

Our Children's Voice

Retarded Children Can Be Helped

VOLUME XXXVI NO. 2

NEW YORK ASSOCIATION FOR RETARDED CHILDREN, INC.

SEPTEMBER 1984

Another NYSARC Success Story

Bill Of Rights Signed By Governor Into Law

When the 1984 Legislative session recessed for the summer a number of NYSARC sponsored bills were acted upon.

The Association had many Legislative goals. Although success was not obtained in all areas, this session of the legislature felt the pressure of NYSARC. Although both the Senate and Assembly have adjourned for the summer, they probably will return before the end of the year, either after the November elections or be called into special session.

BILL OF RIGHTS

Highlighting this years accomplishments was the passing of the Association's Bill of Rights for persons who are mentally retarded or developmentally disabled and residing in community residences.

The Bill sponsored in the Senate by Senator Frank Padavan, R-Queens (S.8203-A) and Assemblywoman Elizabeth A. Connelly, D-West Brighton (A-9748-A) was passed by both houses of the Legislature. The bill was signed into law by Governor Mario Cuomo.

ORIGIN

The initial draft of the Bill of Rights was developed by an Ad Hoc Committee of the Association chaired by our former Executive Director, Mr. Joseph T. Weingold. Serving with him on this Committee were Mr. I. Joseph Harris, Former Executive Director of our NYC Chapter and recently a Commissioner for the NYS Quality of Care Commission and Mr. Peter Knauss of the NYS Office of Mental Retardation and Developmental Disabilities.

The draft was then reviewed and contributed to by the NYSARC Community Residence Committee.

At the Association's 1983 annual convention in Lake Placid, the Bill of Rights was again reviewed and revised further by both the Board of Governors and the Delegate Assembly.

The NYSARC Delegate Assembly passed the Bill of Rights and it was adopted as NYSARC policy. Additionally, these rights were also incorporated into our Association's 1984 Legislative initiatives.

LEGISLATIVE COMMENTS

At a press conference announcing the introduction of this Bill, Senator Frank Padavan stated... "I have introduced legislation vital to the interest of the 13,800 individuals living in community residences and their families." It was then "resolved" that a Bill of Rights be established for all residents of community residences and for the parents and guardians of such residences."

In June of this year, the Legislature sent the Bill of Rights to the governor for his consideration. The Bill of Rights was signed into law by Governor Mario Cuomo. A copy of the Bill of Rights can be obtained by writing to the NYSARC Office in Delmar.

Legislative Seesaw Tips NYSARC's Other Goals

**ORS — Bill delayed in Senate —
Education Bills delayed in Assembly**

O.R.S. Bill Report

Of primary importance to the Association (for many years) is the removal of the Office of Vocational Rehabilitation from the State Education Department to a separate Office in the Executive Branch. Governor Cuomo in his State of the State message in January called for such action.

In the closing hours of the legislative session, Assembly Bill #A.11530, calling for the establishment of an office of rehabilitation services, in the Executive Branch was passed. The companion Bill the senate, Senate bill #S-.9143 never reached the floor of the senate and although many attempts were made by our Association to have the leadership bring the Bill to a vote.

INTEREST MAINTAINED IN LEGISLATURE

On the positive side, both the Senate and Assembly votes indicate the desire to address vocational rehabilitation problems for New York State's disabled community. Our Association will continue to work for passage of a separate office of vocational rehabilitation.

DOLLARS VOTED FOR SEP

The Senate did pass S.8388-C which increased payments to the Sheltered Employment Program (SEP) from \$1,500 to \$2,500. There was no companion Bill in the Assembly. The Bill while increasing SEP does nothing to address our Associations real concerns regarding rehabilitation services.

In addition, although the Senate was willing to amend the Bill three times, because of Technical problems, it still has language that is inconsistent with the original SEP plan.

Home Reared Planning Challenged



**Marc N. Brandt
at Westchester ARC**

When WESTCHESTER ARC hosted a panel of distinguished experts in June, the Rights of the Home Home reared as they fit into community residence plans sparked a spirited discussion.

Barbara Hawes, Asst. Commissioner of State-Wide Services for OMRDD participated with Eugene Aronowitz, Westchester Commissioner of community health services and NYSARC Executive Director, Marc N. Brandt.

After listening to an extensive description of OMRDD plans for the home reared entering community residences Brandt summarized NYSARC's beliefs. "It is true that there has been an improvement in the quality of life in community residences in the last decade," Brandt said, "but what we need now is more space and more dollars.

The planning for these needs should be met carefully or be left to our parents in the community through the ARC Chapters!!"

Reporting Of Client Deaths

At our NYSARC October convention the detailed recommended policy on reporting client deaths was reviewed, approved and adopted.

Chapters are to inform NYSARC State Office of all deaths of clients receiving or enrolled in services or programs by the Chapter within 72 hours of the death. Notification will be by copy of the form required by the N.Y.S. Commission on Quality of Care for the Mentally Disabled (QCC-100).

NEED FOR POLICY EXPLAINED

During the past year, there have been a number of clients who have died while in the care of our Chapters. As the individuals were serve age, and as we

continue to serve more medically fragile clients, the incidences of death, unfortunately, will continue to grow. The painful loss of individuals whom we work with and have cared for makes us all more sensitive and heightens our feelings of responsibility to the developmentally disabled entrusted to our care.

We all share in the responsibility for reviewing all occurrences of client deaths to assess the circumstances surrounding the death and to determine if any action is necessary to assist our families, staffs, and clients in coping better with this life circumstance, to provide better services to other clients, or to design safeguards to prevent or avoid accidental deaths.

EDUCATION BILLS BOGGED

For many years the Association has been working hard for laws which would mandate pre-school education for the handicapped and summer school. In the closing hours of the legislative session, the Senate passed S.8622.

The Bill mandates summer school for certain children between the ages of 5-21 placing those children under the responsibility of the Committees on the Handicapped (totally eliminating family court) and is 100 percent funded by the State Education Department. It allows counties to fiscally audit programs and to place out for bid the transportation of pre-school children and allows for a three-year study of provision of services for youngsters from birth to three by the Council for children and families.

ASSEMBLY EDUCATION COMMITTEE SLOW TO ACT

NYS Assembly amended the Senate version during the closing days. Unfortunately, for a variety of reasons, the Bill did not come out of the Assembly Education Committee and did not reach the floor of the Assembly so it could be voted on.

While the Bill does not include everything, the Association has been advocating for the Bill, as it is, is a giant step forward in the provision of services for children as with the ORS Bill, the Association will combine to enlighten legislators as to the importance of this Bill.

LETTERS to the EDITOR

Dear Editor

Dear Editor,

I would like to make mention of the fact that my class, a trainable mentally retarded group from Amsterdam High School, participated in the Bowl for Kids Sake drive.

On Friday, March 9, during our physical education program at Imperial Lanes, my retarded children bowled and received two cents per pin for their efforts. I am proud to say that we raised two cents per pin for our efforts and raised a total of \$68.90 which we turned over to the Big Brothers - Big Sisters Foundation.

We made this effort to help show how mentally retarded people can and do participate in community activities and are in fact very useful members to society and should be recognized as such.

Credit goes to my class members: Peter John Terplak, Gregg Tokarczyk, Lori LaMori, Karen Parillo, Claudia Canale, Kelly Griffin and David Somers.

I would sincerely appreciate your mentioning this achievement to your publication as an aide to helping advance the importance of recognizing my children as participating citizens of our fine community.

Nicholas J. Miseno
Special education teacher
Amsterdam Recorder

Dear Editor

Dear Editor:

I wish to say a very special thank you to a very special lady.

Mrs. Jean Emerson is such a person. I first met Mrs. Emerson during the NYSARC Convention in 1980. In 1981, I was asked to chair the newly formed NYSARC Prevention Committee. Mrs. Emerson was the first person from any of our chapters to respond to a request for those interested in prevention to submit their name to the State office. She did that and more (as per Mrs. Emerson's style). She personally called me at my home and told me of her genuine interest in prevention. She offered to form a group in the Northeast Region of New York State in order to generate interest in specific topics relating to Prevention.

She immediately formed a group who met, and still meet, almost monthly since that time. This dedicated group represents such multi-disciplinary backgrounds as services for alcoholism, New York State Education Department, cooperative extension programs, retired school administrators, the Office of MR-DD, services for young children, state and public health officials, etc.

Not only has this committee worked well together, but there is a camaraderie among them that seems to bind each to the other. I strongly suspect this bond is a result of the personality of Mrs. Emerson. Sincerity, honesty, integrity, loyalty, and a compassion and concern for others are characteristics that fit Mrs. Jean Emerson to a tee and are reflected in the work of this group.

Under Mrs. Emerson's direction and later with the assistance of Dr. Judith Tate, this Northeast Region NYSARC Prevention Committee has generated interest in this region in bio-medical issues of prevention of MR-DD. These include car safety for adults and children, fetal alcohol syndrome and fetal alcohol effect, good parenting skills for teenagers, prevention of childhood lead poisoning and additional issues to be addressed during the coming year.

Mrs. Emerson, I salute you! I cherish our friendship and I thank you for your realization of the fact that "Children Won't Wait".

Your friend,
Joan Edwards

A Handbook Of Assistive Devices For The Handicapped Elderly

NEW HELP FOR
INDEPENDENT LIVING
Ed. by Joseph A. Breur
Haworth Press

While titled for the "Handicapped Elderly," we found this book to be of great value to anyone working with handicapped persons in need of assistive devices for self-care. There are many clear illustrations and photos of commercial and handmade devices for helping with eating, toileting, dressing and washing.

The book is concise and would be of value in the training of direct contact staff.

One Voice Sounding Off On 'Parent Maturity'

A Way Of Life, Not A Miraculous Cure!

SALLY PUFF, in the Washington State publication, PAVE, responded to various definitions of "maturity" which highlight patience to accept some injustices towards their children as a focus of maturity. We thought our readers would enjoy her response.

— The Editors

What then, is real maturity?

Parents of handicapped kids need some patience, but not very much — in attempting to change the system. They need a sense of the possible and to insist on their child's rights and services right up to the limits of the possible — and even stretching beyond, with the constant awareness that any time that is being wasted is their child's childhood and very life.

Parents of handicapped kids need the awareness and strength to reach out to each other and band together and support each other in the face of frustration and failure. They need fans, they need true friends, supporters, focused on past successes and future victories, not today's defeat.

Parents of handicapped kids need to be able to admit they were wrong and forgive themselves because they are good people fighting the good fight and recognizing if

they never made any mistakes, they probably would never make anything.

Parents of handicapped kids not only need to make decisions, they need to explore possibilities, to continually believe and expect the exciting new idea, service or technology while implementing the constants in their son or daughter's life — loving them for who they are not who they will be after the latest breakthrough.

But parents must be open — all the hurts and scars in the world must not seal their vision for the precious person in their charge. "Love him/her as he/she is. Expect positive change — first in the environment, then in your child."

Parents of handicapped kids need to give and receive dependability, keeping of word, and coming through in a crisis. When nobody else is there to do it, they must reach out to each other. None of us can stand alone.

Parents of handicapped kids need to live in peace with their child and to accept their own responsibility to change themselves in a way that elicits the most positive growth in their child. And when they blow it, they need to settle for a good cuddle.

If that's not maturity — so be it.

A Parent Articulates A Heartache

Some reasons for mental retardation are never explained. My 14-year-old is one of that majority whose mental retardation cannot be medically explained but the fact sadly remains that he IS mentally retarded and that the range of his ability falls within the trainable category. Educable is the highest or closest to "normal" and trainable is lower or lesser.

Although he continues to grow in size and in chronological age, Derek will always be limited in his mental functioning, his social maturity, his ability to conceptualize and understand, his ability to reason and to learn. Yet, even with these medically acknowledged limitations and the assertions that he will never catch up or really grow up, we, his family, absurdly have to deal with his "aging out" of this society.

As his body grows and changes from an adorable, acceptable child, the problems surrounding him grow also. He'll grow to represent an unacceptable, possible frightening man to others.

What should I do? How should I feel? Is this a complaint against an uncaring society? An accusation against an uninterested, ignorant society? A plea for mercy and pity? I've experienced all those feelings... and a constant sadness. Day - today living brings new heartaches living with a mentally disabled adolescent.

Derek likes to go to the library and is interested, of course, in pre-school and first grade books like any other young child might be, but now I cannot let him just browse around the baby books... at age 14, he's out of place and people would

laugh at him... stare. And one of the constant aims we have as parents is to instill socially appropriate behavior in our retarded children.

Derek, like any other young child, asks for a Burger King paper crown and would like his birthday party at McDonald's but again, he's too old for that.

He also wants to play in the kiddy playground which is clearly marked for 9-year-olds and under. He wants to go to puppet shows but would inappropriately stand out in the audience. He wants to sit on my lap for comfort like any other small child might want to but I have to push him away because he's too big for that... but he doesn't know it.

Normal age contemporaries as playmates passed him years ago and now the only relationship he has with them is when I pay them to come over and babysit.

At present, trying to maintain a normal family home atmosphere is hard enough but as time continues the strain intensifies. When Derek reaches age 18, the normal age of adulthood, his father and I will have to file for legal guardianship through the court system as do all parents of retarded young adults.

And at age 21, Derek will age out of school although his education will never be completed and he needs constant reinforcement and attention to retain what he has learned.

In other words, Derek, with his probable eventual age of 60 will just get too old to be helped in this society.

—A Saddened Parent

I Live With A Label!

I live with a label,

A label that reflects less than my humanity — not because of who or what I am — but because of the way you look at me and allow me to be me.

I am retarded —

What are you? — bright in every way? Able to meet all demands? — personable and acceptable to all your peers? — capable of all jobs? ... me neither —

Does that mean you're like me?

— Anonymous
Madison ARC
"Reflections"

Our Children's Voice[®]

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NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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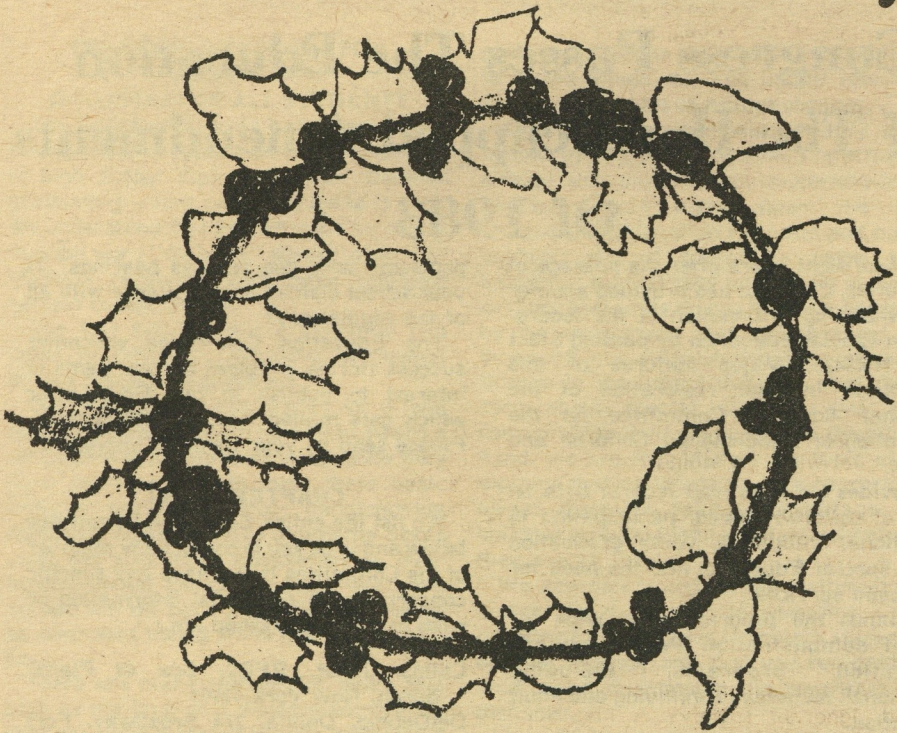
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Christmas In July For Steuben ARC



Third Prize Natalie Laino 1984



Second Prize David Hoffman 1984



First Prize Diane Lester 1984



First Prize James Devore 1983

Diane Lester of 29 Murray St., Newark, N.Y. won the 13th annual Christmas Card Contest, an artist's design promotion sponsored by NYSARC. Her entry was one of the 173 submitted from around the state and will be used on the Christmas cards sold by the Association this year. Diane Lester participates in the Day Activities Training Program of the WAYNE COUNTY ARC.

This year STEUBEN ARC will unite its past expertise in screen-print and offset work to produce the Christmas cards for our parent association. An anticipated 125,000 cards will be printed up for sale in

boxes of 25, 50, 75 and 100 cards. Cost will be \$9 to \$12 according to the design and number, half price to Chapters for re-sale.

Winning Designers for this year were, in addition to Diane Lester who received a \$100 Savings Bond, David Hoffman (\$75 bond) whose design was submitted by SCHOHARIE CHAPTER ARC; Natalie Laino, design submitted by SCHOHARIE ARC, and Special Mention to artist Marie Duryee on a design submitted from Painted Post West High School and Tammy Edmonson on a design from MONROE ARC.

OOPS! RED FACE DEPARTMENT . . .

The last issue of Our Children's Voice went out under an incorrect Volume No. and date line of December 1983. It should have been designated VOLUME XXXVI No. 1, April 1984. For this we are sincerely sorry.

The Printers.

Handicapped Funding Frauds

NYS Attorney General Consumer Frauds Bureau Head in Buffalo has volced a warning to various people asked to help children or the handicapped.

In an article in the *Buffalo News*, written by Modesto Argenio, the Frauds Bureau leader cautions consumers and donors about "schemers who cash in on people's philanthropy."

Telephone solicitation, often used by legitimate fund raisers, (the boiler-room approach) in the hands of unscrupulous people can deplete the financial success of legitimate requests in an area.

Knowing your receiver organization is the best counter-measure. Slick operators know how to take advantage of a person's instincts to help the downtrodden.

So even though the magic words to elicit dollars — "scientific study" or helping handicapped or retarded children" are used — be sure you can track where your pledge or gift goes.

Wallpaper

to Jacquelyn Kitchen
by
Christabel Fowkes

I want to say something about life
So I sit in a dark room.
And stare endlessly at the wallpaper
A child died today
We called her "Special"
But that was yesterday
Today . . . she isn't anything.

Yesterday, she slept and ate a little
Today I was enraged
She was only two
Somewhere, hidden in the wallpaper
There's an answer

I pressed a kiss on her cheek
That was the last time I saw her
I like to think she took it with her
I really want to say something about life
But all I see is wallpaper

— From Orange County
Newsletter, TORCH

NEWS AND VIEWS EDUCATION COMMITTEE

Siblings Who Help Disabled

By Dorothy Gaiter

"I may have passed up marriage a couple of times because of this," Rita Haahn, 52 years old, said of her responsibilities for Grace, her retarded 48-year-old sister. "But as I look back on life, I didn't lose a thing."

Miss Haahn's voice seemed sincere as she spoke to a cluster of participants who gathered at Hunter College recently for a seminar on siblings of the mentally retarded or physically disabled. However, a few minutes later, Betty Pendler, whose daughter, Lisa is retarded, said gently, "If a sibling doesn't feel trapped in some way and feels that 'Gee, I'm not leading my own life,' I think if they deny it, they're really not being honest."

The relationship between a sibling and his or her handicapped sister or brother is an ambivalent one, Dr. Jack Gorelick, Associate Executive Director of the New York City Chapter of the Association for Retarded Children, said in an interview.

"On the one hand they are resentful because they have so many obligations," he said. "But almost universally, there's a tremendous sibling tie and a feeling of responsibility and in most cases real genuine love."

"Sharing the pain, the anguish, the shame and the guilt of having a handicapped person is a family affair," said Rose Medicus, a social worker at Westchester Jewish Community Services, co-chairman of a workshop called "The Forgotten Ones Who Got Together to Talk." "It is not," she said, "just a parents' affair."

The two-day seminar, which drew 300 people, was sponsored by the Association for the Help of Retarded Children, Hunter College, the Social Work Program of Kean College of New Jersey and the Mental Retardation Institute of Westchester County Medical Center.

SIBLINGS FEARS EXPRESSED

Siblings shared the remembered pain of stares and other cruelties. Some recalled not dining out and missing weddings and parties because their handicapped siblings who lived at home could not go. Others felt neglected by preoccupied parents. There was talk of promises forced by dying parents to care for their sister or brother for the rest of their lives. Others expressed fears that their children might be born retarded.

A 58-year-old woman, whose retarded sister is 53 and who has lived at home with her mother, now 85, all her life, said that although she has an older brother, it was implied that she would inherit the care of their sister.

"It has only been recently as sibling groups have started that I've been hearing other people voice things I thought only I felt," she said, "that I felt guilty for saying

I really didn't want this responsibility."

Miss Haahn said her high school guidance counselor told her that she, the valedictorian, would not be allowed to attend commencement if her mother brought her sister to the exercises. Another teacher baby-sat so that her mother was able to hear her give the valedictory address.

While group homes and respite programs are available for the retarded, a few are accessible to the autistic, said Daphne Greenberg, a 21-year-old graduate of Brandeis University whose autistic brother is 23. "I feel very trapped because I know about all of these services and they're just not interested in people like my brother," she said. At school she organized a sibling support group.

FAMILY INCIDENTS RECOUNTED

"We're concerned about dating," Miss Greenberg said. "What do you tell your boyfriend or girlfriend about your brother or sister? And how are you going to incorporate your future husband or wife into your problems?"

Mrs. Medicus said that when some of the siblings of retarded people in one of the Westchester center's homes were asked if they would make a long-term commitment to do volunteer work in the home the answer was "a resounding 'No!'"

"They're tired of the pain and the anguish," she said. What they wanted, she said, was information about their role as siblings, what happens when a handicapped person becomes old and incapacitated, about guardianship and how to deal with guilt. The center will offer a program in September for Westchester families.

Bonnie Cohen, 28, said growing up with a retarded sibling had been difficult at the time. "But I also felt a lot of enhancement of my personal value system," she said. "I needed help to see all of that and to balance it." She participates in the Sibling Network that the Association for the Help for Retarded Children Sponsors at 200 Park Avenue South.

Her brother is 31 and works as a messenger at McGraw-Hill. He has worked for 11 years, traveled, has a "very active social life" and lives in an apartment where he gets some supervision. "I'm very proud of my brother," she said.

Geri Zatlou, whose brother is autistic, spoke of the "chronic sorrow" that many siblings experience.

"When I look at my brother, and he is so beautiful to look at, I think wouldn't it be wonderful if he were normal," she said. "I mean he doesn't look handicapped and then he opens his mouth or does something absurd and that's blown away. That's when the sorrow comes in."

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Congress Passes The Education Of The Handicapped Amendments Of 1983

Almost eight years after the passage of P.L.94-142, Congress has provided another overwhelming affirmation of the federal role in Special Education by passing S1341 and HR3435. Major features of this legislation include: restoration of the National Advisory Committee on the Education of Handicapped Children and Youth.

Provides for improved federal data on ages of children served, participating in Vocational Education, youth graduation from Special Education and the need for improved services.

Expands the program to provide for model demonstration Post-secondary Education programs, including vocational, technical, continuing and adult education.

Refocuses personnel preparation resources on the preparation of Special Education personnel and requires colleges and universities receiving grants to meet state and professionally recognized standards.

Provides for an increased Congressional role in proposals to revise Special regulations (Biaggi amendment).

Establishes a PARENT CONTROLLED training and information program.

We want to give special thanks to Senator Lowell Weicker, Congressman Silvio Conte and Congressman Mario Biaggi, who among others, worked hard to include all of the provisions regarding parents. There's always a woman behind the scenes, and we know that Nina Droma, a member of Senator Weicker's staff worked very hard to come up with the final and most difficult negotiations on behalf of the Senate version.

WELCOME THREE NEW MEMBERS TO THE EDUCATION COMMITTEE:

We are very pleased to welcome the following new members of our committee who have already stepped knee deep into activity: Dahlia DelDebbio, Warren - Washington Chapter, Sue Lyons, Fulton County Chapter and Elizabeth Villani, Westchester Chapter.

EDUCATION COMMITTEE MEMBERS ARE YOUR RESOURCE FOR PROBLEM SOLVING

Have you had success with parents on due process hearings? Have you had

problems with due process hearings? Is your school district in compliance with all of the regulations?

The Education Committee welcomes success stories, problem stories, items of interest to publish in our Ed-U-Letter which gets mailed free to 4,000 persons. Please send us your items of interest.

CHAPTER ALERT

We list the entire Education Committee below and urge you to contact any member of the Committee if you have any specific concerns, wish additional information or wish to run a workshop etc.:

Calins, Janet, RFD2, Box 48 Plattsburgh, New York 12901

DelDebbio, Dahlia, 274 Broadway, Fort Edward, New York 12828

Lyons, Susan, 127 E. State Street, Gloversville, New York 12078

Murphy, Mary, 41 Dirksen Avenue, West Seneca, New York 142 (chairperson)

Pendler, Betty, 267 West 70th Street, New York, N.Y. 10023

Reynolds, Shirley, Heritage Village Apts., 101 Patroon Drive, Apt. No. 7, Guilderland, New York

School, Thomas, 7528 Moon Valley Drive, Liverpool, New York 13088

Shalvey, Judy, PO Box 961 Miller Place, New York 11764 (co-chairperson)

Villani, Elizabeth, 159 Bolner Avenue, Yonkers, New York 10703

Kemmer, John, Warren - Washington Chapter ARC, Box 389 Glen Falls, New York 12801 (Liaison for Executive Directors)

NEW REPRINT AVAILABLE...

"THE UNTESTABLE CHILD"

SEND FOR IT BY WRITING TO

NYSARC STATE OFFICE.

Ed-U-Letter is for you. . . It's primary purpose is exchange of educational information to all chapters. . . We hope by now someone in your chapter has a copy of the handbook issued by the Education Committee. A guide for the Education Committee of your chapter, we would like to have the name of a particular individual to address when we have new information to be inserted into this valuable handbook. Please forward such information to the Education Committee at the State Office.

A Sibling's View

A Sister Speaks

To A Work Conference

The following statement by Monica Arellano was read during the closing ceremonies of the Second International Down's Syndrome Convention in Mexico City last year:

"I must tell you that this was not research or work chosen by chance, but a problem that has touched me very closely. I say closely because my youngest brother — I can't say is afflicted, or even suffers, because these verbs are inappropriate — I must say exists, and lives, and is, a child with Down's Syndrome, loving, caring, gentle, mischievous, kind, somewhat irreverent and irresponsible, but always respectable.

"This is not due to his intelligence in a world thirsty for champions. It is not due to his science in a world in the midst of industrial, technical, and scientific advancements. It is not due to his strength or

physical ability, since his muscles and bone structure do not correspond to an athlete and even less to the human archetype that TV tries to sell. It is not due either to his beauty, because we tend to respect, mistakenly, the human beings that fashion and trend impose on us.

"In a few words, my brother is respectable because in his world he fights to better himself, to be brave, to be strong, to be beautiful and, most of all, to understand a social environment that, to a greater or lesser degree, rejects him. In conclusion, I leave you with the great question: Will we find human truth if we go on building nuclear men, Adonis archetypes, bionic women, supermen; or, will we find it in the love that my brother feels, in his tenderness that overflows, and in the candor of his attitudes?"

Courtesy Down's Syndrome News

ARC Clients Do Well

In Special Winter Olympics

Let me win;

But if I cannot win;

Let me be brave in the attempt

(Special Olympics Oath)

To Pay Or Not To Pay — That Is The Question:

School Evaluations/Private Evaluations

By Marilyn R. Wessels

This question was discussed at some length in the Spring, 1982 (Vol. 5 No. 2) issue of the Ed-U-Letter. Since that time we have been trying to further clarify the process that parents should use in getting independent evaluations done on their children.

Part 200 of the Commissioner's regulations, 200.5 (b) (2) states that; "The parent has a right to such independent evaluation at public expense if the parent disagrees with the evaluation obtained by the school district. However, the school district may initiate a hearing to show that it's evaluation is appropriate. If the impartial hearing officer's recommendation is that the evaluation is appropriate, the parent has a right to an independent education evaluation, but not at public expense."

SO WHAT IS THE PROBLEM?

Unfortunately, the correct interpretation of this section of regulations, on occasion has lead to confusion and may in fact cause parents to have to go through an appeal for payment that would be an unfair burden.

An example of this interpretation can be found in the State Education Department's publication entitled, "Questions and Answers About Serving the Educationally Handicapped in New York State - Number 2 - Referral, Evaluation and Developmental of the IEP-Phase I, dated September, 1981 as follows:

"Must the COH pay for an independent evaluation? An individual must be provided at no expense to the parent. If the parent disagrees with the evaluation obtained by the school district, he or she may wish to obtain an independent evaluation. However, parents must inform the district of their intent to obtain the outside evaluation."

A further example can be found in the SED's parent handbook, "Your Child's Right To An Education" on page 10 as follows: Indicate your right to an independent evaluation which, if the district agrees, or if decided by an impartial hearing officer, will be at public expense.

On page 17 of that same publication, it is stated that "your district will send you a formal letter" that will inform you "of the right to obtain an independent evaluation at your own expense . . . An independent evaluation may be provided at public expense if the school agrees to do this . . .". The U.S. Department of Education informed the SED that this information appeared to be contradictory to the intent of Section 300.503(b) of the Part B Regulations (federal). New York acknowledged this and has indicated that these publications would be revised to indicate the correct information.

SO WHAT IS THE PROCESS?

In most cases, when parents really believe that a less than appropriate evaluation has been done, or no evaluation(s) done at all, by or on behalf of the local school district, then it is suggested that:

(1) Parents request that the COH have an independent evaluation done and if they refuse, (2) In writing (keeping copies) inform the district that the parents will seek an independent evaluation and bill the school district.

Parents should keep in mind that request for payment of an independent evaluation should be made only when the parents feel that the school's evaluation(s) are inappropriate or missing.

If the district chooses to go to an impartial hearing rather than pay the bill, and proves that their evaluations are appropriate, the parent will end up paying. However, it must be re-emphasized here that there is no requirement that parents must inform the district before seeking an independent evaluation.

The following, which is excerpted from a letter dated November 29, 1983 from SED, indicates when parents can be assured of obtaining an independent evaluation at public expense: (1) The parent and the school district agree to obtain an independent evaluation at public expense as a part of the individual evaluation or re-evaluation conducted by the district, or (2) The parent disagrees with the evaluation obtained by the school and the school district does not attempt or fails to show that its evaluation is appropriate in an impartial hearing initiated by the district, or (3) An impartial hearing officer requests an independent evaluation as part of a hearing."

In summary, while it is most certainly advisable to notify the Committee on the Handicapped of the intent to seek an independent evaluation, there is nothing in the law (federal or state) to mandate that it be done. Hence, when the district is provided the bill with request to pay, there are only two alternatives for the district to pay or have an impartial hearing conducted to prove that the district's evaluations are appropriate.



Right at home. Right in the neighborhood.

OMR 26.00 (9-83)

When Does A School District Become Responsible For A Child Who Has Turned Or Will Be Turning Five and Planning To Enter School In September?

The problem arises when a parent notifies the school district that their youngster who has turned five or will be turning five, will be entitled to enter school in September and the district informs the parent that they do not have to accept the responsibility for that child until September.

While this does not seem to be a widespread problem, there are occasions when it does happen.

If the district refuses to accept referrals of these cases in the spring, then the parent should wait until July 1 and refer the child to the Committee on the Handicapped at that time. July 1, according to Section 2 of the Education Law, subdivision 15, states that July 1 is the official beginning of the next school year.

Since Committees on the Handicapped are required by the State Education Department to meet **during the summer if necessary**, once the referral is made, it would then be necessary for the Committee on the Handicapped to evaluate and meet with the parent within the thirty day time frame as indicated in Part 200 of the Commissioner's regulations.

Once Again-

School Was Out-And Special Kids Were Out Of Luck!

No Summer Education

NYSARC, along with numerous other major parent and professional organizations have advocated for **several years** that the New York State Legislature should mandate pre-school and summer school for certain children. In spite of all the documentation that exists which supports the need for certain children with disabilities to have available to them early intervention programs and an extended school year, in spite of all of the negotiating that has been going on for years to secure these much needed services, in spite of the heart-rendering pleas that come from parents to obtain this necessary help for their children, we unfortunately, at the end of the 1984 legislative session, do not yet have a bill.

Senate Bill #8622, the bill that NYSARC worked so hard to obtain, did indeed pass the Senate in the closing hours of the session.

We were not so lucky in the Assembly. Although we received many letters from individual members of the Assembly indicating that they favored the bill (A-11089), it unfortunately never got out of the Committee so that it could be voted upon.

So, once again, we go away empty handed and many deserving children sit at home significantly regressing because they do not happen to live in a county that looks with favor on the needs of children with continuing special needs.

SUMMARY

Admittedly, this bill does not go as far as The Education Committee had hoped for. We urge mandating education for children between the ages of 3-5.

The bill, as it is, is a giant step forward in the provision of services for children. Simply put, the bill mandates summer school (July and August) for **certain children** between the ages of 5-21 placing these children under the responsibility of the **Committee on the Handicapped**. It estimates Family Court petitions and is 100 percent funded by the State Education Department. It allows for **counties** to fiscally audit programs and to place out for bid the transportation of pre-school children. It allows for a three-year study of provision of services for youngsters from birth to three by the Council for Children and Families.

BETTER LUCK NEXT SESSION?

We have been told that because of all of the work that has been done by so many (including the many letters written by parents on behalf of their children) that the Legislature is not only sensitized to the need for such a bill but is committed to seeing it passed.

There is a possibility that the Legislature will reconvene its 1984 session some time this fall and there is a hope that this bill will then pass the Assembly.

Therefore, letters directed to Assemblyman Jose E. Serrano, Chairman of the Education Committee, Room 836, Assembly, Legislative Office Building, Albany, N.Y. 12248, and to your own local Legislators could be of great help in moving this bill onto the floor of the Assembly.

Letters should also be sent to Governor Cuomo requesting his assistance.

Additionally, although we have been told that eventually we will achieve our goal, we should begin to think about alternative actions. In the event that in spite of all the hard work, we once again come to the end of the 1985 session with no bill, one of the alternatives could be legal action.

Before we make that decision, we need to hear from parents whose children have been left to languish at home during the summer months because no program was available to them in their community.

A letter or phone call to NYSARC State Office indicating that your child was without a program and that you would like to help is all that is needed to assist us in determining what approach to take.

NINE YEARS OR NINETY — WE PURSUE OUR GOAL OF SUMMER EDUCATION

P.L. 94-142 was a major piece of legislation. It took many, many years of hard work on the part of many individuals and organizations to finally get Congress to do what most of the states and local communities did not wish to do - let children with disabilities into school.

The intent of that law was to provide for the individual needs of all children, no matter how disabled they might be. A rigid state rule, such as we have in New York State limiting education to 180 days, is direct contradiction of P.L. 94-142 and a blatant violation of federal law.

While Public Law 94-142 does not require that all handicapped children receive special education and related services on a twelve month basis, the Act does state that disabled children have available to them both special education as well as related services if recommended in Phase I of the child's Individualized Education Plan.

The U.S. Department of Education has indicated to the New York State Education Department in a letter dated October 18, 1982 that "a state rule which limits the provision of special education and related services to 180 days **precludes** an individualized determination of a handicapped child's needs for services in excess of 180 days and has been held by the U.S. Court of Appeals for Third Circuit not to be consistent with the Part B regulations." In the same letter is stated "The New York State rule, which requires parents to petition the Family Court for the tuition for handicapped children to attend summer **educational** programs appears to be inconsistent with the Federal position".

Since this law was signed in 1975 we are now in its ninth year of operation. For nine years, New York State has been out of compliance on this very crucial issue. We must do everything necessary to let this be the last year that it is violated. Because of it, our children are the losers!

April Forum Awards

NYSARC Education Advocate

Recognition as "The Outstanding Volunteer in New York State" by the New York State Developmental Disabilities Council was given to Betty Pendler in Hartford, Connecticut at their Annual Forum. Jean K. Elde, PH.D., Commissioner on Developmental Disabilities Planning said that this peer selection is an outstanding honor.

Mrs. Pendler was cited for "leadership and significant contributions in the area of developmental disabilities at the local and state levels".

The Developmental Disabilities

program has long recognized the vital services being provided by thousands of volunteers who have given selflessly of their time, resources and energy to make a better life for persons with developmental disabilities.

"You are an excellent example of how one person can make a difference. I commend you on the generous manner in which you have shared your expertise and expressed your concern as an advocate in behalf of citizens who are developmentally disabled throughout the State of New York", the Commissioner said.



Cookbook author David Lurio tastes and approves one of his recipes created for easy preparation by developmentally disabled folks.

What Do Reading And Cooking Have In Common?

What do reading and cooking have in common? A Philadelphia special educational consultant again replies, "very little" by publishing his second sequentially illustrated cookbook for non-readers.

More Special Recipes (Skylight Press, Philadelphia) features fourteen dinner menus which have been approved by a certified nutritionist. By following the clear, concise recipe drawings, the cook will delight in the preparation of such meals as Lasagne and Waldorf Salad or Chicken ala Mushroom and Carrots Vichy.

"According to the U.S. Department of Education, there are over 26 million people in the United States who, for one reason or another, are unable to read," says David Lurio, 26, who worked in a halfway house

for the mentally retarded. "Incredibly, among the countless cookbooks available, all but a handful are directed towards those who are able to read. The implicit assumption seems to be that one must be able to read in order to cook. I don't agree with this assumption."

Mr. Lurio's first cookbook, **Special Recipes for Special People**, was created to bring the basic joys of cooking to the aspiring, non-reading cook. Encouraged by the book's enthusiastic reception, he has written **More Special Recipes** for those ready for additional cooking challenges.

For more information about this original book, contact Skylight Press, 3603 Hamilton Street, Philadelphia, PA 19104, or call (215) 387-8215.

Prevention Of Lead Poisoning,

A Threat To Our Young

Invisible Danger

By Gary Costello

There are no "child-proof" lids on this poison. You won't find the immediately identifiable skull and crossbones symbol or even a "yuk" sticker on it. It's not under your sink and you won't find it in your medicine cabinet. It has no label describing the antidote. For this poison is in the air, in the soil and even in our food and water. Lead!

LEAD POISON PERVASIVE

This poison, lead, is especially cruel because it does its greatest damage on young children: one, two and three year old children. Through decades of indiscriminate lead mining, smelting and uses in hundreds of ways from paint, to gasoline, to solder, to pipes, to batteries, to inks, we now live in a totally lead contaminated environment in which every one of us consumes some lead everyday. Little children with immature central nervous systems are most vulnerable and stand to suffer from learning disabilities or behavior disorders, mental retardation and a host of other impairments. Continuing aspects of this problem, is that young children like to "mouth" their toys and hands and whatever they come in contact with. This "mouthing" behavior contributes small amounts of lead to a child's body burden of lead each day. It is becoming increasingly certain through new research that very small amounts of lead, much smaller than previously thought, are capable of causing the subtle

impairments now associated with lead toxicity — learning disorders, behavior problems, etc. Children's systems absorb more lead than the adult system does.

TESTS NEEDED EARLY

All parents of young children (especially 1-4 years of age) should insist that their health care provider (doctor, health center, etc.) test their children for elevated blood lead levels. Ideally, this should be done at least once a year, each year until the age of five years. This should be done routinely and a parent should not wait to see symptoms of illness, as the early symptoms of lead poisoning (loss of appetite, stomach pain, irritability, paleness) are too easily overlooked or mistaken for the signs of some other disorder.

Depending upon where a child lives and other circumstances regarding his environment and surroundings, as many as 12-15 children per hundred will test positive to elevated blood lead levels. (The cost to families and society for health care and maintenance, special education, income maintenance and other support services surely runs into millions of dollars.)

Whether one child or fifteen, all of these children are important, and all should be screened for blood lead. The test is a simple finger prick test. It takes only a few minutes and is inexpensive and accurate!

Gary N. Costello is Director of the Lead Poisoning Prevention Program, Department of Health, Erie County.

Touch Me..Touch Me Not

By Donna Fletcher

(Excerpt From **Exceptional Parent's Magazine**)

Most developmentally delayed people will always be, to some degree, different from the average person. But to the extent that those differences can be lessened, the social acceptance of developmentally delayed people can be increased.

Unfortunately, parents cannot depend on normally occurring socialization experiences to lessen these differences. The developmentally delayed person generally leads a relatively sheltered life and therefore is likely to have fewer opportunities for normal social development to occur.

TOUCHING

It is both normal and desirable for parents to freely hug, pat and pet their children.

Parents who view their developmentally delayed child as an "eternal child" are likely to continue these physical expressions of affection well beyond the time that parents of most other children have substituted other forms of expressing affection for physical expression.

Everyone expects childish behaviors from children. Children whine, they tantrum, they giggle incessantly, they interrupt conversations, they pull on adults' arms to get attention, they hit each other, and they run and scream. Society tolerates these behaviors in children, but it will not tolerate these same behaviors in adolescents or adults. With help, the developmentally delayed child can discontinue these childish behaviors at about the same time that other children

outgrow them.

Parents and family members must make a strong commitment not to accept inappropriate, childish behaviors.

Each instance of childish behavior (e.g., interrupting a conversation) must be dealt with immediately (e.g., "Sue and I are talking now. If you want to talk to us, wait until we stop talking. I will come and get you when it is your turn to talk," rather than mentally excused and accepted as usual, childish behavior ("Sorry Sue, you know how children interrupt conversations. . .").

OTHERS NEED INSIGHTS TOO

Parents are not the only ones who sometimes view developmentally disabled people as 'eternal children.' Some professionals share that misperception and treat their developmentally delayed clients as children.

When parents feel that a teacher, social worker, or other professional is treating their developmentally delayed adolescent or adult as a child, they must not assume that "the professional knows best." Professionals can be wrong. Any professional who is treating an adolescent adult as one would treat a child is wrong. Parents must immediately speak up and request that their child be treated in an age - appropriate manner.

When developmentally delayed adolescents and adults are treated as other adolescents and adults, and when they are expected to act like other adolescents and adults, they will be well on their way to gaining social acceptance in their community.

Parents Can Change What They Don't Like

Developmental Center Committee Claims

NYSARC has a very active Developmental Center Chapters Committee which coordinates information, problems and needs of those persons who reside in developmental centers within New York State. At the meeting held in March, the committee took on a major initiative of preparing an annual report on administrative and quality of care issues.

The committee plans to obtain information for the report from a request for information addressing important issues relating to the quality of services. This request will be sent to various developmental center chapters for their comment on overriding issues experienced at their respective developmental centers. The

survey of information will be collated into a report for the Executive Committee.

Additionally, the committee is sponsoring a one day conference on relevant developmental center issues for concerned parents, relatives, friends and staff.

The conference is entitled "Parents Effecting Change" and will address the major theme of strategies and dilemmas in making the existing system of services responsive to parental concerns and individual need.

The conference has been scheduled for Saturday, September 22, 1984 at the Ramada Inn, 1228 Western Avenue in Albany. Look for more information in our upcoming brochure mailing.

Brain Defect Believed Linked To Autism

Two scientists have discovered a brain defect they believe may be linked to autism, a baffling mental disorder that causes children to withdraw into their own world, it was reported recently.

The scientists said they found striking abnormalities in the brain of a 29-year-old man afflicted with autism who drowned off Cape Cod in 1977, the Boston Globe reported.

The abnormalities were found in the so-called midbrain and brain stem — in areas that control emotion, processing of memory, balance and coordination.

The findings suggest that the biological

capacity of autistic children to respond to affection is severely flawed. If confirmed, it also supports a growing belief among scientists that many mental and behavioral disorders stem from damage to the brain early in fetal life.

But the scientists said more study of autistic brains will be necessary to confirm their findings.

"We had been waiting 10 to 15 years for this brain to turn up," said Dr. Thomas Kemper, a neuropathologist at Boston City Hospital and Boston University Medical Center.

United Press International

Sibling Info Network Newsletters Available

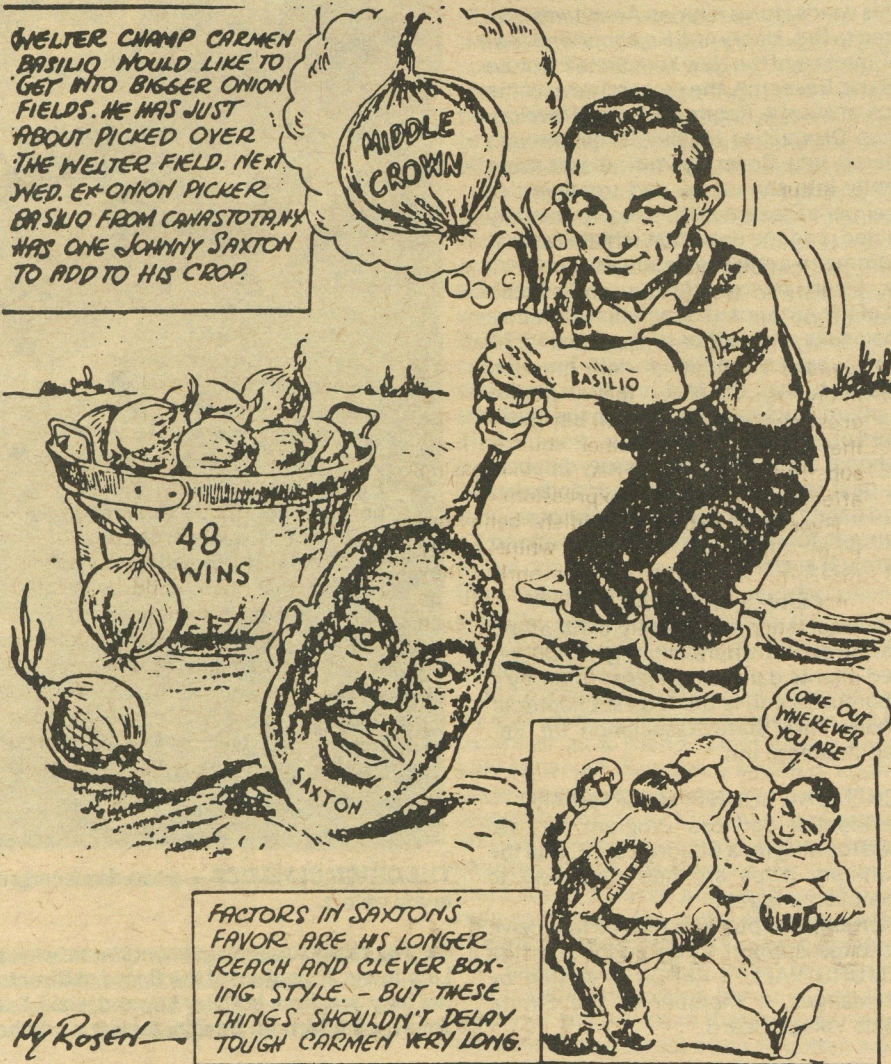
Distributed five times a year by the Sibling Information Network, this newsletter publishes manuscripts, announcements, and information for and about siblings of the handicapped, as well as other issues related to families of the

handicapped. All manuscripts, announcements and information should be sent to the Sibling Information Network Newsletter, Department of Educational Psychology, Box U-64, The University of Connecticut, Storrs, Connecticut, 06268.

CHAPTER NEWS . . .

Humor Preceded The First World Onion Olympics

In keeping with Onion Olympics



Carmen Basilio will be one of the Guard Marshals for the Onion Olympics held in Canastota August 18-19 to benefit the Madison County ARC. A former onion farmer himself, Carmen was featured in this 1956 sports cartoon by Hy Rosen of the N.Y. Daily News.

OTHER PROMOTIONAL ASPECTS (Including applause from the Public Information Committee)

"Canastota boxing champs head ARC's 'Onion Olympics' Weekend." Former World Boxing Champions Carmen Basilio and Billy Backus were Honorary Co-Marshalls of the Madison County ARC's "Onion Olympics" weekend August 18-19th in Canastota . . .

"National Onion Association Makes ARC's 'ONION OLYMPICS' Official" Denver, Colorado . . . The National Onion Association formally announced its endorsement of the Madison County ARC "Onion Olympics" as the World's 1st Only Original Omnipotent Onion Olympics.

FULTON COUNTY

FULTON COUNTY ASSOCIATION FOR RETARDED CHILDREN has launched its 1984 membership drive, hoping to double its current membership, according to Mrs. Marguerite Ackley, membership chairman. This year marks the ARC's fourth decade of service to the children and adults in Fulton County who have mental, physical or emotional handicaps, Mrs. Ackley said, "and we want to continue to build on this record of service."

ARC-sponsored programs for the handicapped include community housing, day treatment, vocational training and placement, sheltered employment, recreation, parent counseling and support and transportation, largely provided through Lexington Center.

Mrs. Ackley said the local ARC programs have been recognized as among the best and most comprehensive in the state.

HERKIMER COUNTY

HERKIMER COUNTY ASSOCIATION FOR RETARDED CHILDREN held the fifth in a series of annual symposiums at Herkimer County Community College recently.

The ARC has sponsored these day-long conferences to provide information and training to professionals working in the

field of developmental disabilities and mental retardation.

Over 250 people from as far away as Watertown, Rochester, Albany, and Binghamton traveled to Herkimer to share in the training opportunities.

In Madison Chapter

Robert R. Haggart's column in the Syracuse Post Standard

"Sometimes I get depressed. It happens when I find myself caught up once again in the stimulating grip of one of America's greatest philosophers, the late Vince Lombardi. Millions of children, some of them athletes, idolize the man's philosophy. He taught it on Sundays, and he drew bigger audiences than most churches.

Vince was the coach of a professional football team, the Green Bay Packers. Lombardi once uttered this line: "There is a secondplace bowl game," he said, "but it is a game for losers played by losers."

Well after losing the cow-milking contest Tuesday to commemorate the opening of the weekly farmers market in downtown Syracuse, I thought of those words and trembled.

It was even worse when I realized I had been brought this low by a cow. Lombardi also said winning isn't everything, it is the only thing. I got depressed. I want to be a winner, not a loser, someone Vince Lombardi would sneer at and tell to take another 100 laps while everyone else heads off to take a shower or tape a beer commercial.

Then I thought of Frank Gerace (at Madison ARC) and realized I have another chance of becoming a winner, of vindicating myself.

I am going to get a team together and enter the Onion Olympics.

It's good this thing is going to be held in an open field. One of the events, for example, will be to see how far a contestant can project his or her bad breath after eating an onion. People driving by on the Thruway August 18 and 19 would be well advised to keep their windows rolled up tightly for at least 10 miles on either side of the Canastota exit.

What I am talking about is the world's first Onion Olympics. That is correct. The first ever Onion Olympics to be held in the entire world.

If the farmers of Madison County can keep up with this — the athletic equipment for the Onion Olympics consists entirely of about 10 tons of onions — there is no telling what will happen. Officials in cities like Buffalo and Cleveland will start fighting with Canastota officials over where the next games will be held.

The Onion Olympics is being sponsored by the MADISON COUNTY ASSOCIATION FOR RETARDED CHILDREN.

The idea of children in Madison County benefiting from my bad breath is exciting. It means I have found a redeeming quality in what is otherwise socially unacceptable, and I can go out again in polite society.

Frank, the ARC's public relations consultant, and Ray Lewandowski, the ARC's director, thought up the idea of the Onion Olympics. It was a natural, they said, since onions are one of the greatest resources of Madison County.

The affair is going to be held in a giant field just off Exit 34 of the Thruway on land donated for the affair by Isadore Rapasadi and Sons, the onion and potato packing company.

There will be all kinds of events that I know will bring out the winner to me. There will be an onion jump, for example. Bags of onions will be stacked up and onion athletes will have to jump over them.

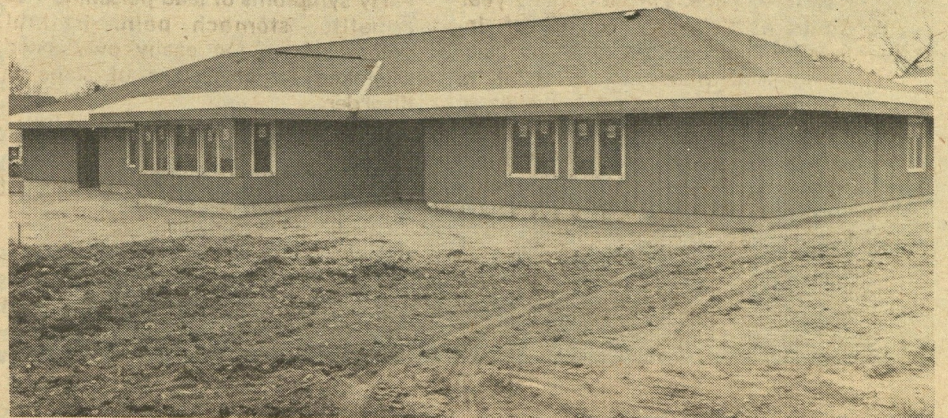
There will be the onion-put. Shot putters are huge, angry athletes who grunt and heave heavy iron balls — sportswriters call them the "iron pill" because they love that kind of colorful language. In this case, they will be writing about the onion pill.

If throwing, running or jumping over onions sounds too difficult, remember there will be a raw onion eating contest.

This is going to be a true Olympics too, not just some imitation. There are two reasons for this. First, I personally called the Russian Embassy in Washington, D.C., where I was told in no uncertain terms that the the USSR will boycott the Onion Olympics.

Secondly, Franks says a torch is being built. A runner will carry it to the site on the games.

The torch will be filled with hot onion soup!



Pictured above is Fulton County ARC's newly constructed Intermediate Care Facility which will house ten elderly persons who are mentally retarded. The house is one of 7 residences being constructed with funds provided by the United States Department of Housing and Urban Development through the New York State ARC HUD Housing Project. The residence will be ready for occupancy in September, 1984.

CHAPTER NEWS... at ou



Judy Alger, left, an employee in Piecework Industries' Country Cafe, and Ed Raish, right, assistant manager at the ALLEGANY COUNTY ASSOCIATION FOR RETARDED CHILDREN (ARC) community residence in Belmont, stand beside the three-stack pizza oven recently donated to the ARC by Southern Tier Pizza Hut.

ALBANY CHAPTER OF THE ASSOCIATION FOR RETARDED CHILDREN (ARC) wasn't sure how to best use its staff to serve its mentally retarded clients.

That's when ARC heard about Decision Techtronics Group (DTG), a group at the State University at Albany's Nelson A. Rockefeller College of Public Affairs and Policy that uses computers to help government and non-profit agencies solve problems.

ARC staffers met for two days in the spring with DTG to discuss staffing problems and possible solutions. DTG then fed information provided by the ARC into a computer and got results showing the staffing pattern that would help the agency the most.

At the end of the two-day session, champagne corks exploded in the conference room where it all began.

Edward Lukomski, Executive Director of the Albany ARC Chapter, said he was pleased with the conference results. "It would have taken three people six months to accomplish what we did in two days," he said.

ALLEGANY CHAPTER

Hot News from ALLEGANY CHAPTER ARC features the gift of a three-stack pizza oven. The donation was arranged by Richard Blears, marketing director for Pizza Hut in the area.



Bob LaGoy listens to advice offered by Patti McLean as he and Robert Lee ready for a Special Olympics practice session in Ticonderoga. LaGoy and Lee are two of the more than 250 developmentally disabled residents of Essex and Clinton counties who competed in the May 5 Special Olympics in Lake Placid. McLean is a recreational therapist for the ESSEX COUNTY CHAPTER OF THE ASSOCIATION FOR RETARDED CHILDREN. (P-R staff photo by Jeff Wright)

Plattsburgh Press Republican

THE ASSOCIATION FOR THE HELP OF RETARDED CHILDREN (AHRC) NEW YORK CITY CHAPTER, the first organization in the country to establish meaningful services for retarded children, adults and their families, celebrated its 35th anniversary with a gala Humanitarian Awards Dinner, May 19th, at the Sheraton Center in Manhattan.

DOWN SYNDROME BREAKTHROUGH

This year's Humanitarian Award was presented to Drs. Henry and Krystyna Wisniewski, Directors of the New York State Institute for Basic Research, the research arm of the Office of Mental Retardation and Developmental Disabilities for their breakthrough research into Down Syndrome and more recently into the cause and treatment of Alzheimer's Disease in the developmentally disabled, and the detection of the Fragile X Syndrome in autistic individuals.

Dr. Henry Wisniewski, currently President of the American Association of Neuro-pathologists and author of more than 270 research papers, continues with his wife, Krystyna, to lead the Institute in its multi- and interdisciplinary search for the basic causes of mental retardation.

In honor of the 35th anniversary celebration, past recipients of the Humanitarian Award dating back to 1949 when the organization was founded, were invited to attend the annual event.

SERVES 3,000 DAILY

The Association for the Help of Retarded Children serves approximately 3,000 retarded clients daily within New York City's five boroughs and is the largest chapter of the New York State Association for Retarded Children, Inc.

CHEMUNG COUNTY CHAPTER ARC

Residential Services Program has received funding for a Children's ICF, and the preliminary steps are now underway to accomplish this goal.

Chemung Chapter was thrilled to receive unsolicited support in an editorial in the CHEMUNG VALLEY REPORTS written by Elna Manges, a member of the Elmira Heights Village Board.

COLUMBIA COUNTY ASSOCIATION FOR RETARDED CHILDREN featured a multimedia presentation "COARC, A Circle of Services" at their annual meeting in June.

DELAWARE

Delaware County Chapter ARC set a one dollar per mile minimum for participants in the annual bike-a-thon in June, 1984. Bike-a-thon tee shirts were awarded to the first ten runners up along each route. This year's annovnation was Bike-a-Thon. Parent's hat's given to each rider. The average Rider had \$85 in pledges, compared to \$47 last year.

DUTCHESS COUNTY ASSOCIATION FOR RETARDED CHILDREN has implemented several Intern Programs serving area colleges and universities who recognize the Associations' ability to provide their students with an in-depth learning experience.

According to Linda P. Smith, DCARC's Executive Director, "This is one more in the many ways in which DCARC gives back to the community with gratitude for the support and generosity shown it through the years for its programs serving the retarded."

THE ESSEX COUNTY ASSOCIATION FOR RETARDED CHILDREN is about to begin a \$1.7 million expansion that will include hiring 60 new people and building three new facilities in the towns of Chesterfield, Willsboro and Schroon.

Construction of the new "intermediate-care facilities," as they are known, were underway in July, according to Charles Hayes, Executive Director of the Essex County ARC.

Hayes said that, with the expansion, the Essex County ARC will employ 200 people and its budget will grow to nearly \$6 million annually.

MADISON CHRC ATT
WORLD WIDE ASM AS
"ONION OLYMPICINTERN
EVENT!"



THE ONION OLYMPICS — a two-day event and a first founty. Bro onion eaters.

Getting ready to serve up hot onion soup on preparation Olympi Lois Jones, President of the Board of Directors of MadAssociation the treat are, from left, Ray Lewandowski, Executive Di; Billy Back Jones; and Carmen Basilio, former world boxing chais and Ba

The Onion Olympics is the brainchild of ARC Directdowski and Gerace. "They say in fund-raising that you should latural res County's biggest natural resources is onions." Of coudmitted, th even more attractive. A radio broadcaster asked if tb a red on sports editor suggested instead a boycott by Bermuc

ERIE COUNTY

THE ASSOCIATION FOR RETARDED CHILDREN, ERIE COUNTY CHAPTER presented certificates of appreciation to the members of Girls Scout Brownie Troop #772 at a party held in their honor on Thursday, April 26, at the Louis J. Billittier Center, 101 Oak Street, Buffalo.

Earlier this year, the scouts participated in a "Sensitivity Awareness" Program provided by ERIE ARC. The girls prepared a poster on the theme "We Are All Special" which is on display at Louis J. Billittier Center. Troop #772 meets at Natavity of the Blessed Virgin Mary Church on Harris Hill Road.



Carmen and Billy prepare r the Onion

at our Chapters are doing for our children and adults

ISON CHIRC ATTRACTS
D WIDE BASM AS LOCAL
OLYMPIC INTERNATIONAL
ENDENT!



a first for h County. Brought funds to ARC and tears of laughter to

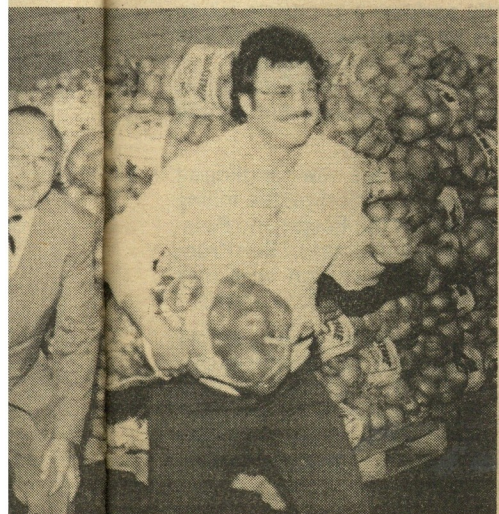
eparation Onion Olympics held in Canastota August 18 and 19 is
of Madisoty Association for Retarded Citizens. Ready to receive
utive DirecRC; Billy Backus, former world boxing champion; Mrs.
ng champckus and Basilio are co-marshals of the Olympics.

Director Randowski and ARC public relations consultant Frank
ould lookr natural resources," Gerace said. "One of Madison
Of course, admitted, the endless supply of puns made the idea
ed if there be a red onion boycott by the Soviet Union. A local
Bermuda.

ERIE COUNTY CHAPTER honored the
Cheektowaga — Lancaster Zonta Club for
its outstanding support of ARC Recreation
Programs.

Richard and Bernadette Bergman re-
ceived the "Volunteer of the Year" award
from the Association for Retarded Children,
Erie County Chapter on May 17, 1984 at the
Louis J. Billittier Center, 101 Oak Street,
Buffalo.

Mr. and Mrs. Bergman were recognized
for the more than 1700 hours of time they
have given as volunteers in the ARC Com-
munity Residence Program in Orchard
Park.



pare thes for the Onion-Bag Run.

GENESEE COUNTY CHAPTER OFFERS THIS LOVING TRIBUTE TO JANET BRAATEN

"Two roads diverged into a wood, and I, I
took the one less traveled by, and that has
made all the difference." These words by
Robert Frost have special meaning as we
reflect on Janet. Her work in behalf of her
disabled neighbors spanned over her life-
time. The less traveled path that she pur-
sued was sometimes hostile, often thank-
less, tiresome and draining. But her direc-
tion and tenacity has proven vital in the day
to day lives of the Mentally Retarded and
other disabled persons in their community.

For many years, Janet worked as a trans-
porter and classroom aide for the Trainable
Mentally Retarded. When the local chapter
of the Association for Retarded children
was organized, during the 1960's, Janet
was a charter member. As a member of the
Board of Directors, Janet always gave from
sincere and deep commitment. She worked
vigorously on Association fund raisers, like
the Golf Tournament, concerts and Bowl-a-
Thon. Janet was constantly involved in
social and recreational activities for our
disabled citizens. These included count-
less picnics, swimming classes, summer
camp and Holiday related events. Janet
would constantly read materials regarding
the disabled and share this information
with the local volunteer group. Her activi-
ties included attendance at Seminars and
State ARC functions.

As a member of the Board of Directors, as
an enthusiastic committee member, as a
parent or as a friend, Janet always gave
fully of herself. She was a wealth of know-
ledge, energy, experience and love. While
others chose to talk of actions, Janet acted.
While some dreamed and reflected, Janet
charged ahead. Because of her commit-
ment to the disabled and because of their
right to share fully in the life and main-
stream of the community, Janet Braaten
was moved to Act. With pride, her family
and friends can point to her work with the
ARC. Her actions mean that those persons
once institutionalized, often forgotten and
neglected, now live as worthwhile, produc-
tive citizens in our community. Each and
every Program Participant of the ARC has
directly benefited from Janet's tireless
efforts.

While these are great pain in her passing,
we are obliged to witness and attest to the
impact — the enthusiastic embrace — that
Janet Braaten has had, not only on her
family and friends, but also the disabled
citizens of Genesee County. Her selfless
giving is a model and will live on.

We will miss a fellow "do-er" — one who
took the less traveled path.

MADISON, ARC LAUNCHES PLANS FOR ONION OLYMPICS

By Jim Stowell, Dispatch Staff Writer
CANASTOTA — Organizers of the first
Onion Olympics outlined plans for the
August 18 and 19 event in May at
Graziano's Casa Mia Restaurant.

The two-day event benefited MADISON
COUNTY ASSOCIATION FOR RETARDED
CITIZENS. It started as a brainstorming
session between ARC coordinator Frank
Gerace and ARC Executive Director Ray
Lewandowski, who were seeking ways to
raise funds for the program.

Also benefiting from the event was the
Greater Lenox Ambulance Service of
Canastota, which is seeking funds to buy a
second ambulance, according to Bob Stur-
devant, Chairman of board of the am-
bulance service.

GLAS sold food and drinks during the
event held just off Thruway Exit 34 on
property owned by Isadore Rapasadi and
Sons.

Lewandowski praised the event as a com-
bined effort of the public and not-for-profit
sectors of the community. "The common



Girl Scout Brownie Troop #772 were recently presented with certificates of appreciation
from the Association for Retarded Children, ERIE COUNTY CHAPTER for their participa-
tion in a "Sensitivity Awareness" program.

element of all the people here today is
strength and endurance," he said.

He added that all those involved in the
event made it an Olympics "that no one will
boycott."

Gerace added the event drew attention to
International Boxing Hall of Fame, Gerace
said it shows the community supports
boxing and takes care of its own.

Former world boxing champions Carmen
Basilio and Billy Backus were co-marshals
for the Olympics.

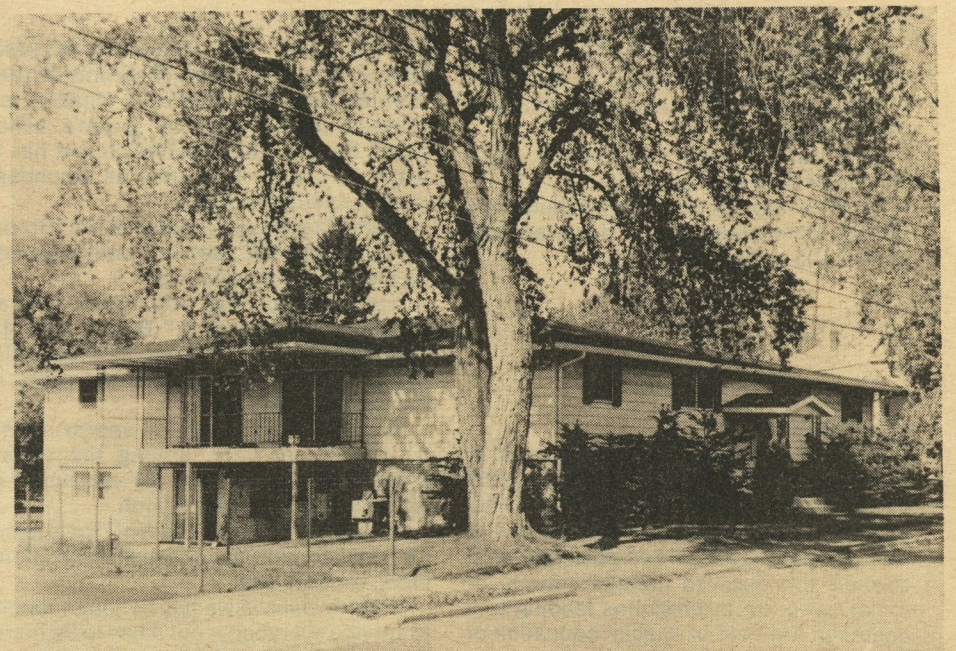
Also noted for their support of the event
were Genesee Beer, P&C Food Markets and
McDonald's Restaurant.

Genesee, "The official beer of the Olym-
pics," donated money for T-shirts and
donated the services of the company for
public relations.

P & C provided a large tent for displays
and printed tickets and posters.
McDonald's provided medals for six partici-
pating teams and banners.

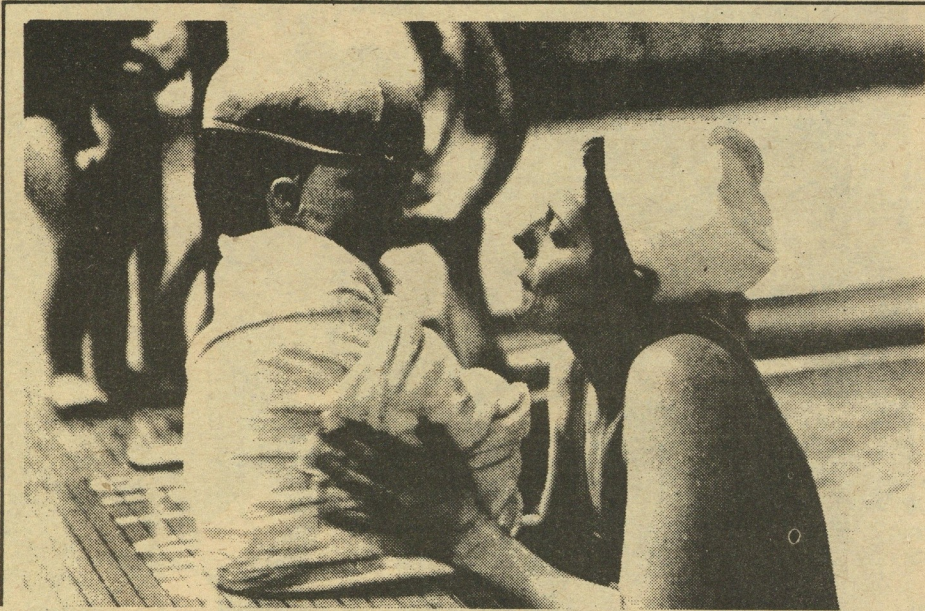
Businesses, restaurants and industries
from Madison, Oneida and Onondaga
counties fielded five-member teams to
compete in "decathal-onion" and "penta-
thal-onion" events involving onions.

Other activities included an onion soup
and onion dip recipe contest, rides for
family members and a hot air balloon ride.



In May, BROOME-TIOGA ARC held Open House to celebrate the opening of the supervised
apartment program. Supervised apartments are a community residence in which the
residents reside in their own apartments with staff residing at the site on a twenty-four
hour basis. Residents receive training in advanced daily living skills enabling them to
reside successfully in an apartment setting. Nearly one hundred people attended the
ribbon-cutting ceremony and toured the facility.

CHAPTER HAPPENINGS . . .



Franklin County Chapter ARC Swim keeps ARC kids "happy as clams"

Timothy Duffy smiles with satisfaction after his dunking in the NCCC pool. Teacher Nancy Martin has him all bundled up.

Watertown Daily Times Photo

Every Friday morning, the North Country Community College pool is a very happy place. THE FRANKLIN COUNTY ASSOCIATION FOR RETARDED CHILDREN sponsors "Adaptive Aquatics," a program that is introducing eight to ten disabled children to the joy of swimming.

Bruce Gugliotta heads up the team of professionals, parents and volunteers that helps these mentally or physically impaired children on a one-to-one basis. For these tots, infant to five years of age, the benefits are many.

Maneuvers that are difficult on land are much easier in the buoyancy of the water. Taking to the water like fish, they gleefully put their little bodies through the exercises the therapists direct.

As they work their muscles, they build strength for accomplishing more when

they're out of the water. In a world where everything is difficult, the pool is a welcome holiday from the intense effort that fills their days.

Their success in the water is a great boost for their self-images. They're delighted that they can take part in a sport; that their bodies respond to their bidding. "They really do well in the water, learning faster than 'normal' children. They're not as fearful of putting their heads underwater, and learn to hold their breath quickly," explained Gugliotta.

The adults move slowly and provide support in this new, wet world. The noses are different. There's the new smell of chlorine, and this strange medium that holds you up and allows you to move freely.

This interaction with others builds social skills, as well.

MONROE COUNTY CHAPTER awarded the ARC Community Partner Award to Mr. Frank Cucola of Rochester Institute of Technology.

Miss Dorothy Alger received the ARC's Volunteer Service Award.

At their annual meeting, scholarship awards were presented to five area high school and college students.

OTSEGO COUNTY

The Hartwick Day Treatment Center of the OTSEGO COUNTY CHAPTER, NEW YORK ASSOCIATION FOR RETARDED CHILDREN, INC., again sponsored a summer internship program. Three positions were opened this year to college seniors or juniors who are in programs leading to a degree in the field of special education or human services.

At the OTSEGO COUNTY CHAPTER ARC Annual Meeting, representatives of Resources for the Handicapped, a local organization that provides literature on mental retardation for parents and agencies, presented the ARC with a number of textbooks on retardation for its library and with subscriptions to professional journals for the benefit of ARC's staff members.

ONONDAGA ARC welcomed NYSARC Executive Director Marc N. Brandt at their Annual Meeting. NYSARC's Director expressed praise with the group's billion dollar budget. The Association just has to learn to spend it as well as Onondaga County spends its share.

State Executive Director Marc Brandt says the local ARC uses its money to benefit as many people as possible.

"Here in Onondaga County you have an excellent use of funds," Brandt told the Onondaga Association for Retarded Citizens' annual dinner Tuesday night at Bellevue Country Club.

The State ARC budget is approximately \$1 billion per year, among the largest amount any state pays for education of retarded citizens, said Brandt.

Onondaga County's share of that is about \$5.5 million, said Onondaga ARC President-elect, Gordon Eyer.

"I firmly believe we have enough money to service everybody, but it has to be better directed. Unfortunately, we can't convince the Governor or the Legislature of that," Brandt said.

"We estimate that statewide 600,000 retarded individuals could use our help. Yet, half of our \$1 billion budget is spent on only 15,000 individuals in state developmental centers," he added.

Brandt praised the Onondaga County Programs as using money more efficiently.

ONEIDA COUNTY ASSOCIATION FOR RETARDED CHILDREN regrets that it will discontinue its Recycling Program as of Friday, June 15, 1984, according to Mrs. Angela VanDerhoof, Executive Director.

"We would like to take this opportunity to thank all the individuals and businesses who have supported our program over the last few years," said VanDerhoof.

The ARC started recycling glass in 1979. At its peak, it was processing over 33 tons of glass weekly. Unfortunately, with the introduction of the Bottle Bill, the program lost about 60% of its recyclable glass because the bars and restaurants started returning the bottles directly to the distributors.

Until recently the ARC managed to keep this program going because they were collecting many returnable containers along with the recyclable glass bottles and jars.

However, according to Bob Small, ARC Recycling Coordinator, the market for recyclable glass is now glutted and therefore the price per ton has dropped drastically. In addition, the ARC was recently informed that the buyer for recyclable glass would not accept green glass for a period of four months.

Vicent Colgan, ARC Workshop Director, said, "We have been studying our options on continuing the Recycling Program for several months now. Currently the Workshop has the capability to absorb the people, employed by the Recycling Program, into other contract areas, so in light of recent events, we felt that now was the time to end this program."

"Monetarily, ending the Recycling Program will not have as adverse an affect now as it may have had several months ago because we will not be forced to lay anyone off," said VanDerhoof.

"The Recycling Program was never a money maker for the Agency, at best it was a breakeven proposition, but it served as a tool in helping develop basic work skills that are a part of our overall training and rehabilitation programs at the ARC, while adding to the positive environmental impact of recycling," said VanDerhoof.



Rockland ARC client happily packs holiday candies at Krum's Chocolatier in Pearl River, N.Y.

Eleven clients from the ROCKLAND ASSOCIATION FOR RETARDED CHILDREN'S SHELTERED WORKSHOP are working at Krum's candy factory in Pearl River, under the auspices of a "Work Stations in Industry" program. Veterans of the ARC Enterprises Workshop in New City, the clients have received on-site training at Krum's Pearl River factory and plant.

The group is directly supervised by Frank Laino, an ARC staff member who is paid by a government grant from the Office of Vocational Rehabilitation.

The "Work Stations in Industry" program is designed to give handicapped workers the opportunity to participate in a competitive employment situation. This pilot program is an alternative to traditional job placement techniques and the continued expansion of the sheltered workshop facility.

The eventual goal is to train clients to

TO THE EDITOR OF THE ALBION NEWS-PAPERS: MEMORIAL TESTIMONY

ORLEANS COUNTY CHAPTER NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC. is considered one of the finest and most productive organizations of its type in New York State.

It is successful for many reasons. One of the reasons was the quality of leadership which Joe Sacco provided in the formative years. Joe served as President during 1979-1982 and it was my pleasure to serve as his Vice President during a portion of that period. Joe instilled enthusiasm in the board members and staff; he had the uncanny ability to develop new and imaginative concepts and programs. He sought and received cooperation from all. Joe did not back away from what appeared as insurmountable problems but rather sought the board and staff's thoughts on ways to overcome the problems. He was always a gentleman and was always considerate and receptive to opposing thoughts and considerations. He demonstrated these characteristics and other inborn leadership qualities.

It is my pleasure to relay these impressions of Joe Sacco.

Yours truly,
EMERSON B. CARLSON

SULLIVAN COUNTY ARC reports that a Day Program client, Mr. Harry Kaplan, who recently moved to the family care home of Eleanor and John Schenck, had wished to be Bar Mitzvahed for some time.

On May 24, 1984 Mr. Kaplan was Bar Mitzvahed by Rabbi Irving Goodman at the Woodridge synagogue. Both his care-providers and Mrs. Ellie Cohen, who had been working with Mr. Kaplan, were instrumental in arranging this day for Harry. Many people, friends and community members alike, attended the ceremony.

A prayer shawl and yamalka were given to Mr. Kaplan by Ms. Ida Weinstein of the Philanthropic Sisterhood.

independently perform a complete job so that they can be hired by companies as regular employees at normal wages.

The "marriage" between ARC Enterprises and the candy company has worked out better than ever expected.

The ARC employees are now handling all phases of packaging, including the foiling of novelty candies for the Easter and Pass-over Holidays. "In our business," Ron Krum explained, "there's no reason why they couldn't participate in 95% of our work."

Ron Krum, who expanded an 83 year old family business into a worldwide manufacturer and distributor of chocolates, says he is more than pleased with the ARC workers. "I don't have to worry about the quality of their work. It's terrific!" he said. They have blended in with the other employees. Any misgivings I may have had at the outset were quickly dispelled."

CHAPTER HAPPENINGS

SARATOGA COUNTY CHAPTER ARC hosted an Open House at their new sheltered workshop facility, Alpha Industries, in June.

Other than Alpha Industries, the ARC sponsors a Day Treatment Program. This effort provides assistance to individuals who need a broad range of support services but who are not so severely disabled as to require 24-hour medical care and supervision. The program focuses upon promoting personal independence and competency in self-help skills. There are presently 88 mentally retarded adults participating in this program.

SARATOGA ARC is planning to operate three supervised group homes in 1984. Each of these homes will provide a place of residence and support services for 10 mentally retarded adults.

SUFFOLK COUNTY CHAPTER ARC reports the long-awaited AHRC Day Treatment and Work Activities facility at Westhampton Beach received approval in the spring by the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD).

The center is designed with ample space to relocate Riverhead's work activities program, and to establish a new day treatment program.

It will also house an audiologist, a dental hygienist, a nurse, a physician, and a speech therapist as well as social workers and behavioral specialists.

The facility is expected to be operational in the spring of 1985.

ULSTER COUNTY ARC ASKED FOR MORE SPACE FOR THEIR SHELTERED WORKSHOP IN APRIL

Their preset site, located on Hickory Street in Ellenville, has become too small for the approximately 75 workers who are trained in assembly line skills, and also do mailings on a sub-contract basis.

According to the letter read at the board meeting by Mayor Ed Jacobs, the ARC also trains residents of the Greenwood Rehabilitation services. The ARC wishes to remain in the village, and is looking into renting space, but will consider the option of buying.

The ARC sheltered workshop trains the educable retarded, while the Greenwood facility is a residential school for the physically and emotionally handicapped in the town of Wawarsing.

A grant from the State Department of Transportation will help the Ulster Association for Retarded Children (ARC) finance two buses specially equipped to transport handicapped persons.

Patricia Parry, ARC Development Coordinator, said the grant for one 16-passenger bus and another bus with a wheelchair lift was given under the State Urban Mass Transportation Administration Program for the elderly and handicapped. It calls for a matching contribution from the ARC, officials said.

The two new vehicles will replace two taken out of service and bring the ARC's fleet up to 28.

WOODSTOCK HOME OPENS

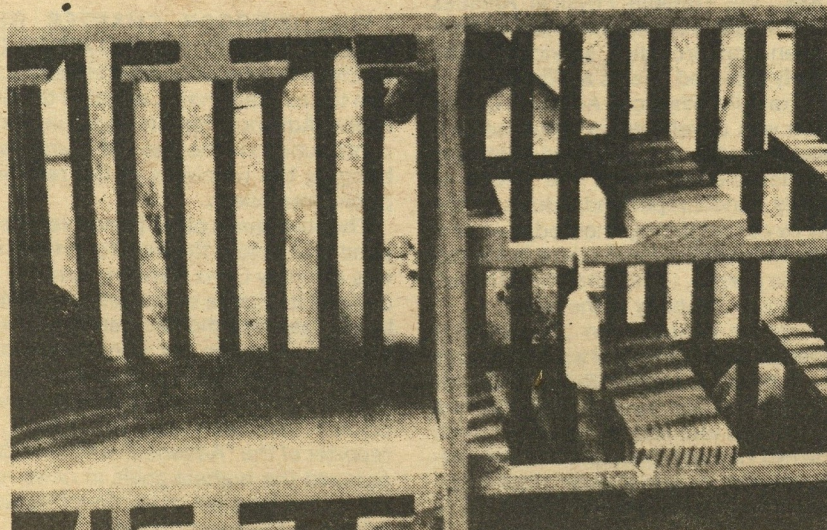
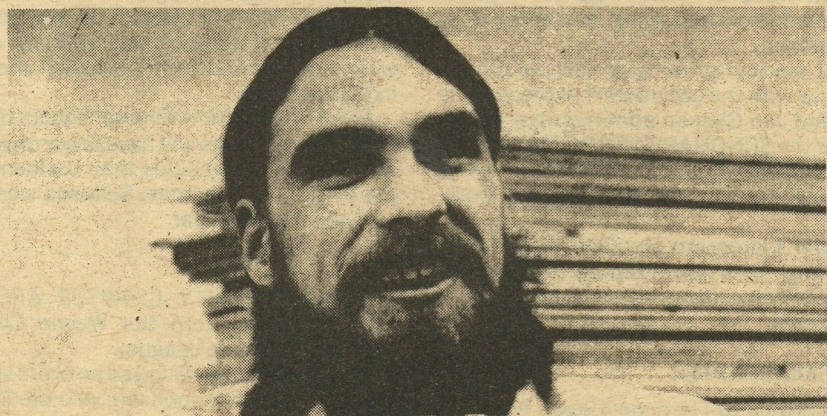
The town and its residents have received kudos for the warm reception given to the newly opened home for mentally retarded adults at the corner of Route 375 and Hasbrouck Lane.

"We want to thank the community as a whole for all that has been done to make us feel welcome and wanted," said Catherine Toye, Director of Residential Services of the ULSTER ASSOCIATION FOR RETARDED CHILDREN. "We are so pleased with our reception," she said, "and we already have two excellent volunteers" referring to neighbors who are giving several hours of their time and services each day.

The former private home was remodeled into a care facility for 10 mentally retarded residents, who were previously institutionalized at the Wassauc Developmental Center in Dutchess County.

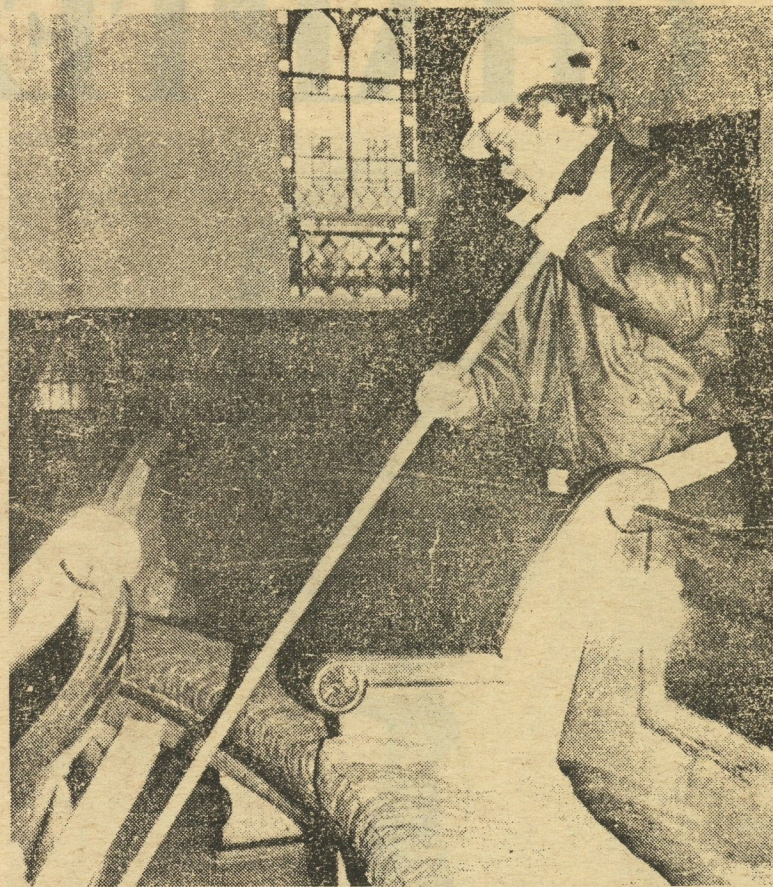


Welcome to new members!



A worker at the DELAWARE ARC Resources for Industry sheltered workshop in Hamden displays a wine rack which he and other clients helped make according to a design borrowed from a defunct Walton wood-working firm.

Oneida Daily Star



Lowville Journal and Republican Photo.
Lewis Chapter ARC custodial Service's Trainee, Bill Irvin keeps the Baptist Church clean.

LEWIS COUNTY CHAPTER ARC praises its crew of six who worked out of ARC in the community.

The men are all employed by the Custodial Service of Lewis County Industries, an agency sponsored by the Lewis County Association For Retarded Children. The crew works under the close supervision of their work adjustment training instructor, Sandy Snow.

Custodial Service has a new idea in the

Lowville area two years ago. The crew began with no tools and a few jobs. They learned early to take pride in their work and it wasn't long before their list of satisfied customers began to grow. Today, their service takes them from the offices of Sweeney Lumber in Lyons Falls to the Baptist Church in Lowville. The crew has recently contracted to provide their custodial service to the Town and Village of Lowville Municipal Building on Dayan St., Lowville.

STEBEN ARC

Directors and executives of the STEUBEN ASSOCIATION FOR THE RETARDED met in February for the second annual planning day to review progress made in 1983 and discuss future plans.

The meeting, on February 21 at the Bath Ramada Inn, was chaired by Board President William Dinehart.

Marilee Hyman, Executive Director of the agency, reported STEUBEN ARC serves 101 clients in the work program and 41 clients in the residents program.

The board learned the offices of the STEUBEN ARC were consolidated to the workshop site for improved efficiency. Hyman reported the vocational program is at full capacity with a waiting list of 15 persons.

Long range assessments suggest there are as many as 50 individuals unserved but eligible for participating in the agency, with an additional five persons per year becoming eligible. These individuals will continue to be unserved under the present program and facility capabilities, she said.

In summarizing the year's activities, she praised Transportation Manager Benedict Sander and dispatcher Gerry Havens for the safety record of the Transportation Department. ARC vehicles travel about 1,000 miles each work day. In more than 200,000 miles traveled last year, there was no personal accident or injury.

Concerning resident homes, Hyman said there have been improvements made in Bath, Wayland and Hornell and the homes and supportive apartments have been recertified by the State Office of Mental Retardation and Developmental Disabilities. The residential program is directed by Nancy Cox.

Hyman said a united effort by Sander, who also is Business Manager for Steuben Services; William Cox, Program Manager; and Sales Director Kate Schefsky, "brought major work contracts to the work program and improved the fiscal health of the pro-

gram, as well as give a better service program for client workers."

In addition, a program was created by Cox to meet the special needs of the elderly clients at STEUBEN ARC.

Hyman also praised Donna Simonson, Business Officer for STEUBEN ARC, for many improvements in the past year, including the joining of a credit union for the staff, changing computer payroll systems to provide an improved method of delivery and better information, starting a staff personnel committee to get input from staff on personnel issues and improving bookkeeping and money management systems.

She also reported a video training grant provided video and camera equipment and the services of a video training. Hyman said, "This grant has been particularly helpful to the rehabilitation staff of Steuben Services to assist in social and behavioral training." She said the equipment will be used to help raise public awareness of the agency, and that still photography is used in promotion, news releases and for an historical record.

STEBEN ARC also received many donations, including a station wagon, video camera and office furniture. "We are grateful for the generosity. Our programs also have been enriched through the donation of time by many people who have supplemented our regular staff. STEUBEN ARC programs make use of trainees and volunteers to provide enrichment to the programs while enriching the lives of persons in training or doing volunteer work," she concluded.

— Hornell Tribune —

STEBEN ARC was visited by Arthur Y. Webb, Commissioner of the New York State Office of Mental Retardation and Developmental Disabilities in April.

This was the first visitation Mr. Webb has made to a regional program site as Commissioner and the first a Commissioner has made in recent years.

CHAPTER EVENTS



SUFFOLK CHAPTER ARC honored attorney Jerome M. Ness, Chairman of the NYSARC Guardianship Committee in June at annual meeting.

Attorney Ness was presented the SPECIAL FRIEND OF THE MENTALLY RETARDED AWARD in recognition of his many years of dedication and services. Mrs. Ness also attended the dinner and presentation.

Did You Know That?

DYSLEXIA is flipping or reversing of letters or words in reading.
 DYSGRAPHIA is difficulty in writing down ideas or thoughts.
 DYSCALCULIA is difficulty in working with numbers such as in balancing a checkbook.
 ORAL LANGUAGE is difficulty in expressing ideas or thoughts.
 AUDITORY PROCESSING is difficulty understanding oral directions or commands.
 NON-VERBAL PROBLEMS is difficulty with depth perception, discrimination, control of body movement, crossing the midline, distinguishing left from right.

Hundreds Vie For Scholarships

NYSARC Scholarships and Awards Committee labored at length to select winning recipients of the 1984 James F. Reville and Jonathan Weingold Scholarships.

Congratulations to Tracy Edwards from SUCP in ERIE CHAPTER ARC and to Terri L. Fowlston from College of St. Rose, CHENANGO CHAPTER ARC.

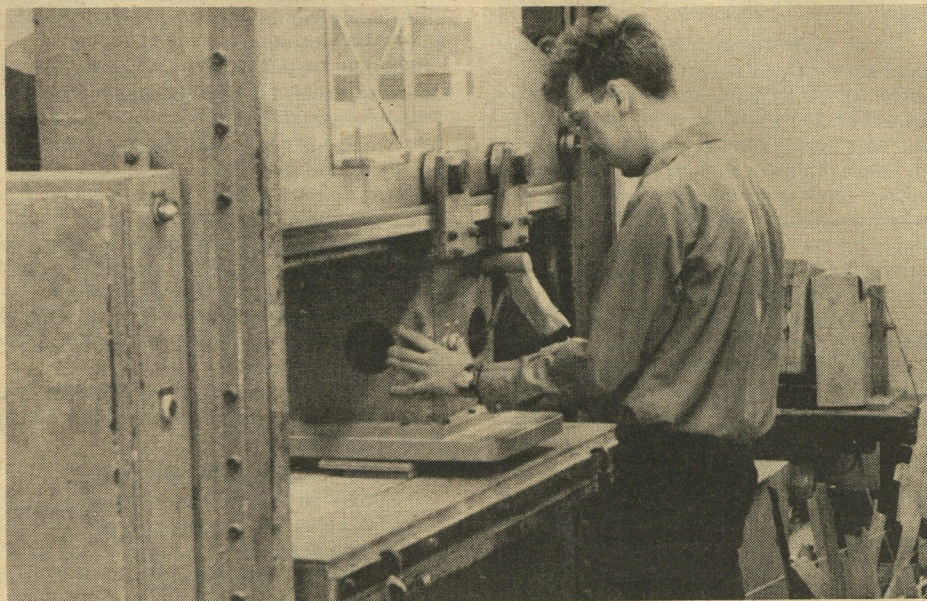
The Jonathan Weingold Scholarships was won by Kevin M. Sullivan, WARREN-WASHINGTON CHAPTER ARC.

In June NYSARC extended congratulations to the recipients of the Joseph T.

Weingold Scholarships which were awarded to Susan Marie Watts from SUCP Buffalo and Arleen S. Muth from Syracuse University.

The Arthur Pense Memorial Scholarship was awarded to Kathleen M. Broderick, Bernard Fineson Developmental Center.

These individuals were chosen from many entries for either their outstanding achievements in their work in the field of mental retardation and/or for their distinguished academic records and recommendations from their respective programs.



SCHOHARIE COUNTY ARC Custom Die Cutter concentrates on his new task.

SCHOHARIE COUNTY ARC reports that Toe Path Industries, the Sheltered Workshop Program of the Schoharie ARC, is benefiting from the recent purchase of its fifth clicker press. The workshop has been concentrating on custom die cutting contracts for over three years, but not until recently have they found it necessary to create double shifts to handle the numerous die cutting contracts.

Some of the major die cutting contracts include hospital slippers, elbow patches, dollhouse and shingles, leather swatches, pan clothes, gasket backings, leather hangers, and finger nail buffers.

Toe Path Industries anticipates and welcomes even further growth in the custom die cutting contracts for 1985.

Toe Path Industries, a nonprofit sheltered workshop for the handicapped, grew from scratch five years ago to a business with work contracts worth more than \$100,000.

The growth of those contracts between last year and this year alone have left the agency swamped, afraid to turn away work and in need of more help to keep its sheltered workshop going, according to its spokesmen.

"We are just growing so fast we cannot keep up with the contracts that are coming in," said Jan Gile, an administrator assistant for the SCHOHARIE COUNTY ASSOCIATION FOR RETARDED CHILDREN (SCARC), the local agency that sponsors the workshop.

Under a program Ms. Gile hopes to get underway in a few months, the agency hopes to solve its problem with the help of volunteers.

WASSAIC CHAPTER

According to Florence Siegel, President of COMMUNITY LEAGUE, WASSAIC CHAPTER ARC, the Franklin Physical Abilities Center at Wassaic Developmental Center is now open and providing services to the physically disabled clients at Wassaic.

The Franklin Physical Abilities Center program was developed in response to a perceived need for a specialized treatment center designed to meet the needs of physically handicapped individuals at the facility by consolidating knowledge and resources in Franklin. Each client is viewed as a whole person, rather than focusing on the particular disability of the client.

The center includes an olympic-size therapeutic swimming pool with a movable floor to control the depth of the pool. Clients who attend Franklin for day programming will be divided into four groups, which will include two Therapy Aides and one Habilitation Specialist. In addition to other interdisciplinary programming offered by a Recreation Therapist, Speech Therapist, Occupational Therapist, Physical Therapy staff, Music Therapist, Adaptive Equipment Specialists, a Nurse and a Physician, a Psychologist will be available to offer counseling services for verbal clients to express their needs.

NEW ICF FOR SCHOHARIE ARC

A proposed Intermediate Care Facility (ICF) for 14 developmentally disabled adults on a site in the village of Cobleskill met no opposition in a public hearing.

In a unanimous vote following the hearing, Cobleskill village trustees approved the proposal, brought by Ira Gelinson of the SCHOHARIE COUNTY ASSOCIATION FOR RETARDED CHILDREN (ARC).

Because the project must meet the approval of several bureaucracies before construction may begin, Gelinson said he can only hope the facility will be completed for occupancy by early 1985.

Proposed site for the structure is Union Street Extension.

Gelinson is striving to build a \$400,000 one-story facility to permit the release of 14 residents of area institutions into a community setting. At least two staffers for the new facility will be on the premises 24 hours a day, Gelinson said.

Counseling and other professional help for the ICF residents will take place at ARC facilities in Middleburgh.

If built, the ICF would be the fourth community residence operated by ARC, which has two houses in Cobleskill and one in Middleburgh.

The main difference brought about by the ICF is the residents will have lower physical and mental capabilities than residents of the existing ARC homes, Gelinson said.

— Oneonta Daily Star

WAYNE COUNTY CHAPTER ARC received \$6,400 from the Wayne County Women's Bowling League.

The contribution followed an event where bowlers recruited sponsors who pledged a certain amount per pin.

WILLOWBROOK CHAPTER BENEVOLENT SOCIETY FOR RETARDED CHILDREN gave Annual Guest of Honor recognition to Les Trautmann, editor of the Staten Island Advance for his most impressive contribution in the field of journalism in bringing the problems of the retarded to public awareness.

The other guest of the Benevolent Society Luncheon held in the New York Hilton Hotel was Attorney Chris Hansen, formerly chief counsel in charge of the celebrated Willowbrook Case who did Yeoman service in the courts to arouse the conscience of the country to the anguish of being retarded.

Also sharing the honors at the Benevolent Society Luncheon was Julie Mack, staff reporter of the "Advance" who persistently pursued the highest goals in news-reporting with a long list of pertinent items that related to the handicapped.

Jane Hanson, reporter "NEWS 4 NEW YORK" of WNBC N.Y. Channel 4 where Miss Hanson regularly contributes reports to the 6:00 and 11:00 o'clock editions of "News for New York," and is also featured as Mistress of Ceremonies at the luncheon.



Regional Vice President, Richard Marcil, smiles at St. Lawrence ARC Annual Dinner - Past President Carolyn Smith and Executive Richard Laurin stay near the champagne! The Fund Raising Awards were wet and welcome.

NYSARC Photo

NYSARC Diplomas Testimony

(Revised Regents' Action Plan
February, 1984)

DIPLOMAS FOR ALL STUDENTS

The Board of Regents has taken a very strong stand in opposition to the awarding of high school diplomas to all students graduating unless certain criteria is met. We understand that the rationale for this is that the word "diploma" should mean that students receiving such have achieved certain competencies.

The fact that there are currently two types of diplomas available somewhat dilutes the above argument.

Our organization has argued for a long time that schools should be able to award a diploma to those students who, while they have not been able to meet those basic criteria because of their handicapping condition, should receive a diploma based upon the successful completion of their Individualized Education Plan. We have agreed that the back of the diploma should be annotated listing skills that the student has.

There are many reasons for doing this such as the lack of a diploma sometimes does not allow a person to even apply for a job and secondly, the refusal to award a diploma after a student completing sometimes as many as 18 or 19 years of schooling, seems to us to be an unfair, cruel and inhumane thing to do.

The awarding of an annotated diploma is not a deceptive thing to do. Certainly in applying for any job, one must present themselves for interviews, test taking and often further presentation of other credentials. If the applicant can not prove himself to be the best candidate for the

position, it will be because of the inability to do the things required by the job, not because of what is on a piece of paper.

One argument that was recently presented by a State Education Department official was that he was concerned that districts would water down the Individualized Education Program and push students out of school by using the diploma. I think it very interesting to point out here that while on one hand we are told by the department that we have got to throw off our distrust and lack of confidence in the school districts, that they care about special students and are committed to their education, on the other hand, we are told that on the topic of a diploma that we should be very concerned about districts taking advantage of children pushing them out of school before they are 21.

We adamantly oppose the continuation and/or the expansion of awarding Certificate of Attendances to certain students and we urgently ask that you reconsider your stand in opposing the awarding of diplomas.

Our children have enough real barriers to break through on the basis of their handicapping condition. None of us should place artificial barriers in their way. All we ask of any student is to work at school as best they can. The rewards reaped are the result of opportunities and how best one can take advantage of those opportunities. Denial of a diploma is saying to those students who have worked to the best of their abilities, through no fault of their own, that their efforts were not good enough.

Sex Needs Of Impaired Discussed At Workshop

By George Basler
— The Evening Press, Binghamton, N.Y.

The mentally handicapped have the same rights as anyone else, and that includes the right to have a more normal social and sexual life, says Winifred Kempton, former director of education and community organization for Planned Parenthood of Southeastern Pennsylvania and an expert on sex education and family planning for the handicapped.

"The mentally handicapped go through the same emotional changes at puberty as anyone else, even though their minds don't function as fast. They can channel their feelings into positive, friendly and warm relationships," Kempton said.

Kempton is in Binghamton to conduct workshops on sexuality education for the mentally handicapped. The workshops are part of a three-day conference on Sexuality and the Disabled, which began yesterday at the Holiday Inn Arena in Binghamton. The conference is sponsored by Planned Parenthood of Broome and Chenango counties.

Kempton, who has lectured throughout the U.S. and Canada and written several books on sexuality and the mentally handicapped, said it is important to teach the handicapped about their sexuality for three reasons:

- To enrich their lives by giving them self-esteem and broadening their experience.
- To help them be socially acceptable by teaching them social skills and what is appropriate social behavior and customary social patterns.
- To protect them so they are not sexually exploited or overwhelmed by ignorance and misinformation.

Kempton said that until recently most mentally handicapped persons were sterilized, and many people still believe they shouldn't be taught about sex because "they'll go out and try it."

This couldn't be more wrong, she said, "There has been no indication that presenting information about sexuality will motivate or stimulate them to do anything. In fact, research indicates students who have a better understanding of themselves will use better judgment in their behavior," Kempton said.

The handicapped need to learn about their sexuality because their vulnerability and trusting natures make them prime targets for sexual abuse, she emphasized.

Abusers also prey on the mentally handicapped because their testimony doesn't hold up in court, she said. Kempton remembered one case when a retarded woman told her counselors she had been brutally raped. Despite physical evidence, the assailant was not convicted because the victim was retarded, she said.

"One of the big reasons to teach the handicapped about sexuality is protection," Kempton said.

Social behavior by the mentally handicapped depends on their level of retardation, Kempton said.

The severely retarded must live protected lives because of their limited capacity. On the other hand, many mildly mentally handicapped people experience social and sexual relationships much like those of non-handicapped persons, Kempton said.

The handicapped need to learn how to build social relationships and how to express love and affection in socially acceptable ways, she said. They should not be over-protected and treated like babies.

Kempton emphasized: "The mentally retarded like relationships and deserve relationships, and they can have warm and loving relationships."

Two, To Our Sorrow

It is with a great deal of sadness that we inform our Association of the passing in June of Augustus Jacobs, better known to all of us as Gus.

Gus will long be remembered for his unselfish and tireless efforts on behalf of our Association. As an attorney, he served for many years as Chairperson of the Legal and Legislative Committee on a State level and in addition was a long-time member of the Board of Directors of both the New York City Chapter and State Association.

We will truly miss Gus.

Also in June we informed NYSARC membership that Adrian Levy passed away at his home on June 5, 1984. Many in our Association will remember Adrian who served in the past as Deputy Commissioner for the N.Y.S. Office of Vocational Rehabilitation.

Individuals in our Association would like to know that a number of Adrian's friends initiated the establishment of a charitable organization, to be known as The Adrian Levy Fund.

The purpose of this fund will be to provide annual scholarships to people entering or in the field of rehabilitation.

Pets-Pallatives Or Problems

Should Pets Share C/R Life?

Most of us would like to promote the picture of a faithful dog trotting along side of his retarded owner as they walk to a store, or a kitten nuzzling in someone's lap after a day in the workshop.

Perhaps we should be delighted that such simple enjoyments are available to persons who have already been denied a great many of life's pleasures. Yet many busy group home managers may very well feel that pet care is but one more job that steals time from an already overburdened schedule.

Pet therapy is beginning to receive increased national attention as supporters lay claim to the mental and physical

healthy benefits they believe to be inherent in close human - animal interactions. The verdict is still out, however, and we would like to hear from those of you who have had experience with pets and-or pet therapy.

Do the benefits to disabled persons offset the costs of maintaining the pets if the "owners" are too incapacitated to provide regular care for the animal, without help?

We are very interested in hearing about both positive and negative experiences with animals in group homes for a future article.

— Kate Klein,
Parent Editor, OCV

Pets As Therapy?

Death claimed an unusual personality in April, that of Boris M. Levinson, professor emeritus at Yeshiva University's Ferkauf Graduate School of Psychology.

Levinson, a specialist in the ways pets affect their owner's lives, died at 76 at the Blueberry Treatment Center for Seriously Disturbed Children in Brooklyn, where he served as director of human companion animal therapy.

In 1972, he published a book, "Pets and Human Development," in which he said that a pet could literally make the dif-

ference between life and death to those alienated and rejected by society.

"Pets are of particular help to those groups which our society forces into a marginal position," he said, "children without families, the aged, the mentally retarded and the emotionally disturbed, both in and out of institutions, as well as inmates of correctional facilities. All of these suffer from isolation, a scarcity of rewarding activities and a sense of rejection."

Sex Education Tragedy

RETARDED MOM, STILLBORN CHILD DIES

DARBY, PA. — A 36-year-old retarded woman who did not realize she was pregnant died during the delivery of her stillborn daughter, authorities said.

Leah Witko and her husband, Harvey, who is also retarded, had lived virtually without supervision since they were married in 1977, said Jean McKay, the couple's unofficial guardian.

Mrs. Witko and her daughter were pronounced dead at the scene by paramedics, said Dr. Dimitri Costavlos, Delaware County medical examiner. Mrs. Witko died of hemorrhaging, he said.

Witko, about 50, said his wife was too sick that morning to walk him to his janitorial job, as she always did. When he returned to their apartment that evening, he found her in the bathroom.

Syracuse Herald American
April 1984

'The Myth Of Early Aging...'

Down's Syndrome Research

Alzheimer's disease occurs in about 20-30 percent of persons with Down's Syndrome over the age of 30 years. Dr. Krystyna Wisniewski of the Institute for Basic Research in Developmental Disabilities has announced that the Institute is undertaking a research project which should have important implications for helping older people with Down's Syndrome.

The New York City Chapter of the New York State Association for Retarded Children has already endorsed and participated in this research project, and many clients have received physical and neurological examinations at no cost.

The project intends to have an impact on programming for agencies working with this population and, more importantly, on persons with Down's Syndrome.

A large percentage of persons with Down's Syndrome who appear to show symptoms of regression have been found to have treatable conditions which are

reversible, other than Alzheimer's, which this research hopes to prove. The study may show that people with Down's Syndrome who live normal and stimulating lives do not have the same type of regression, which would dispel the myth of early aging. This would impact on the type of programming given to this population in day treatment centers, workshops, and recreation for older persons with Down's Syndrome.

Dr. Wisniewski is willing to speak to any individual and-or agency with regard to participation in the research project. Contact either Dr. Jack Gorelick, Association for the Help of Retarded Children, 212-254-8203, or Dr. Krystyna Wisniewski, Institute for Basic Research in Developmental Disabilities, 1050 Forest Hills Road, Staten Island, N.Y. 10314, telephone 212-494-5202, or Ms. Betty Pendler, 267 West 70th Street, New York, N.Y. 10012, telephone 212-873-6094.

NYSARC Prevention Committee News

Teaching High School Students About People With Disabilities

English literature, science, health education and social studies all lend themselves easily and appropriately to the task of fostering understanding of people with disabilities. Moreover, improved understanding may go a long way toward dispelling the discomfort of not knowing how to act or what to do in relation to a disabled peer. This "discomfort of not knowing" is at the base of much of the separation of distancing which occurs between disabled and nondisabled adolescents and adults.

One of the few curriculums about the disabled currently available for use with secondary school pupils is *A Curriculum to Foster Understanding of People with Disabilities*. Like the AID curriculum, this package of guides was produced by the Special Education Development Center, City University of New York, under a grant from the New York State Education Department. A major premise of this curriculum is that content and activities about disabilities should be attached to appropriate points in the existing curriculum of the secondary schools. Thus both New York City and New York State curriculum designs were studied and mini-units were produced to infuse into specific units of existing curricula.

The English literature guide contains lessons on books already widely used in

the high schools which include disabled characters. It adds another dimension to the kind of interpretation which this literature usually receives. Teachers are provided with information, discussion guides, and additional suggested activities for individuals and groups. Social studies mini-units at both junior and senior high school levels deal with the rights of the disabled in the larger context of human and rights. Mini-units in junior high school science are attached to the study of body systems, e.g., sensory impairments to the study of vision and hearing; epilepsy and cerebral palsy to the study of the nervous system; scoliosis to the study of the skeletal system. A mini-unit on Love, Marriage and Family in the Physically Disabled is attached to the high school health education study of family living.

This curriculum consists of five guides: A Staff Orientation manual; The Handicapped in Literature; The Handicapped in Society; and Science and Health Education Perspectives on the Handicapped. It is available for \$6.00.

Both of the above curricula can be ordered from:

New York State Education Department, Publications Sales Desk, Room 164, Education Building Annex, Albany, N.Y. 12234.

Obesity In Down Syndrome

By: S.M. Pueschel, M.D., M.P.H.
Director, Child Development
Center
Rhode Island Hospital

There are numerous reports in the literature concerning obesity in persons with Down Syndrome. Why should one be concerned with increased weight gain in children with Down Syndrome as this is said to be a minor problem? It is well known that obesity may have adverse effects on the health of children with Down Syndrome as well as in non-Down Syndrome persons. In addition, there are non-health related concerns. Increased body weight may reduce a child's level of physical activity affecting his/her capacity to participate in recreational opportunities. Moreover, an individual's physical appearance may also be an important factor in his/her social acceptability. In our society, obesity is usually looked upon as a social stigma. Because of these aspects, one should be concerned with increased weight gain in Down Syndrome.

Usually, the newborn infant with Down Syndrome is small and is not overweight. It is of note that, during the first year of life, some children with Down Syndrome, in particular those with congenital heart disease, do not gain weight well and at times exhibit failure to thrive. After the first birthday, however, most of these children have normal weight gain. Also, children with significant congenital heart disease will have average weight gain once cardiac surgery is done. Some children become overweight during the second and third years of life. However, the majority of children with Down Syndrome have increased weight gain during adolescence and young adulthood. What is the cause of this increased weight gain?

Several investigators have studied the caloric intake relative to weight gain in children with Down Syndrome. They did not find that children with Down Syndrome had an increased food intake which could account for the excessive weight gain.

Another group of investigators even reported that the caloric intake of more than half the children they studied was less than that of normal children.

Another factor that could account for the increased weight gain is the child's reduced physical activity. We know that more we exercise the more calories we will burn. Yet, no scientific studies have been performed investigating physical activity levels in children with Down Syndrome in relation to weight gain. One often observes that youngsters who are overweight will be less active, perhaps watch more TV and become more obese. Unfortunately, recreational opportunities and sports activities are frequently not available for children with Down Syndrome to the same extent as they are for other children.

Some investigators have studied the skeletal system and the stature of the child with Down Syndrome in relation to his/her weight gain. According to these studies, abnormalities of skeletal maturation and differences in growth of children with Down Syndrome might also contribute to the obese or stocky look of some children with Down Syndrome. Some reports mention that endocrine and metabolic aberrations in children with Down Syndrome may influence weight gain. We know that some children have thyroid problems. Others have abnormal sugar tolerance, and also increased blood fat has been noted in some persons with Down Syndrome. Any of these metabolic disturbances can lead to increased weight gain.

Although some research has been done in overweight children with Down Syndrome, very little is known about the intracellular metabolic dysfunctions and genetic aspects that might be involved in increased weight gain in children with Down Syndrome. These areas should be investigated in longitudinal studies of children with Down Syndrome at the ages where the risk of obesity is the greatest.

Down's-Syndrome News

People's Doctor/Robert S. Mendelsohn, M.C.

Mental Retardation Can Be Doctor-Produced

Dear Dr. Mendelsohn:

When I was growing up, **mental retardation** was thought to be hereditary. But now, that seems to be changing. I have heard you believe that damage during childbirth and childhood can lead to mental retardation. Can you elaborate on this? — J.M., Chicago

Dear J.M.:

Over the years, one of my favorite examination questions for medical students has been, "Given a population of pregnant women, list 12 ways in which you can produce a high yield of retarded, brain damaged children."

The correct answers to this question include:

1) Before the mother even gets pregnant, take plenty of medical and dental X-rays during her first decades of life. This will insure a high yield of Mongoloid (Downs syndrome) babies.

2) Restrict the mother's weight gain during pregnancy so that she will be more likely to deliver a premature baby. Premature, low birth weight babies are more likely to suffer from mental retardation, cerebral palsy, and learning disabilities.

3) Prescribe Bendectin for morning sickness. (This drug, linked to many forms of congenital defects, recently was removed from the market.)

4) To induce labor or to "enhance" labor speed by the process with pitocin so that some mothers will develop tetanic contractions of the uterus with subsequent compression of the umbilical cord, interfering with blood flow to the fetus.

5) Give the laboring mother intravenous sugar water. The sugar (glucose) passes right through the placenta into the baby's bloodstream, creating at first a state of hyperglycemia (elevated blood sugar) which then is followed by a reactive hypoglycemia (abnormally low blood sugar which can have damaging effects on the brain.)

6) Give the laboring mother analgesic and anesthetic drugs which also go right through the placenta into the baby's bloodstream, and then into the central nervous system.

7) Perform a Caesarean section, exposing the baby to the risks of maternal anesthesia, too-early delivery, and hyaline membrane disease (a serious lung condition that can interfere with the passage of oxygen through the lungs into the bloodstream and central nervous system.)

8) Wash the newborn baby's skin with hexachlorophene soap which many years ago was shown to pass right through the skin, particularly the skin of premature babies, and to be destructive to the brain cells. This chemical, which should have been abandoned years ago in nurseries, still is being used in many places.

9) Starve the newborn infant for a certain number of hours after birth. This period of fasting will lead to a drop in blood sugar and a rise in serum bilirubin, both of which are threatening to the central nervous system.

10) Make sure that the mother does not breastfeed, thus insuring that the baby is fed infant formula which contains hundreds of times as much lead (a substance which is toxic to the nervous system) as does breast milk. At the same time, the baby thus can be deprived of some of the very enzymes-*taurine* included-which are vital for normal development of the human brain.

11) Give the newborn infant a Vitamin K shot which can lead to hyperbilirubinemia.

12) Make sure the infant receives early immunizations, including the pertussis vaccine, which is known to be particularly toxic to the central nervous system, causing mental retardation and cerebral palsy.

Reported with permission
New York Tribute Daily
Columbia Features, Inc.

Reye's Syndrome Prevention

Reye's Syndrome can be fatal. There is a 90 percent chance of recovery when the syndrome is treated in its earliest stages by physicians and nurses experienced in the treatment of Rye's. The disease affects children from infancy through adolescence and can develop 3 to 5 days after the chicken pox, an upper respiratory illness or other viral infections. It affects the liver and brain, is noncontagious and is often misdiagnosed as encephalitis, meningitis, diabetes, poisoning, drug overdose, or sudden infant death.

After a viral infection has seemingly run its course and the child is feeling better, development of the following symptoms should be treated as serious and possibly the first indication of Rye's Syndrome. Watch for these symptoms, usually occurring in this order:

- Persistent or continuous vomiting.
- Listlessness (loss of pep and energy, drowsiness)
- Personality change (such as irritability, combativeness or slurred speech)
- Disorientation (unable to identify whereabouts, or family members)

— Delirium, convulsions.

A child's life can depend on early diagnosis. Rye's Syndrome should be suspected in any child with chicken pox who vomits repeatedly. Phone your physician immediately if these symptoms develop and tell him you suspect Rye's Syndrome. If your doctor is not available, take your child to an emergency room promptly. Anti-nausea medication may mask the symptoms of the disease and because of the possible association of aspirin with Rye's Syndrome, parents should consult their physician before using these drugs.

For more information contact the National Rye's Syndrome Foundation, P.O. Box 829AB, Bryan, Ohio 43506, or call (419) 636-2679.

Did You Know That...?

The former National Association for Retarded Citizens officially changed its name at the Convention to: Association for Retarded Citizens of the United States.

The Mentally Retarded Offender — A Special Need?

A Look At The Corrections System

THE MENTALLY RETARDED OFFENDER

When an offender comes before the court on an assault charge, the maximum penalty is generally thirty days. If that same offender is found to be mentally retarded, and is subsequently institutionalized in a facility for mentally retarded persons, he has received a potential life sentence.

The inequities and misunderstandings surrounding the mentally retarded offender comprise some of society's most pressing problems. The mentally retarded person frequently violates the law for reasons that differ from those of the non-retarded offender. Naivete, for instance, quite often brings mentally retarded persons in conflict with the law.

There is a need, then, to take a look at the criminal justice system as it relates to the mentally retarded person. There is a need to talk about a more flexible approach to sentencing — not so much in terms of time incarcerated, but in terms of placement and help.

Personnel responsible for administration of the prison system must recognize that there is every reason to believe that most mentally retarded persons are subject to rehabilitation. Such a premise offers mentally retarded persons considerably broader options for the future.

SPECIAL NEED

Is there a legitimate justification for treating the mentally retarded offender as a member of a special class within the correctional system? It appears obvious that the mentally retarded individual is a disadvantaged person within a correctional institution. And if he is, there is a reason for treating him in a different manner, utilizing a different set of values. It is not uncommon to find that the mentally retarded offender becomes a victim himself within the prison environment.

Efforts should be made to encourage the correctional system to provide educational, vocational and developmental programs for mentally retarded persons in prison.

Certainly, such programs would tend to be rehabilitative. A clear case could be made for the fact that mentally retarded persons tend to regress without proper help, training and education.

— (Excerpted from "The Future of Legal Services for Mentally Retarded Persons"

— President Committee on Mental Retardation.)

Don't Sell The Shirt Off Your Back!

It's A Gift

A large number of football Jerseys and T-shirts have recently been donated to the NYSARC by a New York City firm. The shirts are fine quality and are emblazoned with the nicknames of players and teams of the NFL. Children's and adult sizes are available.

The firm is willing to ship, freight collect (which should be a nominal charge), virtually as many shirts as you may wish. These may not be for resale. The shirts are pre-packaged by the dozen in each size and in each name. A quick call or note to the firm's representative can give you more specific information. Orders will be taken on a first come, first serve basis.

Contact:

Mr. Michael Greenwald
Harmony Art Ltd.
327 Walnut Ave.
Bronx, N.Y. 10454
212-292-4600

"Future Guardians — Get The Best There Is in Quality Of Care For Your Wards!"

When We Look Back To The Beginnings Of Our State Association

It Is Hard To Realize That The Guardianship Process As We Know It Today

Did Not Even Exist At That Time For Our Older Retarded Children

NYSARC

Guardianship Committee Chairman
Jerome Ness, Esquire

TODAY, THANKS TO THE EFFORTS OF SOME OF OUR FOUNDING FATHERS, WE HAVE LAWS THAT PROVIDE THE MEANS TO ESTABLISH PROTECTIVE/SUPPORTIVE GUARDIANSHIP FOR OUR CHILDREN. OVER THE YEARS, THE EMPHASIS OF OUR ORGANIZATION HAS BEEN ON LEGAL ASPECTS OF GUARDIANSHIP: FIRST TO GET LAWS ON THE BOOKS; NEXT TO PROVIDE COUNSELING AND GUIDANCE FOR SETTING UP WILLS AND TRUSTS TO BEST SERVE OUR CHILDREN UNDER THE UMBRELLA OF GUARDIANSHIP, INCLUDING THE POSSIBILITY OF NAMING THE STATE ASSOCIATION AS THE GUARDIAN WHEN WE ARE NO LONGER HERE.

We Are Now At The Beginning Of A New Era

As our Association ages, so do we. And as a result, we have more and more of our children for whom we are becoming the ultimate or primary guardian.

Our emphasis now should be directed towards implementation of a good solid **state-wide** program that will achieve the basic goals that have been set so that our children will get maximum benefits.

That is why the NYSARC Guardianship Committee has adopted a Quality Assurance Program.

By plotting out the areas that need attention and then systematically and diligently taking action, we intend to accomplish the implementation we seek, and at the earliest practicable time. For starters, we have selected seven items. As we achieve implementation new topics will be added.

Before listing these seven, here is a synopsis of the approach we are taking, which by the way is based on well established and proven methodology used in industrial management. There are three steps involved, each in turn has three parts:

Quality Assurance Applied To NYSARC Guardianship Program

By George F. Gerstheimer Committee member

STEP ONE — DEFINE THE QA SYSTEM FOR THE ITEM.

- A) Breakthrough any bottlenecks
- B) Establish appropriate parameters
- C) Collect and analyze data.

STEP TWO — ACHIEVE CONTROL.

- A) Republish requirements to Chapters
- B) Set time limits for action
- C) Review and update periodically

STEP THREE — IMPLEMENT.

- A) Carry out in an organized fashion
- B) Keep score, measure progress
- C) Develop models/flow charts

As you can see, this involves many details to consider much work by many people. But the objective warrants the efforts required.

Without going into all the details, here are our first seven topics with brief comments regarding the reasons they were selected.

IMPROVE CHAPTER PARTICIPATION IN THE GUARDIANSHIP PROGRAM.

As of this writing all NYSARC Chapters do not have a viable, active Guardianship Program. If we are to be strong and speak with one voice we must encompass all. Considering today's mobility of the retarded (such as the mass shifting of institutionalized clients out into the community) this takes on new importance.

ESTABLISH ACCEPT/REJECT CRITERIA FOR REQUESTS THAT NYSARC BE DESIGNED AS STANDBY OR ALTERNATE GUARDIAN.

We need clear, frank, plain language advice so that all concerned will understand the conditions under which the state association will accept designation. While the individual chapters are charged with the responsibility of administering guardianship for any individual for whom NYSARC is the active primary guardian when the parents are deceased, our children have been known to move to **other** chapters, so a considerable degree of uniform consideration should exist which would apply to **all** chapters.

EXPEDITE PROCESSING OF GUARDIANS

Some of the delays of the past (literally years in some cases) have discouraged parents and others applying for guardianship.

We are working with, and becoming acquainted with as many of the Surrogates of New York State as we can. We are consulting with attorneys who have not had occasion to file for, or be exposed to the guardianship process. And happily, we can report that there now are no appreciable delays in our internal processing at our NYSARC headquarters in Delmar.

DEVELOP NYSARC GUARDIANSHIP MANUALS.

While the NYC Chapter manual has been distributed for reference and guidance, there are some desirable additions which should be made including a comprehensive glossary of legal terms for the benefit of parents and laymen who normally do not use such terms, specific guidance regarding financial arrangements, etc.

Provisions for updating (looseleaf format) as well as suggestions regarding areas which should be considered but apply only to an individual chapter and therefore should be developed locally, are also being considered.

IMPROVE/STANDARDIZE NYSARC DESIGNATION REQUEST FORM.

This ties in with items above and is a natural follow-on. It deserves a separate listing because it is the future source document that will indicate the wishes and desires of parents when NYSARC becomes the ultimate guardian.

While all important data must be included on this form, the science of good form development dictates that all superfluous and repetitious items must be eliminated and that it be neither overwhelming nor intimidating to the parents making the request.

IMPROVE/STANDARDIZE REPORTING SYSTEM FOR ALL INDIVIDUALS FOR WHOM WE ARE PRIMARY GUARDIANS

In order for the NYSARC Guardianship Committee to review and assure that all the wards for whom we are the ultimate guardians are indeed getting the care and treatment that they should be getting, we need periodic reports from the chapter which is administering the actual "hands on" guardianship operations which include proper housing programming, recreation, etc.

The importance of this report cannot be overemphasized — it is the very heart of our whole guardianship program!

For this item, the periodic review feature built into our Guardianship Quality Assurance Program may prove to be much more important than any first review we do at this time. As we again experience, and with feedback data from visits (audits) with our wards, we will be able to review the elements of this report and make whatever modifications are indicated to serve their best interests.

DEVELOP/ISSUE A NYSARC GUARDIANSHIP NEWSLETTER TO CHAPTERS.

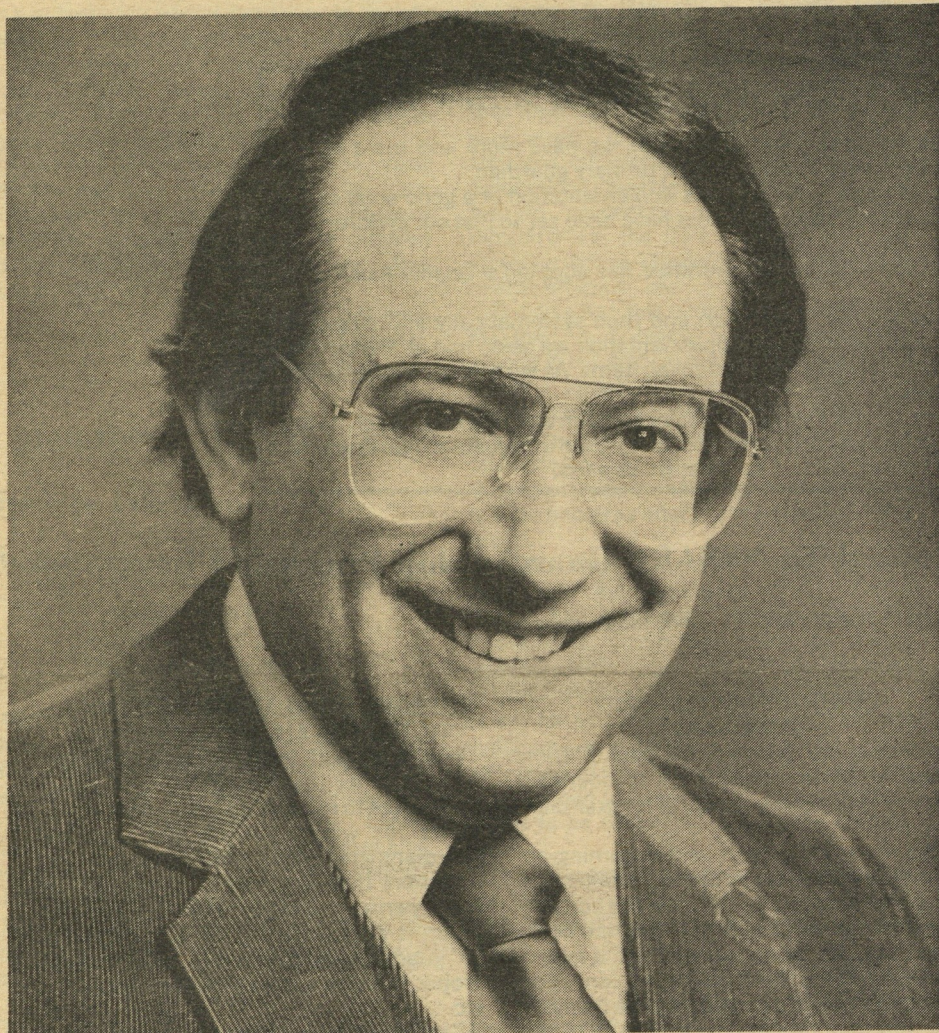
As cases come up it is very desirable to disseminate the facts involved/decisions made for the benefit of all concerned with: counseling parents; processing and administering NYSARC Guardianships. As committee members meeting with various groups, we find the same or similar questions being raised time and again. By including such a newsletter in the NYSARC Guardianship Manual to be held by the chapter, a new person coming on board will have the reference material available to them. As a two way street, the newsletter will also become the direct path for anyone in the chapter to have their guardianship questions answered. (Action on this item has been tabled temporarily because of the heavy load on the committee by the first six items — but we will dig out!)

Watch for future articles in Our Children's Voice as your Guardianship Committee keeps you informed on progress.

BROOME - TIOGA CHAPTER ARC

Our Future Is Not Our Present

NYSARC'S 1984 Convention Will Advocate For The Future Of All Who Are Mentally Retarded



DAVID LETTMAN

Once more as we approach NYSARC Convention it becomes obvious to all our membership that the challenges we face to better the lives of all who are mentally retarded never cease but only become larger as our successes accumulate.

We still have the enormous task of creating within the structure of our communities the facilities, programs and new attitudes which will contain the changing roles of our mentally retarded as they adapt to the technology of our times, the benefits of our past efforts and the perception about all who are mentally retarded as a functioning element in each community.

We face the challenge of complacency. Those of us who have been involved in the 35-year struggle to change the public's attitudes and perceptions about the

developmentally disabled can say with authority that the most difficult aspect of this challenge was changing our community's expectations about their mentally retarded. It is a job not completed.

With effort, interest, and full anticipation of and consideration for the rights of the mentally retarded individuals, the courageous parents, professionals and advocates who have helped to build our support services for the future may dream that it will not take another 35 years to erase the labels and strike the barriers to human dignity which still exist.

Join me in our continued efforts to make certain that "Our Present is not our Future." there is still much to do.

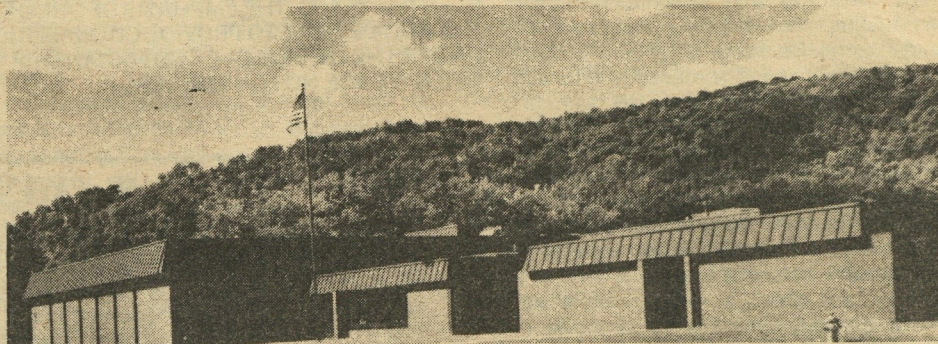
— NYSARC President
David Lettman

An organization of parents and friends to help all the mentally retarded, wherever they are, regardless of race, color, creed or age.

WELCOMES
NYSARC Conventioneers!
October 25-28

Spend four days in October with us and gain new insights to help us face the challenges that successful advocacy has brought to the lives of all our mentally retarded!

Broome-Tioga President
Joan Fiala



"Meeting the Challenge — Thirty-five Years Later" is the theme of NYSARC's 1984 Convention to be held in downtown Binghamton in October.

Host Chapter Broome - Tioga ARC predicts the workshops and deliberative input from every level of activity in NYSARC should make this one of our most memorable Conventions.

Broome - Tioga President, Joan Fiala and Executive Director, Matthew Guokas, anticipate a "full house" both in accommodations and in food for thought

about NYSARC's thirty-five years of success and challenges.

Convention workshops will emphasize program design, legal issues, and will be geared to professionals, parents, and lay people who advocate for Quality of Care in the continuum of services, according to NYSARC President, David B. Lettman.

Former NYSARC President Irene L. Platt, now NYS Commissioner for Quality of Care, will be the keynote speaker.

A detailed agenda of workshops, times and presenters will be available soon.



Members of our Broome - Tioga Chapter busy at work preparing for our 1984 Convention. From left to right is Joan Fiala, President, Richard Marcil, Convention Co-Chairperson, Matthew Guokas, Executive Director, Sandra Green, Staff Coordinator, Raymond Linder, Hospitality Chairperson and Eugene Craver, Credentials Chairperson.

BINGHAMTON — "A CITY IN THE COUNTRY" HAS MUCH TO OFFER NYSARC CONVENTIONEERS.

— the NYSARC CONVENTION COMMITTEE

The Broome-Tioga ARC Convention Committee is not planning to conduct any formal tours at the 1984 State Convention. However, if anyone has any interest in seeing the Broome-Tioga Workshop or the Supervised Apartment Program, we may be able to make special arrangements for those conventioneers who give the agency notice at least two weeks prior to the convention.

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

393 Delaware Avenue

Delmar, New York 12054

Our Children's Voice

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