to assure the child's right to a "free appropriate" education. The necessary fact omitted in the guide is that the child's IEP must include and indicate a need for a continuous education through the summer months to prevent regression.

3. Page 10 "Child Ineligible for Special Education" — if a child is found ineligible for special education the fact that parents must be notified of their right to challenge the decision is not incorporated in to that section on page 10. This information is found 8 pages away, requiring a legal degree to discover and interpret. A real guide for parents would include this pertinent information in the same paragraph.

4. Page 12 — Essentially the guide describes special class programs in a vague manner; perhaps attempting to avoid addressing the issue of mixing children with different handicapping conditions. If SED lacks adequate written language to explain to parents how children will be grouped, this stands to

reason that no one fully comprehends how this action is to take place, including Committees on the Handicapped and Boards of Education. This mystery is exemplified on page 12 which states "if your child is placed in C and D, you are entitled to receive counseling and education for the purpose of helping your child at home". Who are "c" and "d"? Further, information is needed to decipher this "code". Additionally, it leads parents to believe that if their children are not placed in "c" and "d", they are excluded from this service — federal regulations make no distinction.

5. Page 12 — The final paragraph under number 4 — implies that only children in specific classes are entitled to receive related services. This is not true in our opinion, and we feel that a real guide for parents would — clearly state that related services are available for any child in any setting as determined by the COH and the parent through the evaluation and recommendation process.

6. Page 25 "Suspension" — The guide states "If the suspension is upheld at the hearing and your child is of compulsory school age (6 to 16 years old), the district must provide other suitable instruction." Omitted is the fact that if your child is between the ages of 5 and 21 and is handicapped, your district must make an educational program available to him-her. What happens when a 17 year old student who is handicapped is suspended? A true guide for parents would provide the answer to this question rather than imply that an educational program will not be available to this student.

In summary, parents need and should have a guide that EQUIPS them with facts to assure a free appropriate education for their children not one that is misleading by vagueness and omission of essential facts.



Kenny Geary helps in the spring cleanup on the Brookville Campus of the Nassau AHRC. Kenny works year round in the horticulture component of the vocational training program. After the spring cleanup, the big activity is the geranium sales which sees over ten thousand plants being bought by the public.

## Delaware Chapter helps parents speak out

Jo Ann Johnston, writer of the Walton's News Bureau, thinks parents of handicapped children must be outspoken when it comes to decisions affecting their children.

There are an estimated 200 handicapped children in Delaware County: Some are receiving the education they need, but for others that education could be improved, according to an agency for the retarded. That's where parents come in.

"I don't feel that anybody is purposefully doing anything wrong," said Stephen Helfgott, director of the Delaware County Chapter of the Association for Retarded Children, "but in some cases kids are not getting all they should be receiving."

Helfgott and Georgia Sullivan, an Orange County resident and parent of a mentally retarded child, recently spoke to a group of about 20 Delaware County residents on the educational rights of the handicapped.

State law, Helfgott says, provides that handicapped individuals between the ages of 5 and 21 shall have a "free, appropriate education at public expense." But it often takes parental involvement to make sure those words are fulfilled, Helfgott said.

"We had one case about a week ago where a mother thought her youngster was getting speech therapy, and she found out the therapy had stopped some time ago. That mother complained, and the speech therapy was put back," Helfgott said. But in another, similar case, "the mother didn't complain, and the child didn't get speech therapy," he recalled.

The only way for a parent to know if his child is getting the education he or she needs, according to Mrs. Sullivan, is to learn the educational laws pertaining to the handicapped, and then check those regulations against the child's schooling.

Since 1968, school districts in New York state have been required by law to have committees on the handicapped, groups that make recommendations to the local school board on the specific educational programs of the handicapped children in that district, Mrs. Sullivan said. Early contact with that committee and with other school officials will aid the education of the child, Mrs. Sullivan said.

Planning for the child's education should begin before school starts, around age 4, Mrs. Sullivan said. At that time, parents of handicapped children should write to the school and request an evaluation of their

child, and a planned academic program tailored specifically for that child. The cost of the evaluation, which may include a visit with a psychologist, doctor, or speech therapist, will be borne by the district, she said.

After receiving the report, the parent should be ready, willing and able to question it, Mrs. Sullivan said. Parents will want to know what tests were used, how much time the psychologist spent with the child before the test, where the tests were administered, and exactly what the results mean.

"Don't be overwhelmed by the school psychologist using four-syllable words: ask him what it (all) means," Mrs. Sullivan said. "Some school psychologists just don't know how to relate to parents."

After an academic program is prepared for the child, Mrs. Sullivan said, be prepared to speak up if it doesn't seem adequate. "They're the professionals, you're the experts," she said. "You have a right not to sign."

Parents should also be prepared to ask for things not included in the planned program, she said. Parents who have children learning sign language, for instance, can ask that they (the parents) be

taught the same skills to bolster the child's learning. Sometimes children might have to be sent to another district or to an area BOCES to receive services, she said, but the local school district still bears the responsibility for arranging those services and paying for them. In many cases, the district will be reimbursed by the state for providing the services, she said.

"They cannot say we don't have it," Mrs. Sullivan said, "It is whatever the child needs."

One exception, Mrs. Sullivan noted, is psychotherapy. Local school districts are not required to pay for such treatment, she said.

Once a program is agreed upon, parents are entitled to periodic progress reports and the children are entitled to yearly evaluations, she said. Parents must be notified of upcoming meetings of the local committee on the handicapped if their child is to be a subject of discussion, she said. Parents also have the right to ask the meeting be re-scheduled if they cannot attend.

Further information on the educational rights of the handicapped is available at local chapters of the Association for Retarded Children.

### Tenant Guide produced

A tenants guide of rights under New Jersey's new condominium conversion law is being made available free of charge by the Department of the Public Advocate. Department officials said that protections under the law are especially needed by senior citizens and disabled persons . . .

who are the tenants most often victimized by such conversions." The guide describes, among other things, legal protections from eviction and from unreasonable rent increases. To obtain a copy, telephone the Department's toll free hotline — 800-792-8600.

### Housing Development Fund provides seed money

Division of Housing and Community Renewal, Housing Development Fund (HDF) Program provides interest-free seed money to non-profit sponsors to build or rehabilitate housing for low and moderate-income families. These funds, also utilized by Section 202 sponsors, may

be used for administrative and preliminary costs associated with the development of housing and are repaid when permanent financing is obtained. For further information, contact: Noel Harris, DHCR, (212) 488-7086.

## AMWAY head named Chairman of National Disability Office

WASHINGTON, D.C. February 12— The directors of the National Office on Disability have elected Richard M. DeVos, president of the Amway Corporation, as the organization's chairman.

DeVos' acceptance of the chairmanship coincides with the designation of 1982 as the National Year of Disabled Persons by the U.S. Congress on February 10. Soon to be signed into law by President Reagan, the bill is designed to encourage and promote progress toward long term goals in the area of disability, especially through community programs. An outgrowth of the 1981 International Year of Disabled Persons (IYDP), the National Office on Disability was established in January in response to a widespread call for continuing the community-based voluntary programs of and for disabled persons generated during the IYDP.

In accepting the chairmanship, DeVos stated, "What we saw in the 1981 observance in this country was inspirational. Disabled and non-disabled people in 1,850 towns and cities across the nation worked together in partnership to identify needs and solve problems.

"This was an outstanding example of self-help and people doing more for themselves," he continued. "The National Office on Disability will build on the IYDP programs they created and continue the momentum achieved in 1981. The problems and challenges of disability go on. While not intended to replace govern-

ment programs, these private efforts are especially important in these times of fiscal retrenchment.

"The presidential and congressional support," DeVos noted, "will help create awareness on the continuity problems of disability. Their action will reinforce concrete program activities furthering our long-term goals."

In addition to the Congressional initiative, governors and mayors throughout the country are also issuing proclamations designating 1982 the National Year of Disabled Persons in their respective states and communities.

As a private sector response to the challenges and opportunities facing 35 million disabled Americans, the National Office on Disability advocates partnership and self-help initiative. It provides encouragement and guidance to communities in such areas as expanding opportunities in employment and education, improving access and rehabilitation, expanding prevention programs, and furthering other long-term goals. It will utilize and build on the nationwide community partnership network created during the IYDP, and promote awareness and disseminate information on disability programs and issues.

For additional information, write:  
The National Office on Disability  
1575 I Street, N.W.  
Washington, D. C. 20005

## Dutchess names new Executive Director

Paul M. Perfetti has been appointed Executive Director of the Dutchess County Chapter of the New York State Association for Retarded Children, Inc. in Poughkeepsie.

Mr. Perfetti had held the positions of Acting Executive Director, Assistant Director and Workshop Director. He joined Dutchess ARC in 1977 after several years with the Montgomery County Chapter in contract procurement. He holds a M.S. degree in mental retardation from the College of St. Rose in Albany.

Now living in Fishkill, South of Poughkeepsie, Mr. Perfetti is married to the former Grace Morini. They have a 7 year old daughter, Carrie-Ann.

Speaking of the recent appointment, Dutchess ARC Board Chairman, Alice Scileppi said, "One of the things I admire most about Paul is his tenacity. Thanks to his determination, we can expect to achieve important goals."

Supervising a staff of 80 and a clientele of 218, Mr. Perfetti's stated goal is to maintain an increase of services to the mentally retarded of Dutchess County and their families despite funding cutbacks, and to continue developing Manu-Corp, the sheltered workshop into a "professionally competitive sub-contracting agency." Manu-Corp serves business throughout and beyond the Hudson Valley.

## Quality of Care Commission reports available

These reports, prepared by the Commission on Quality of Care, are available from the Commission at 99 Washington Avenue, Suite 730, Albany, New York 12210:

Converting Community Residences into Intermediate Care Facilities for the Mentally Retarded: Some Cautionary Notes, (ICF-MR), October 1980.

Conference on the Needs of Emotionally Disturbed - Developmentally Disabled Individuals — PROCEEDINGS, November 1980.

Profit vs. Care: A Review of Greenwood Rehabilitation Center, Inc., A Private School for the Mentally Retarded and Related Regulatory Processes, March 1981.

Family Care Revisited: Buffalo Psychiatric Center Family Care Follow-Up Study, March 1981.

The Endless Quest: The Autistic and Their Families, August 1981.

### BOARDS OF VISITORS MATERIALS (\$2.00)

Conducting Better Facility Site Visits; A Guide of New York State's Board of Visitors.

The Review and Investigation of Allegations of Patient Abuse or Mistreatment; A Guide for New York State's Board of Visitors.

The Law and Boards of Visitors, February 1981.

### Guide to human services changes

This is a very useful publication which clearly details the changes in federal legislation and appropriations which affect human service programs. Edited by Jule M. Sugarman, September 1981. Order from:

Human Services Information Center  
1408 N. Fillmore Street, Suite 7  
Arlington, VA. 22201

(703) 537-1634

Price: \$7.95 each



## NYC Chapter offers creative recreation

If you happen to meet a member of the AHRC Recreation Therapy Program, ask what he or she has been doing lately! You're likely to hear a long list of out-door recreation activities that may surprise you! You're sure to hear about camping, backpacking, canoeing, cross-country skiing, and cave exploring. And you'll probably hear about apple-picking, flea market and antiques, beach combing, and farm weekends. Some members will also tell about the delights of long vacation trips meandering along the Virginia coast or exploring Quebec and Montreal.

For the past year, AHRC Recreation Therapy Services has been offering its members new and challenging experiences in the outdoors. The trips have been designed to introduce members to the outdoors, promote personal satisfaction through challenge and learning in nature, foster social interaction, physical and mental health, and provide normalization experiences and equal recreation opportunity to retarded citizens.

These outdoor Recreation trips have been done in cooperation with SPROUT — a non-profit outdoor recreation

organization specializing in special needs programming. Participants travel by van, accompanied by leaders from AHRC and SPROUT. Each trip is limited to 10 members in an effort to make the experience more personal and normalizing. The cost is reasonable and the benefits substantial!

One participant noted: "I like the trips and to go different places! It teaches us a lot; to do things and be useful!" Another participant added, "I hope there will be other trips this year! Without these trips there is no way I can have a real vacation!"

But the real success can be seen in the exhausted but happy faces of a group of backpackers who have just been challenged by a 6 mile hike and succeeded!

If you would like more information on the outdoor recreation programs and other recreation activities, please call the AHRC Recreation Therapy Program at (212) 254-8203 Ext. 215, or write New York City Chapter, 200 Park Avenue South, NYC 10003, Jan Karst — Coordinator.



Irene Platt, Senior Vice President, stands next to Ben Golden, Legislative Budget Analyst on Ways and Means Committee as Ellie Pattison and Shirley Valachovic look on.

## How automation helps Association

The newest employee of the Westchester ARC has only one name — Calvin. But Calvin is now doing his job without being fed any more than a heap of names and numbers. As you may surmise, Calvin is an obedient and hard-working computer. Arriving already programmed and humming with the proper instructions to handle ARC types of data and reports.

For instance, there is a special program to take in and process the workshop data for the clients, payroll, quite different from the program for the more standard staff payroll. Other programs handle all regular business accounts up through the general ledger but also produce the many special reports and budgets required by all the various agencies and state offices. The latest special is the billing of Medicaid charges to Bradford Administrative Services, which is now spilled onto a transportable tape.

Fortunately, WARC's computer is not a clumsy, demanding mystery to its users. In line with the latest type of business computing, Calvin guides and assists the clerks who feed it data one piece at a time. Even while the data sits inside, each piece is still quite easily retrievable at any time by the human users who may need to look at or change it. Most useful of all is a language, called 'English' by the manufacturer, which permits requests for special reports to be simply and quickly produced, though not previously programmed.

WARC stepped into the world of automation only after a period of careful preparation. The first stage was the working out of what is called a "Request for Proposal" which was sent to eight likely computer firms. Those that responded each brought along their preferred software firm for the programming side of the project. Meanwhile WARC's Controller and his Assistant completed the development of design specifications for the desired system — all the records needed, the reports and

budgets to be produced and all the other services needed.

The response to these specifications narrowed the feasible bidders down to one team that combined the Microdata Computer Co. with a software firm called People Machine Interface (PMI) of New York City. This team was then contracted to implement the total system now effectively serving WARC's processing needs.

WARC invites the officers, controller or any leader of other chapters to contact WARC's office in White Plains to learn for themselves what such a system might do to lighten their business and administrative load. At least one of the team that guided WARC's installation would be available by pre-arrangement to demonstrate and even counsel on how another chapter might do the same. Meanwhile, the team of implementing firms has assured us that the scope and cost of this system, both the computer and its software, can be scaled to the size and requirements of the individual chapter.

**SUPPORT  
YOUR  
LOCAL  
CHAPTER**

## Guardianship Committee meets



At Guardianship Committee meeting, Hy Clurfeld, Chairman and from his left Toni Parisi, Jane Gerstheimer, Nat Mills, Richard Cohan and Jerome Ness.

## Down's Syndrome readings

1. **Teaching Your Down's Syndrome Infant: A guide for Parents**, by Marci J. Hanson. University Park Press, 233 East Redwood St., Baltimore, Maryland 21202. (\$12.95)
2. **Down's Syndrome: Growing and Learning** by Siegfried M. Pueschel, M.D., and others. Sheed Andrews & McMeel, Inc., 6700 Squibb Road, Mission, KA 66202. (\$8.95 hardbound — \$5.95 paperback). Developmental Evaluation Clinic, Children's Hospital Medical Center, Boston MA 02115. (\$3.50, payable to DS RESEARCH)
4. **Sharing Our Caring**, P.O. Box 400, Milton, WA 98354 (\$10-year).
5. **Down's Syndrome Congress**. Linda Koplan, Membership Secretary, P.O. Box 1527, Brownwood, TX 76801 (\$10-year includes DS NEWS monthly).
6. **To Give An Edge: A Guide for New Parents of Down's Syndrome Children**, by J.M. Horrobin and J.E. Rynders. Colwell Press, Inc., 500 South 7th Street, Minneapolis, MN 55415 (\$2.00).
7. **Down's Syndrome: Papers and Abstracts for Professionals**, 10404 Leslie Court, Silver Spring, Maryland 20902 (\$5-year).
8. **Aim to Fight Low Expectations of Down's Syndrome Children**, by J. Lucille Poor, North Central Publishing Co., 274 Fillmore Avenue East, St. Paul, MN 55107 (\$3.95).

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

175 Fifth Avenue

New York, New York 10010

**Our Children's Voice**  
and the Children's Voice

Non-Profit Org.  
 U. S. POSTAGE  
 PAID  
 New York, N. Y.  
 Permit No. 8245