

Our Children's Voice

Retarded Children Can Be Helped

VOLUME XXXV NO. 3

NEW YORK ASSOCIATION FOR RETARDED CHILDREN, INC.

DECEMBER 1984

NYARC Alters Charter At Convention

At the Convention in Binghamton, on the thirty-fifth anniversary of its existence, NYSARC altered its charter to allow the operation by chapters of clinics under Public Health Law. Chautauqua Chapter lead the way in requesting such status for the Association but certain changes in the Articles of Incorporation had to be approved by the Board of Governors for the clinics to be permitted.

Such centers were prohibited under the present auspices of NYSARC. Seven chapters are certified to operate clinic treatment services in some form. Sullivan, New York City, Chautauqua and Putnam Chapters currently operate OMRDD programs. Most of these are funded primarily through Medicaid and third party insurance.

TREATMENT CENTERS

The codes, rules and regulations of NYS Health Department state that centers shall meet standards set in the State Hospital Code. These will be independent out-of-hospital health facility operations providing therapeutic services for diagnosis treatment and preventative care by means of organized clinics.

Rehabilitation services include physical therapy, occupational therapy, speech pathology, audiology and social services. Clinical services corresponding to branches of medical care include medicine, surgery, laboratories, radiology, pharmacology, dental and dietary services.

Additionally, maternal, child health, newborn and family planning services may be given. An agency may provide all or any combination of these services, once certified.

In general there are two obstacles that prohibit ARC Chapters from providing clinical services presently. These are the OMRDD moratorium on the establishment of a Clinic Treatment Program and the prohibition of Article 28 Services (Under Health Law) in the NYSARC Articles of Incorporation.

Approval was given at the convention for NYSARC to establish Health Department Certified Treatment and Diagnostic Centers so that NYSARC would have greater applicability to serve all age groups. Also this will allow greater access to more adequate reimbursement structure and a broader base and range of services. Under this new approval NYSARC Chapters will have the ability to establish clinical services given the unspecified period of time of the OMRDD moratorium on Clinic Treatment Programs.

The intent of this alteration is not to duplicate generic services where they are available in the community but to make full use of such services where applicable. Community-based programming, by its very nature, is not a self-contained system but should be integrated into the network of community services.

The Board of Governors made it clear that the approval does not give license to avoid full-time programming of, or undermine the priority in, programming for individuals who are mentally retarded and/or developmentally disabled. This

(Continued on Page 2)

Governor Cuomo Proclaimed October Down's Syndrome Awareness Month In NYS Calendar



Advocate Job Is Unending; Commissioner Stresses

Commissioner Irene L. Platt, keynote speaker for NYSARC's Convention in Binghamton stressed the unending role that advocates must assume in the care of the mentally retarded. Commissioner Platt, a New York Attorney and former President of the group she addressed told the NYSARC Convention that "Your involvement as parents and advocates carries the responsibility for in depth monitoring of programs." She expressed concerns over the ineffective regulations of state agencies.

NYS Office of Mental Retardation and Developmental Disabilities has indicated its intention to improve regulations to make sure that incidents like those found in the Niagara ARC report of mismanagement of two years ago and of faulty quality of care are not repeated.

Supervision of the 13,000 people who are mentally retarded is not a responsibility inside a time frame, Commissioner Platt pointed out. She stressed that advocacy must be regarded as an ongoing task by volunteer agencies with built in safeguards against complacency.

NYSARC responded to the Niagara Report by taking swift and meaningful action to correct the immediate problems. New policy directives towards better oversight and effective response to crises are being established.

Looking ahead to the increased demands for programs for our mentally retarded will only increase our efforts towards quality of Care, the Commissioner said.

Irene Margolin, Member of Governor's Staff Les Bernard, President of Down's Syndrome: Aim High, Inc., Matthew J. Wessels, son of NYSARC Staff Member and Governor Mario Cuomo in October ceremony at the Capitol.

— Governor's Staff Photo

NYSARC Seeks Court Action To Nullify Sheltered Employment Regulations

In September, NYSARC, Inc. on behalf of all its chapters, served a summons and complaint against New York State Department of Education Commissioner Gordon Ambach and the New York State Board of Regents concerning Sheltered Employment Regulations.

The Sheltered Program known as SEP, as conceived and enacted by the State Legislature, is one of the finest pieces of legislation on behalf of the severely disabled. The original law and subsequent amendments addressed the true intent of the legislature and Executive Branch to provide long-term sheltered employment to New York's severely disabled persons.

The SEP law provides for an annual payment of not less than \$1,500. The State Education Department, as well as the Office of Mental Retardation and Developmental Disabilities, has stated that actual annual costs for the SEP program are about \$4,500 per year per client. It is our feeling that \$4,500 is at the low end and realistic estimates are probably \$7,000 per year per client.

While the original intent of the SEP law was to provide a subsidy to agencies so as to provide long-term sheltered employment, the \$1,500 figure has not been fully accessed. The end result has been a slow death by starvation of agencies providing long-term employment to persons who are severely handicapped, because the promulgated regulations, for the most part, have not allowed our sheltered workshops to receive the \$1,500 mandated by law.

Our Association feels strongly that the State Education Department and the Office of Vocational Rehabilitation does not now and has never fully understood the intent of Section 1004-a of the Education Law. Instead of advocating for the needs of the long-term sheltered workers, instead of documenting to the Legislature the positive gains being achieved throughout New York State through the SEP program. OVR promulgated regulations that far exceeded the Legislature's intent of SEP and violated the language of the Bill.

Further action will be reported to the membership.

LETTERS to the EDITOR

December 1984

Dear Editor,

I am writing this letter out of frustration and also of anger to people who perhaps can alleviate my depression and unhappiness on behalf of my brain-injured sons's problem.

Steve will be 21 years of age on October 19th. After completing education in an educable program, I was given the choice of mainstreaming him or putting him into OTC (Occupational Training Center). I carefully chose OTC and at the age of 17 he entered this program. It was supposed to prepare him for his future livelihood. It offered trade training in different capacities. He is responsible, gets along well with people and therefore was given a position in a nearby hospital and home for the elderly. He is travel - trained, has a good memory, is responsible and well liked. The program was that of a volunteer for 10 months and during the summer (7 weeks) he was paid. He also learned to work in X-ray. He's been working approximately 3 years there. I therefore was under the impression that when he reached 21, he would remain there as a full-time employee. I was completely wrong.

This is where I totally am convinced that parents are improperly informed and their

hopes and that of their children are a complete let down. I was informed that since his 21st birthday came out during this year, he could continue — but next year the answer was no. Why in heavens name then, didn't they prepare him in OTC during the last 4 years for a trade of some sort? My alternative, or rather his, is a sheltered workshop making buttonholes or other insignificant items. Why bother giving a person with a handicap a secure place and feeling of self-esteem only to take that away? Don't these youngsters who go through their lives with enough obstacles deserve better? Why can't money be distributed through government or private contributions to help place in their facilities people like my son? He is heart-broken knowing next year he won't be there.

Also why spend money through the Board of Education on OTC programs? They do NOTHING. I could have taught him at home for all the so called "Training" given him. He also does laundry at home, food shops with his dad, sets the table and is completely self-sufficient. I just had to get this in writing. Thanks for listening.

Sincerely,
Eileen Cohen
Brooklyn, New York

December 1984

Dear Editors:

Your most recent September issue of "Our Children's Voice" was very thought provoking to me.

It had two articles that brought back many unpleasant memories.

One article was on page two "A Parent Articulates a Heartache". All the words written by "A Saddened Parent" are so true in our relationship with our 36-year-old mentally retarded adult son.

He lived with us for 15 years, then for what we thought good for his own sake, and that of our other teen age children, and the health of my husband, we had him admitted to the West Seneca Developmental Center in West Seneca, N.Y. We brought him home weekends and for vacations, but he remained there for 15 years. At 30, we brought him home again. He is trainable and is now working for the past 5 years at the Allentown southtown workshop in nearby Hamburg, N.Y.

This child adult of ours is out of place in this world but we take him to church, out to McDonalds for hamburgers and to other public functions. This six ft. four inch man doesn't look handicapped, but people do laugh at him and stare when he opens his mouth and says something absurd, but we can't hide him away.

He still can't tell time, read or write. We have to be here every day when he comes home from work as we don't trust him home alone.

The next article is on page four "Siblings Who Help Disabled".

My other children, a younger daughter and a son are still filled with hostility over having an older mentally retarded brother. They never wanted any of the responsibility and figured our son was "just a parents' affair".

They are both now married and living away from home. Our daughter has two girls we haven't seen in five years. At 34 and 31, I don't think either one has their head on straight, I think they both need counseling but I am reluctant to suggest it as our relationship has not been good with them for a long time.

At 38, my husband had cancer when our children were very young. They were four, seven and nine. He was put on total disability Social Security four years later and hasn't worked for a wage in 23 years.

I was so glad when my husband got to be 60 years old. We were able to get into a senior citizen meeting place for lunches and activities. He is a changed person now with a different outlook on life.

I wonder if there are other families where there is more than one disabled person in it? How do they cope with hostile, thankless children? The tiresome draining experiences of day to day being with a mentally retarded adult child and disabled spouse?

Sincerely,
(Name withheld by Editors)

December 1984

Dear Editor,

I was very moved by your September 1984 article on page 4, "Siblings Who Helped Disabled."

I have a 32 year old Downs Syndrome brother who I now care for 5 days a week. I, too, feel "mixed up" with my feelings and would like to organize a Sibling Support Group in Oswego County. I volunteer with my brother's bowling league and also his social group and in talking with others involved feel the need to try and start a small group. It would help me sort out some feelings and maybe

help others also.

If you could please refer me to the Sibling Network in New York City (the address was not complete in the article) I would appreciate your help. I would like to write them and get information on starting a group in our area.

Thank you for your help.

Sincerely,
Diane C. Barbour
Editor's Note: The address is:
Diane E. Barbour
R.D. 2, Route 3
Box 496
Mexico, N.Y. 13114

December 1984

Dear Editor:

I have been thinking for a long time to write to your paper but somehow there was no energy left to explain my problem.

I am a mother of a 30 year old daughter who was stricken with cerebral encephalitis at the age of 17 months. She was in a coma for many months and after she came out of the coma, she was totally destroyed and classified a "vegetable".

Against all the odds and predictions by doctors, she did progress slowly but steadily, eventually started to walk, then to talk and began special schooling at the age of 7. It took all our lives, our strength, our efforts, our money to work with her 24 hours, 365 days a year to achieve the unexpected recovery, without any help since we have no relatives. I am a survivor of the Holocaust.

She attended and graduated the OTC in New York and is now enrolled in a workshop for very high functioning clients. She travels by herself everywhere, reads on a third grade level and is an absolute lady in behavior and speech.

She got married a year and a half ago, and this should have been the crowning glory, but here is the problem. He is also mentally retarded but holds a maintenance job in the Post Office. They were supposed to move into a house that his mother owns, but the situation became obvious after two months that there was no way my daughter could survive living with her mother-in-law. She moved back to my apartment and now they see each other only on weekends when he comes to my place for three days. He doesn't support my daughter at all because he has to give

the money to his mother as long as he lives there.

We looked everywhere for an apartment, but the rents are exorbitant. I want her to live not far from me because she needs my help and also because I need her help. I became a widow a year ago and I am a senior citizen.

My question is how come the organizations are not providing supervised apartments for couples? It took almost half of my life to bring her to this stage of almost independence, we were told by all the experts, "try and make them to become normal citizens" and when we come to this point, there is nothing available. Sure there are many apartments (supervised) but for single retarded) so what about the ones that can and want to love and have a spouse and try to take care of each other with the help of parents and a concerned organization. Why are not some projects planned for setting aside in a building a few apartments for our couples?

I have received an offer from the AHRC of an apartment but it was very, very far and Betty could never come if I was sick or I would not be able to come and help her. I am not giving up my responsibility. I am proud of my daughter and my only dream is to see her finally settled in her own little place.

If the letter is too long, please forgive me and shorten it if you think it is fit for publication. I thank you for your attention.

Sincerely,
(Name withheld)

P. S. The AHRC is trying to find something but it may take another 8 months. What should we do?

CHARTER ALTERED (Continued from Page 1)

approval allows each chapter engaged in the operation of a Treatment and Diagnostic Center to develop specific admission criteria to safeguard this intent.

Upon analyzing its thirty-five years of

existence, NYSARC feels this is part and parcel if its growth as an organization interested in all facets of well-being for the mentally retarded.

Our Children's Voice

Retarded Children Can Be Helped

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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

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

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Support Group Aids 'FORGOTTEN' Kids

Often referred to as the "forgotten children", siblings of the mentally retarded are beginning to speak out and are finally being heard, says Jack Gorelick, Associate Executive Director of the ASSOCIATION FOR THE HELP OF RETARDED CHILDREN (AHRC), New York City Chapter.

"These children have been neglected and ignored by professionals in the field and taken for granted by parents and families," says Gorelick, adding that a new force is emerging in the field of developmental disabilities: sibling power.

There are approximately 6 million Americans who are mentally retarded, according to Gorelick, and about one in 10 people in the United States has a mentally retarded person in the family.

"In response to the overwhelming demand and need for sibling support groups and related information, AHRC has started a pilot sibling network program, which has begun to address sibling issues locally and nationally," he says.

It is, he reports, one of the first organized self-help groups in the county for brothers and sisters of the mentally retarded.

"We are involved in the family situation whether or not we want to be," says Bonnie Cohen, a social worker in the field and a sibling herself. "We want to meet with other siblings, to sort out our own feelings and find our own directions."

"Normal" siblings want to have their own lives but are torn by family relationships and responsibilities, Gorelick notes. Many express guilt and anger over their situations and siblings.

ROLES

"Siblings are forced to play many roles... that of caretaker, child and surrogate parents," he says. "Some siblings have so much responsibility that they become adults at a very early age, even though they haven't finished being children themselves."

Siblings often feel that they grew up deprived of parental attention and that they were not praised as much for their achievements as were other children in households without a handicapped child, he adds.

"Two persistent issues," Gorelick explains, "are identity and genetics. Will I become like my brother or sister? Am I

handicapped myself? Will my children be retarded? Siblings have anxieties about dating, marriage and having children, as well as about having a continuing relationship with their handicapped brother or sister in the context of their own lives."

Many adults are also worried about the futures of their handicapped siblings, including guardianship issues and what arrangements are possible for residence, occupation and care should their parents die, he points out.

"Siblings of all ages frequently feel isolated and need to talk to other people about their feelings and thoughts on living with a handicapped brother or sister," Ms. Cohen says. "To be able to say publicly that you feel murderous rage at times towards your handicapped sibling is a boon."

Until recently, she says, sibling groups were non-existent and a typical parent reaction was, "I'm afraid to hear what my daughter is going to say."

Many siblings resent professional help because they feel that professionals tend to view them under a microscope, Gorelick says, explaining that professionals sometimes have an urge to solve or cure the problem and siblings know that the "problem," the handicap, is not conducive to a quick fix.

"In the past, professionals have dutifully listed siblings' names and ages on intake sheets and then usually have ignored their needs and their concerns," Gorelick says. "Associations for the handicapped must remember that very little work has been done that could ever qualify or blueprint the roles siblings play, the emotions and responsibilities they experience or the relationships they have with their handicapped siblings."

Traditionally, he says, associations have been concerned with providing services for the handicapped or advocating, with governments and society, better treatment. Associations have primarily been parents' or professionals' organizations and siblings have not been a main focus.

Recently, however, due to siblings' articulation of their needs, more time and effort is being focused on the families of handicapped persons as well, Gorelick says. The result has been conferences covering sibling concerns, newsletters, case studies, research articles and formation of sibling groups.

—Cortland, N.Y. Standard

'Never Doubt That Your Presence Makes A Difference'

Parental Issues And Concerns About Residential Placement Catalogued At

Developmental Center Committee Conference

— Ellen Maroun, Chairperson

Community Residence

Ellen Maroun, former President of the Association of Boards of Visitors presented a panel of parents whose children represented varying levels of required care. These nine parents spoke frankly about their decision to place a child in an institution and their resulting experiences. These parents now must face another kind of decision — the placement of their child in a community residence after years of institutional care and the family adjustment to that first sometimes painful decision. They spoke of their feelings of abandonment both by the parents and by the child in the initial decision to place the child in a developmental center.

"Parents all come from the same place," Ellen Maroun said, "from the need to salvage family life from the exhausting demands of home care and the crucial importance of quality of care in placement when it is available."

The panel of parents outlined their reasons for the initial placement, their concerns about the institution, their ex-

Committee NYSARC

perience as parents dealing with the personnel at the developmental center and the kinds of programming provided. They recounted their feelings at the prospect now of actual placement in a community residence. They hoped to see the community residence as an extension of family care. Concerns were highlighted by parents of a child requiring special medical care.

Parents of a child in the special medically fragile population of the institution related their concerns that a community ICF would not meet such needs.

Summarizing for parents Moderator Maroun said "Never doubt that your presence makes a difference — both to your child and to the care-givers."

The system is better off with you than without your presence.

The conference summation was that to the extent that you are not there, the flaws in the system will continue and even gain in entrenchment."

A Personal Editorial

PARENTS PANEL

By Ann Nehrbauser

My husband and I have made two major decisions concerning Stephen's life. The first was no choice at all but an absolute desperate decision to place him in Willowbrook. The second was really a choice as we did not accept the first community placement that was offered, but when a suitable situation for him arose, we accepted that.

Stephen was sent away solely because, despite eight years of earnest, continuous effort our family's daily living, growth and health were falling apart by his presence. We never felt that we hadn't done our best but we finally realized we were failing, and that is a very hard admission to make to yourself and others.

It was only about ten years ago, we began to realize that contrary to our thinking all along, we had really done the right thing for Stephen also, rather than just for the family. Stephen did adapt and

grow to the life structure and tempo of both the institution and the group home.

He does have his own world. God knows it is certainly not our world, but he is quite happy and settled and does know a large number of people and a pattern of life. The days do dwindle down and my husband and I are at peace concerning Stephen's life after we are no longer here.

He does have his own world and will be able to function without us and that is what is so important to establish yet, that thought had never been considered when we made our first decision.

To all parents still considering or hesitating about an initial placement, I would say it is better to make a placement too early than too late. It is far better to make a placement that you can be involved with and control than to have it done by someone else when you are no longer in the picture.



Welcome to new members!

At NYSARC Convention — The Delegate Assembly requested the Executive Director to send a letter protesting an article that appeared in Time Magazine describing Trivial Pursuit. The article described individuals with Down's Syndrome as being "brain dead at one in the morning." The letter requests an apology.

Family Court Justice William Kellick in a problem which came to his court a year ago ruled that a mildly retarded Niagara Falls couple be awarded custody of their one-year old mildly retarded son who was being cared for by the Niagara County Department of Social Services.

The Warwick Valley Humane Society, Inc.'s "Pet Therapy Program" visited 110 children from the Association for the Help of Retarded Children in the Middletown area. The program in which adoptable animals from the shelter are also taken to nursing homes and institutions is on a regular basis.

A toll-free "aging-out" hotline has been established to aid families facing the crisis called "aging-out," for those 21 and older. "Aging out" is the term used when mentally retarded, emotionally disturbed and developmentally disabled individuals reach 21 and are turned out of residential facilities or daytime special education programs.

The toll-free number is 1-800-522-3103.

Several Indonesian teachers currently studying for Master's and Doctorate Degrees on State University of New York campuses were impressed by their visit to the CLINTON COUNTY ARC and hope to develop similar programs in their native land.

The Supreme Court has let stand a ruling that states may place centers for the mentally retarded in residential neighborhoods even though deeds limit the homes to single-family dwellings.

The State of New York in a Legislative Resolution proclaimed the month of October as Down's Syndrome Awareness Month in the State of New York.

Baby Jane Doe, whose entry into the world created a furor involving the federal government celebrated her first birthday in October.

To be an ARC advocate — you've got to pick your issues consistent with broad goals, be committed and WORK.

Guardianship More Essential Than Ever

Jerome Ness

Chairperson, Guardianship Committee
Guidelines from the Guardianship Committee designed to promote development of guardianship applications in chapters where such action is at various stages of development.

From time to time changes may be made in the NYSARC policies and procedures which govern the operation of the guardianship program at least annually within the context of the State Association's currently existing programs.

ATTENTION APPLICANTS

We recognize the concern shared by you as parents and relatives for guaranteeing that the best interests and general well-being of your child or other family member will be protected and fostered throughout their lives.

NYSARC, through its Chapters, offers a unique lifetime commitment to parents and relatives of individuals who are mentally retarded by providing a Guardianship Program. This Association offers to back up your family guardianship planning by becoming the last or "ultimate" guardian of your child or relative, therefore ensuring that the care and protection you have provided him or her thus far will continue for the rest of his or her life.

Since there is no public funding for guardianship, the Association is dependent upon private funding (contributions) to insure the future of the program. Thus, where funds are available, we hope and encourage you to make provisions to

support the operation of the ARC Guardianship Program.

Provisions for your family member for the program may be made through a Will or Trust and should be drawn by a knowledgeable attorney. Information on the Retardate Trust may be made available to you or your attorney on request.

Your application will not be rejected because of inability to provide funds.

PROCEDURES TO START

If you wish to be immediately involved in NYSARC's Guardianship Program, first request an application from NYSARC Guardianship Committee through your local chapter. The application form has been designed to meet the need for a single format which is easily understood by the applicant yet comprehensive enough to provide adequate information to the chapter and NYSARC in their consideration of applications.

A checklist format of the guidelines in filling out the application will be enclosed for those reviewing applications at the chapter level. The application must be signed by the Guardianship Chairperson (Chapter) and submitted to NYSARC along with the application. This check list was developed in consideration of the applicant's need to obtain the NYSARC's consent before proceeding in court.

The application will be entitled Request for NYSARC to accept designation as guardian of a person who is mentally retarded. All information on the request will be treated confidentially.

New York Seat Belt Law

New York State passed a landmark bill in June 1984. It requires that all drivers, front seat passengers and children under the age of ten, riding anywhere in the vehicle, be properly secured. Children under four must be secured in an approved child safety restraint device.

As of December 1, 1984, warnings will be issued by police until January 1, 1985 at which time penalties will be imposed. The penalties will include a fine of up to \$50.00.

The driver is responsible to pay the penalty for any passenger under the age of 16. Passengers 16 and over are responsible for their own fines.

The NYSARC Prevention Committee supports this law for the following reasons:

— Currently available safety belts are the most effective preventive measure to protect against serious and fatal motor vehicle - related trauma.

— New, young drivers ages 16-17 represent less than one percent of the total driving population in New York State yet, they account for more than 3 percent of all crashes and approximately 3.5 percent of both fatal and serious injuries.

— National Highway Traffic Safety Association estimates that 17,000 lives would be saved every year, the severity of almost 4 million personal injuries would be reduced every year, 20 billion dollars in costs incurred through motor vehicle accidents would be substantially reduced every year and the total number of motor vehicle accidents would probably decrease if every driver and passenger in the United States would wear safety belts during every trip in a car.

Joan Edwards, Chairwoman
NYSARC Prevention Committee

Girls Being Tracked For Unusual Diagnosis

RETT'S SYNDROME, recognized in Europe for nearly 20 years, exists in the United States, mostly undiagnosed. This disorder affects only girls.

Although infants develop normally mentally and physically during the first 7 to 12 months, speech and hand use deteriorate at 18 months to 3 years. Shakiness (ataxia) in arms, legs and body, poor balance, teeth grinding, facial grimacing and social withdrawal are common. Hand movements are stereotypical with a soft closed-hand clapping, tongue thrusting and grabbing.

Severe mental retardation remains relative stable, but regression occurs again in early teens. Also in adolescence, spasticity, scoliosis, loss of ability to walk (if developed), and poor circulation in legs appear. Seizures develop in about two-thirds of the girls.

If you know of such a child, direct inquiries to: Dr. Vanja Holm, C.D.M.R.C. Mail Stop WJ-10, University of Washington, Seattle, Washington 98195, or to Claudie Weisz, 3817 44th Avenue SW, Seattle, Washington 98116 (for parent support group).

Albany Conference Honors Joseph T. Weingold



SMILES AND HONORS GO TOGETHER

Carol Anderson, President, NYSARF and Joseph T. Weingold face the applause.

At the NYS Association of Rehabilitations Facilities annual convention in September in Albany, Joseph T. Weingold of NYSARC, Inc. was presented the first Commissioner Adrian Levy Award.

The award is presented to an individual who has made an outstanding contribution to the field of rehabilitation. Nomination was made by NYSARC's member facilities.

Governor Mario M. Cuomo was chosen to receive the Outstanding Public Official Award. The award was presented to Ms. Eileen Margolin of the governor's office.

Ms. Madeline Will, assistant secretary of the federal Department of Education,

was the keynote speaker at the conference. Other speakers included ARthur Webb, Commissioner of the State Office of Mental Retardation and Developmental Disabilities and Dr. Johanna Ferman, Deputy Commissioner of Clinical Services at the Office of Mental Health.

The Rehab '84 conference was held in conjunction with a state of art trade show. More than 600 people attended. The trade show included more than 40 exhibits of interest to the disabled and to the agencies which serve them.

Carol Anderson, Executive Director of the Columbia County Association for Retarded Children, was installed as the new president of the New York State Association of Rehabilitation Facilities.

Did You Know That...??

Six million Americans are mentally retarded. Sixty-thousand babies will be born or will become mentally retarded each year.

Almost 20 years have passed since Burton Blatt, Dean of SU's School of Education expose "Christmas in Purgatory" had been published. The expose and its pictures were financed by a parents' organization for the retarded and has caused more controversy in the last 18 years than any other publication written.

New... just out... from the State Education Department, Office for Education of Children with Handicapping Conditions, "A Parent's Guide to Special Education... Your Child's Right to an Education in New York State" — designed to assist parents in understanding the special education process — rewritten to incorporate the changes in Part 200 of the Regulations.

Part I of the guide provides in-depth sequential content related to the special education process.

Part II is a practical handbook with suggestions for parents record keeping, due process assurances and resource material. For copies write to: New York State Education Department, Division of Program Development, Room 1071, Education Building, Albany, New York 12234, Attention: Parent's Guide.

Pathfinder Village is the only residential center and school in the United States solely devoted to Down's Syndrome children and adults.

"Your Rights Are Our Business" — a new brochure describing the Bureau of Protection and Advocacy of the N.Y.S. Commission on Quality of Care. This brochure briefly describes those rights, who is served and the services provided. It also lists the regional officers with names of contract people as well as telephone numbers. For a copy please contact the: New York State Commission on Quality of Care, 99 Washington Avenue, Albany, New York 12210, telephone (518) 473-7378.

"Exceptional Parent Magazine" expanded its issues to eight a year. The Education Committee has found this magazine a most helpful tool not only for parents, but to help bridge the gap between parent and professionals. Each issue addresses the care and concerns which arise in raising, treating or teaching a child. This magazine covers a wide range of subjects: I.Q. testing, curriculum, sibling, tax information, sex education, reading lists, understanding your rights, etc. We recommend it highly. Subscriptions are \$16.00 for 8 issues. Subscribe today — The Exceptional Parent, 605 Commonwealth Avenue, Boston, Massachusetts 02215.

Self Advocates Bring Convention Listeners Close To Laughter, Close To Tears



Joan Warren and Pamela Scoggins from Chester, Pa. and self advocates Dan Kolb, secretary of the Chester County Chapter, Speaking For Ourselves with President Jerome Iannuzzi on the speakers platform at Convention.
— Public Information Committee Workshop

Where the line of self-advocacy, self-help intersects with appropriate assistance in life skills was a concern highlighted by the Public Information Committee's Workshop at Convention.

Statistics on the aftermath of the Pennhurst Decision were presented by Marietta Bates, Associate Director for the Resource Center for Developmental Disabilities (based in New York City). She recounted difficulties in Pennsylvania in developing appropriate community programming for the mentally retarded who left institutions, particularly those in the Pennhurst Decisions framework which compares to the Willowbrook Decision in New York State. Historical perspectives were itemized by Ms. Bates.

But the highlight of the workshop was two "in person" reports from two young men who are mentally retarded and who are part of an organization known as "Speaking for Ourselves."

This organization is unique in that it is a self-advocacy organization run by people who are handicapped. Members live in community living arrangements, in institutions, or at home with their families. They attend vocational training programs, are competitively employed, or are looking for employment.

WHAT IS "SPEAKING FOR OURSELVES?"

Speaking for Ourselves is a statement by consumers with handicaps that they want to make decisions on their own, to take responsibility, and to become more independent.

It began two years ago when six people living in community living arrangements began planning a convention for people like themselves. The convention, held in conjunction with the ARC-PA convention had over 100 people attend and was an enormous success. Since that time Speaking for Ourselves has grown to a membership of 300 consumers and has held four conventions. There are now five chapters in Southeastern Pennsylvania, located in Montgomery, Bucks, Philadelphia, Chester and Delaware counties.

These groups meet monthly to work on solving their problems and to learn how to

speak up for themselves.

Jerome Iannuzzi, President of Speaking for Ourselves told the group "Believe me, when they told me I could go out on my own — I was scared!" Lead by coordinators Joan Warren and Pamela Scoggins, Jerome Iannuzzi and Daniel Kolb, both from Chester, Pa., frankly and with no attempt to color their personal reactions and experiences told the group about their self-advocacy activities.

Their current projects are: **Voter education** which means they educate and train consumers about the voting process, from registering to vote to picking a candidate, to operating a voting machine. "Speaking for Ourselves," Iannuzzi explained, has its own Board of Directors which identifies agencies willing to appoint consumers to their Boards. This includes training, visiting board meetings and creating an ongoing support system.

HUMAN RIGHTS COMMITTEES — all consumer membership work with and participate in agency and county human rights committees; advocacy which they explained, means working with other members of the group by either helping them to advocate for themselves or advocating for them.

PUBLIC INFORMATION which covers planning conventions and making presentations with the use of video tape (made with the help of local TV station) to parents, colleges, community and service organizations "to make them aware of what we are doing and to convince them that we can do things for ourselves," Dan Kolb told the group, "all help the community better understand and accept us."

"Speaking for Ourselves" is for everybody. It is run by and for people who are called mentally retarded. It is for everybody, no matter how severe the disability, Kolb said.

Volunteer advisors initially help to organize the group. They then help to facilitate decision-making and are available for support and direction as needed.

In clarifying his role, President Iannuzzi said "We should have the right to speak for ourselves — we are learning how to stick up for our rights together as one big group. It's a little hard but it is getting easier."

Retarded Adults Learn By Example, Speaker Says

By Pat Louise
Staff Writer

Corning, N.Y. Leader

KANONA — Social skills instead of academic skills will help mentally retarded adults cope in a normal environment.

That theory was stressed by Dr. Sol Gordon at a recent Wednesday's Agency Training program of the Association for Retarded Children at the Tally Ho Restaurant. Gordon is a professor of Child and Family Studies at Syracuse University and director of the Institute for Family Research and Education.

"There is one fact we all know but no one will say," he told an audience of 60. "Mentally retarded people are boring."

Amid laughter and nodding of heads, Gordon told the audience this was not necessarily the mentally handicapped person's fault. "We reinforce inappropriate behavior. People respond as they are trained to respond."

He cited two examples of inappropriate reinforcement. "I was travelling and a 23 year old mentally retarded man came up to me and asked 'Do you love me?' I said 'no, I don't even know you.' Many of you would have played along, but that is not normal behavior for most adults."

Another example is perseverance — the tendency to repeat things. "A lot of mentally retarded people will ask 'Did I do good?' four or five times. And how many of you say 'Yes, you did.' just as many times? Instead of reinforcing his behavior, tell him he is being a pain and that behavior is not acceptable. He'll stop just like any six-year old will when the attention-getting device no longer works."

Gordon said a lack of socialization skills is the biggest problem for mentally retarded adults. "We teach them coloring when we should be showing them how to shake hands. And when someone asks how they are, they should replay 'Fine, thank you.' Tell them to lie; anyone who asks the question is being polite and doesn't care how they really are."

Gordon said efforts must be made to promote self-esteem among mentally retarded adults. "We all know someone who is almost totally unlikeable. My unlikeable challenge was a 25 year old woman named Suzy."



SOL GORDON speaking in Kanona.
Corning Leader Photo

Suzy did not get along with anyone and had no friends, Gordon said. Even her parents had a hard time liking her. "She was 'un' everything. All she did was sit around and eat chocolate."

Two weeks before Suzy's birthday, Gordon told her to prepare a party at her house because doctors and patients are her clinic were coming over with presents. "It was a miracle. In two weeks she learned to cook, clean, sew and shop. She didn't shut up once during the party, but we had a great time."

Gordon said Suzy now is successfully employed. "We found her a job in an old folks' home. Every year she wins the Employee of the Year award. She manages to talk to all 150 of the patients almost every day."

Gordon said the job for every member of the audience was to see that every mentally retarded adult had an interest or hobby. "Constructive leisure time is necessary. The first stage of depression is boredom."

Willi-Prader Syndrome

The Appetite Disease

Prader-Willi Syndrome is a neurological impairment resulting from a birth defect. The syndrome leads to some degree of mental retardation in 95 percent of the cases, although good performance in some areas and very poor performance in others is common. The central nervous system dysfunction creates insatiable appetites in persons with Prader-Willi syndrome.

Where can you learn more about this unusual disease? The New York Chapter of Willi-Prader Syndrome hosted its first annual conference on November 1, 2 and 3 in Pawling, New York. Future plans involve a national conference to be held in June of 1985 in Connecticut. For future information contact: Ms. Rita Welch, President, New York Chapter, Prader-Willi Syndrome Association, 6-12-160th

Street, Beechhurst, New York 11357.
Telephone number: (212) 767-6077.

HELP REQUESTED

The New York Prader-Willi Syndrome Association, in conjunction with the Resource Center for Developmental Disabilities, is conducting a statewide search for victims of the syndrome. If you know of someone who may be suffering from Prader-Willi, please contact Duncan Whiteside, Resource Center for Developmental Disabilities, 30 East 29th Street, New York, New York 10016. Telephone number: (212) 889-5760. Funds have recently been made available for help and programming for such individuals in New York State.

Special Note From Former NYSARC President

At this time, it is impossible to write individual notes to everyone, however, I would like to take this opportunity to thank all of you for your best wishes and warm thoughts while I was convalescing from surgery in July and August of this year.

Your cards, telephone calls, flowers and yes, even contributions were greatly appreciated and I was deeply touched by your thoughtfulness.

Thank you for remembering me.

Robert J. Hodgson

Legislative Committee Reports

The Legislative Committee feels strongly that two bills in the Legislature should receive continued support from NYSARC. They are:

A. 1315B — This act calls for the amending of the Public Health Law in relation to prevention of lead poisoning in young children. Also the committee asks that Chapter 89, Laws of 1984 be amended to exempt persons who are mentally retarded from the corroboration requirement.

OTHER LEGAL OUTLOOKS

The Association has strong feelings concerning the current laws pertaining to the issue of medical consent. The Committee's recommendation is to develop three separate legislative initiatives to do the following:

1) Amend the Mental Hygiene Law and Surrogate Court Act to allow for legal guardians of the person to sign for medical or dental consent. Also to allow directors of voluntary agencies to sign for medical or dental consent for people who are residents of programs operated by the agency where there is no legal guardian for that individual. Also to allow developmental center directors to sign for medical or dental consent for people who are residents to developmental centers where there is no legal guardian for that individual.

OTHER MATTERS, LONG-TERM PRIORITY

The Association has over the past several years been successful in having laws enacted pertaining to interest reimbursements. The one area left is on personal property in local assistance funding. Our recommendation is to amend the Mental Hygiene Law to make interest a reimbursable expense in local assistance when personal property is acquired.

GETTING INTO RESIDENCES

The existing policy for new community residence development discriminates for placement into community residences using a quota system sensitive to whether individuals lived in a developmental center or with their families.

The Legislative Committee recommends to develop legislation to amend the Mental Hygiene Law to assure that individuals will be accepted into community residences irrespective of prior living situations. This amendment would prohibit the use of any quotas in the development and/or contracting for the establishment of new homes.

ISSUES CLARIFIED

Issue: Unavailability of necessary funds for the repairing or renovation expenses to voluntary operated community residential sites.

Recommendation: Establishment of a grant program to fund necessary building repairs.

Recommended By: Chapters, Executive Directors and part of 1984 position on the Governor's budget for program and services delivered to persons who are mentally retarded and developmentally disabled.

Issue: The Committee on the Handicapped recommendations to the Board of Education should be final unless appealed by the parents to the Commissioner of Education.

Recommendation: A) Develop legislation that would remove the Commissioner's rights to approve the C.O.H. recommendation for private school placements; and

B) to remove financial incentives that encourage placement of children in more restrictive environments through equalization of rates to programs providing educational services. The Education Committee recommended this.

Issue: Handicapped students who are not able to pass the basic competency test

should be awarded an annotated diploma on the basis of their successful completion of their I.E.P.

Recommendation: Assembly Bill A.1068 passed during the 1984 session. Continued support and pressing for Senate Bill S.8601.

Recommended By: Consistent with previous NYSARC policies recommended by Education Committee.

Issue: Provisions for summer school, pre-school services and studying of services for the zero to three year's old population.

Recommendation: Senate Bill S.8622 — Assembly Bill A.11089 combines a number of educational goals. This bill begins to establish pre-school programs, bill for the 0-3 population, and a twelve-month program for certain handicapped children. It is consistent with NYSARC's involvement with the drafting of this bill.

Note: The Education Committee, although supporting this bill, wants the requirement that pre-school programs be mandated.

Issue: The need to remove O.V.R. from the State Education Department to a separate office.

Recommendation: Assembly Bill A.11530 passed the Assembly. Continued support and pressing for Senate Bill S.9143. Recommended by Board of Governors resolution April 1984 Vocational Rehabilitation Committee.

Issue: Appropriate action necessary to prohibit co-location of developmental centers.

Recommendation: Senate Bill No. 8485 passed the Senate. Continued support and pressing for Assembly Bill A.11509. Recommended by Executive Director, Developmental Center Committee.

Issue: Unavailability of clinicians for some of our programs.

Recommendation: The development of legislation authorizing the State Education Department to establish a scholarship fund for students to become mental retardation professionals in return for employment in our chapters for a specified period. Recommended by Executive Director in response to Board of Governors assignment from Spring Board of Governors Meeting.

Issue: The human resource and financial expense associated with multiple reporting requirement of OMRDD.

Recommendation: Develop legislation mandating that OMRDD allow for the submitting of one agency-wide cost report for the entire agency's programs on an annual basis. Recommended by Executive Director and Executive Directors of most NYSARC Chapters.

Books On Our Favorite Topics

UNRAVELING THE SPECIAL EDUCATION MAZE

An Action Guide for Parents

By Barbara Coyne Cutler

Although subtitled for parents, this excellently written and readable book, belongs in every household sheltering handicapped persons of school age.

Advocacy is still the issue of the day and this book provides an effective plan of action for anyone needing to secure the rights of appropriate education for handicapped persons. Ms. Cutler's approach is logical and supportive, providing the most basis of suggestions for preparing arguments and making assessments as well as conversational scenarios.

The book begins with a clear explanation of Public Law 94-142 and moves through an analysis of the public school system political control structure to the development of advocacy techniques. An appendix lists names and addresses of organizations to contact for additional assistance and a comprehensive chart listing special education eligibility ages state by state. A bibliography is also included with suggestions for additional books on legal rights, parent advocacy, assertiveness, and so forth.

New Issues Are Constantly Arising — Case Tests Rights Of Retarded

Ruling Due On Whether Retarded Man Must Be Donor For Ill Brother

By Kathleen Kerr

In the upstate town of Greece, 42-year-old Paul Lampman lives in a state-run home for the mentally retarded, unaware that a judge will soon decide whether he must donate life-saving bone marrow to his brother who has leukemia.

Lampman is the only person having a compatible tissue type with his brother, Michael. Michael Lampman wants State Supreme Court Justice Ronald Cicoria to force his brother, who has the intelligence of a 2-year-old, to give him life-saving bone marrow. The procedure for obtaining the marrow is not considered life-threatening, although Lampman would suffer temporary pain as a result.

The judge's decision in the case is expected to have an important impact on the rights of the mentally handicapped. In court, the case has been a poignant struggle between the state attorney who represents the Long Pond Group Home where Paul Lampman lives, the attorney for Lampman's brother, and the court-appointed guardian for Lampman, who opposed his participation in a transplant.

In court papers, Sylvester Zielinski, director of the state office that oversees the group home, did not oppose the transplant providing there were no grave risks. "We believe that in a matter so grave as the life of his brother and absent any grave medical risk to Paul... we must act in a manner which supports the preservation of his brother's life," Zielinski said.

But the guardian appointed from the court department that represents the interests of people judged legally incompetent objected, saying that Cicoria should not attempt to use "substituted judgment" to determine whether Lampman would want to donate bone marrow to his brother if he were fully competent. The attorney, Arlene Hughes, would not confirm that she represents Lampman in the court hearings, which have been held in private.

And Assistant Attorney General Carlos Rodriguez, who generally approves the proposed transplant, argued that the issues are not so clear-cut. Rodriguez represents the New York State Office of Mental Retardation and Developmental Disabilities, which oversees state homes for the retarded.

"The agency must point out the strong public policy against permitting in-

stitutionalized or incarcerated persons to serve as 'organ banks' for normal society," Rodriguez said in court papers, "Where the individual never expressed a preference or intent, and where said individual will receive no medical benefit from the procedure, the decision becomes both difficult and dangerous."

Rodriguez asked Cicoria to ensure that Lampman would derive some benefit from the procedure, such as his brother's continued participation in his life, and that the bone marrow be removed in a hospital close to the group home where Lampman lives. Lampman's brother, Michael, was unavailable for comment.

In several cases involving competent relatives, judges have refused to order one relative to donate bone marrow to the other. One was the case of David Shimp in Pennsylvania. The court refused to order Shimp to donate bone marrow to his dying cousin.

The Lampman case, however, is the first known case in New York involving an incompetent person. Advocates for the mentally retarded are split on the issue, but all agree it is important in terms of the future rights of the mentally handicapped.

Murray Schneps, a New York City attorney who has represented the mentally handicapped, opposes the transplant. "My feeling would be that if a person is unable to give their consent then nobody should be able to give that consent for them to donate," Schneps said.

But Norman Rosenberg, an attorney with the non-profit Mental Health Law Project in Washington, D.C., believes there is no great danger to persons like Lampman. "The courts have been pretty scrupulous about taking steps to assure that somebody is not being taken advantage of," Rosenberg said. "The problem is somebody else has to make the decision for him."

Art Kaplan, a bioethicist at the Hastings Center in upstate Hastings-on-Hudson, said that the issue should be decided on a case-by-case basis. Whether a procedure is done, he said, should depend "on the severity of the procedure being asked... If it could be shown to me it's not terribly disconcerting, I could see a proxy saying okay, but I could also see a proxy saying no."

Newsday Garden City, NY

Social Security Information

Social Security estimates indicate that retirement, survivors, and disability benefits can be paid on time well into the next century on the basis of four sets of economic and demographic assumptions, according to the annual report of the Board of Trustees. Over the next 75 years, the retirement, survivors, and disability programs are in close actuarial balance based on the intermediate set of assumptions.

The Social Security Board of Trustees consists of the Secretaries of the Treasury, Labor, and Health and Human Services. They report annually on the condition of each fund and the projected future financial results. Single copies of the complete annual report can be obtained without charge from the Social Security Administration, Office of Public Inquiries, Room 4100 Annex, Baltimore, Maryland 21235.

CALL FIRST FOR BETTER SERVICE

People who plan to visit a Social Security office for any reason should call first. Most Social Security business can be handled by phone. Or someone in the office can tell them what they need to bring with them if they do need to come in. Avoid telephoning

during peak lunch time periods, especially Mondays or Fridays, and during the early part of the month. Of course if your business is urgent, do call at any time. Remember free Social Security literature covering the entire program is only a telephone call away.

CHECK YOUR NEST EGG

Wouldn't you want to know the balance in your bank account? Of course! Well, you can find out how much is currently credited to your account in the Social Security System by a simple procedure. Just telephone or visit your nearest office and ask for form 7004, which is self-explanatory and easy to complete. We'll even mail it for you. This will be especially helpful for people nearing retirement age, who will also receive an estimate of benefits payable on those earnings. Younger people can also use this report to verify the accuracy of their account. Should there be an error, this report will give you an opportunity to call or visit your nearest office to correct your record. The statute of limitations to amend most records is 3 years, three months, and 15 days.

Suffolk Lamplighter

by Fredda Stimell,
Executive Director
Association for Children
with Down's Syndrome

Second Ad

TO MOTHERS OF SLOW CHILDREN OF ALL AGES. WOULD YOU LIKE TO JOIN AN ORGANIZATION OF PARENTS WHICH IS BEING FORMED FOR THE WELFARE OF YOUR CHILDREN? WE WILL TRY TO HELP ALL PARENTS WHO NEED ADVICE OF ALL KINDS. OUR MAIN AMBITION IS TO HELP IN EVERY POSSIBLE WAY TO INSURE A FUTURE FOR OUR CHILDREN.

One year later, the Agency's first Executive Director, Joseph T. Weingold, reviewed the circumstances of AHRC's foundings and its subsequent development.

"And this is not only true of New York. All over the country the parents of mentally retarded children are banding together so that their children will get their birthright as citizens and human beings. The time of the idea has come and it is stronger than all the armies of the world."

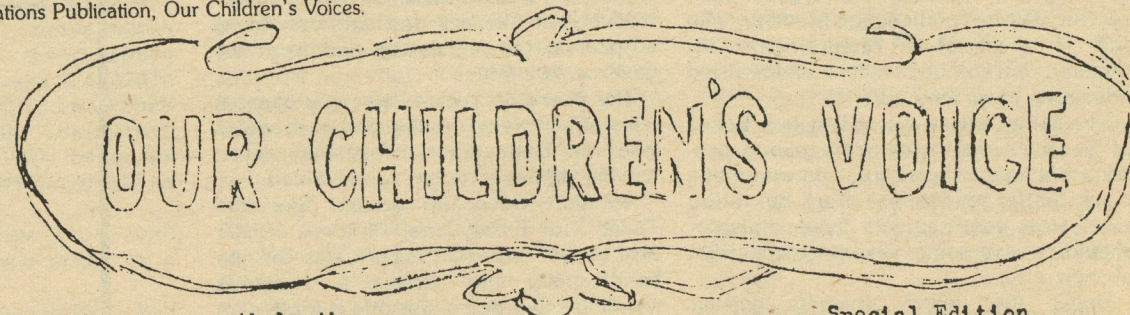
AHRC Chronicle 35th Anniversary 1949-1984

Convention 1984

Double Anniversary NYSARC and AHRC and the 35th Anniversary of Our Children's Voice

All reports confirm that our 1984 in Binghamton was a success. It joins us in thanking our Broomfield hospitality as well as their excellent

The first issue of the first AHRC Publication, the forerunner of the Chronicle and the State Associations Publication, Our Children's Voices.



Issued once a month by the
Association for the Help of Retarded Children, Inc.
Chartered by the State of New York

Special Edition
March 18, 1949
Vol. 1 No. 1

Editor-----Eugene J. Gramm
Co-Editor----Joseph T. Weingold

Acting President
Julius Schwartz

RETARDED CHILDREN CAN BE HELPED

TO OUR MEMBERS:

THIS IS YOUR NEWSPAPER(!)

With this first issue we inaugurate the official organization-newspaper. You will receive this paper about once a month, usually through the mails. There is no subscription charge contemplated at this time.

OUR CHILDREN'S VOICE will try to live up to it's name in every respect, giving full expression to the problems and rights of the mentally retarded. In addition, these are other important objectives:

1. To carry the news of the progress and direction of our organization directly to its members.
2. To give our membership a voice in the policy-making affairs of its association, and to keep members in close unison and contact between meetings.
3. To keep our membership posted on new developments in the fields of medicine, education, and training of the mentally retarded; as these developments are made known to us in newspapers, magazines, or through personal contacts.

The success of this newspaper depends to a large measure, upon you. We want you to write us material to be printed in these

CONCERNING:

OUR GUEST-SPEAKER THIS EVENING.

Dr. Lloyd Yepsen, in the opinion of the editors, is one of the most eminent authorities on mental deficiency...and one of the most stalwart champions of our cause. His many important writings are read with keen interest by members of his profession, and others interested in all phases of this subject. Though most of us are familiar with his background and position...it bears repeating:

He is immediate Past-President of the American Association on Mental Deficiency and at present, Executive Vice-President. He is Director of Division Classification and Education for all institutions and agencies in the State of New Jersey, for which he is Chief Psychologist. He is Secretary for the International Congress on Mental Deficiency. He is in the Research Department of the Training School of Vineland, New Jersey. Some years ago, he established the first special classes for the mentally retarded in Chile, South America. Having taught at a number of universities, he is at present teaching in the Graduate School of the New York University.

The title of Dr. Yepsen's talk this evening is "The Retarded Child in Society".

what we mean by "normal" parents? And what do "normal" parents achieve in the development of their children?

It is obviously impossible for the parents of mentally retarded children to be "normal" parents in the sense that their lives and attitudes towards their children can ever become smooth flowing, with the ordinary cares and problems of normal growth, development, etc. In fact, I am not sure that a completely so-called normal attitude towards their children would be a good thing. The normal attitude of society towards these children has resulted in crowded institutions, inadequate training in our school systems, and an utter lack of guidance on the part of competent authorities. No. Our children need more than a normal attitude on our part; they need more than normal solicitude, care, and concern for their education and future.

Ours is, however, a two-fold problem; our attitude towards society in addition to our attitude towards our children. These problems are not simple; they are as complicated as our lives, our backgrounds, our homelife, our education, - in fact, everything about us. But here are some things we can try to achieve to make our task easier and more "normal".

First, our attitude towards society. I say this advisedly. We are all too prone to think that society has cast us out, looks askance upon our children, talks about us behind our backs. I will not deny that some of this takes place. But in all truth, on careful self-examination, don't we find all too frequently that with the first shock of diagnosis, in the terrible emotional beginning, we withdraw from our friends and our families? Don't we feel that every passerby in the street is staring at us? Don't we tend to retire to the little fortified island of our homes, away from prying eyes and whispering tongues? This may be "normal" for us at the beginning, but it must not continue, because a continuation of this attitude towards society will influence our attitude towards our children to their detriment.

This brings us to our attitude towards

our children's betterment and security. In other words, we must be a part of society, not merely parents of retarded children. This is a healthier attitude. The terrible tensions will be eased; we will be able to appraise our children's possibilities realistically and work within that framework; we will not push them beyond their abilities; we will not smother them with affection one minute and have our disappointments show the next.

It all adds up to this; our attitude towards our children must be on an even keel and realistic, but with undiminished hope. Don't think for one minute that our children do not feel our stresses and strains and react to them. By the same token they will also feel the change in us and become better adjusted little individuals, - yes, more normal, if you will, in their behavior patterns. We must conquer ourselves to help our children. And under any circumstances, we must continue to believe in them.

J.T.W.

ODDS 'N ENDS.

One of our members suggests that we have a warm-weather outing with our children this spring. "We can take in Van Courtland Park, Prospect Park, or the Palisades," he suggests...Take in? Take over would be more like it! However, it is a good idea, worthy of more consideration. What about it?

Another of our members, in light-hearted moment, comes up with a nickname for our little ones. He calls them "Tardies"... Better late than never, we presume.

PHILOSOPHICAL THOUGHT: Who is it that's really slow--is it our kids, or is it the world, in understanding them?

POETRY CORNER BY E.G.
THE RETARDED CHILDREN

Listen! We hear them calling through the night!

CHAPTER NEWS...

What our Chapters are doing for our children and adults

ALLEGANY COUNTY ARC started a program for its elderly individuals in September. The goal of the program is to create an innovative program for the aging developmental disabled adult in our Day Training Program.

Through cooperative planning and guided participation in a structured leisure program, Allegany ARC anticipates the gradual integration of our seniors into the senior functions in the surrounding communities.

Each day, our small group participates in a comfortably structured, totally flexible program which is designed to encourage active participation in senior-tie activity. Activities such as going for a ride, shopping, visiting friends, going out for lunch, and even a trip to the hair salon encourages individuals to relax and enjoy the transition as a senior citizen.

AN ALLEGANY THANK YOU

I would like to thank the New York State ARC Christmas Card Judges for selecting my Christmas design. I was thrilled to have won first prize in the 1983 Christmas Card Contest. I would also like to thank Diane Loper for assisting me with design and the Steuben County ARC for printing the Christmas Card.

Many of my friends, colleagues, and neighbors have purchased my Christmas cards, and I would like to thank them and wish them all a very Merry Christmas. Thank you.

Sincerely,
Jim DeVore
ALLEGANY COUNTY ARC, INC.

FULTON COUNTY

In October, Lexington Center (FULTON COUNTY CHAPTER) hosted an eight hour radio program on local Johnstown station WJZR.

Lexington Radio Day, arranged as a public service by the station, gave Lexington

**CAYUGA CHAPTER DEDICATES
NEW FACILITY**
"COMPLETION OF THIS CAPITAL
PROJECT ENABLES US TO EXPAND OUR
PROGRAMS AND SERVICES AND TO PRO-
VIDE SERVICES FOR AN ADDITIONAL 100
PLUS CLIENTS."

ANTHONY J. TERRANOVA, JR.
EXECUTIVE DIRECTOR

On Sunday, November 11, 1984, the Board, membership, employees and staff of the Cayuga Chapter held a double-barrelled celebration. Combining the dedication of its new facility and its 31st anniversary celebration as a Chapter of NYSARC was a gala event.

The November 11th date marks to the day a six-year effort to acquire expanded space via a new building. The pre-engineered steel and brick building allows for 22,000 square feet of new program and production services for an additional one hundred disabled residents of Cayuga County.

A sincere thank you to the following organizations who participated in a rather complex financing plan: Security Trust Bank of Auburn; U.S. Small Business Administration; U.S. Urban Development Action Grant Program; City of Auburn; N.Y.S. Job Development Authority; N.Y.S. Office of Mental Retardation and Developmental Disabilities; Industrial Development Foundation of Auburn, N.Y.

Board members, staff, and community leaders a chance to explain the Center's programs to the listening public.

Also discussed were their abilities and potentials of people with handicaps and the history of ARC programs in New York State and Fulton County.



CAMP CRAFTS — Children at the Columbia County ARC day camp in West Copake make crafts. They were taught by Mary Sapp and Helen Bazonski with counselors Alan Macher and Laurie Jackson. (Register-Star photo by Virginia Jonas)

COLUMBIA

COLUMBIA COUNTY ARC has found a "permanent home" for its summer children's day camp and adult camp at Upper Rhoda Pond here, and work is in progress to make part of the new site a year-round community residence.

The planned community residence is "a really nice next step for us as an agency,"

said Director of Program Operations, Lisa Gasstrom. The setting at the old Flamingo Motel off Rte. 7 in West Copake will be less restrictive than other community residences and will not provide as much structured activity — geared toward higher functioning clients, she explained. It will represent an "in between point from community residence to independent living."

DUTCHESS COUNTY

DUTCHESS COUNTY CHAPTER ARC invited everyone to tour their facility during the Presidentially proclaimed National Employ the Handicapped Week.

The tour was Manu-Corp's way of saying thanks to the business community who have found that by using Manu-Corp's quality services, they have reduced costs and increased profits. At Manu-Corp., developmentally disabled employees earn wages commensurate with their abilities by performing sub-contracting work for industries. Highlighting the week's events was a reception on Wednesday, October 10th, at the workshop in the LaGrange Industrial Park.

At that time, refreshments were served and Dutchess County Executive, Lucille Pattison, presented Linda P. Smith with a coordinated proclamation proclaiming the week "Dutchess Employ the Handicapped Week." The proclamation states, "All across our country, disabled people are striving to obtain their control over their lives to choices that minimize their reliance independence; they are taking charge of their own lives and becoming responsible for their own affairs, participating in the day to day life of their communities and fulfilling the whole range of social roles possible in our society."

According to Executive Director, Linda P. Smith, "One of the reasons the shop was open to the public and private sectors was to let people know that we are here, that we have services that can be performed for

industry and that we are providing training and employment to individuals with a wide variety of disabilities." She continued to say, "We are proud of our competitive pricing, excellent quality control and guaranteed on time deliveries for services such as blister sealing, shrink wrap, skin packaging, assembly, bulk mailing and storage warehousing."

According to Smith, "It has been demonstrated in recent years that the retarded and the handicapped can be trained to work productively, that they have skills that can be refined, that they can be useful citizens in our communities."

Linda Campbell, Marketing Director for Manu-Corp., commented that "Being able to work and receive pay also makes the handicapped worker happy and adds to their self-esteem."

Earlier this year, the workers at Manu-Corp. had been trained on the assemblies of a variety of fluorescent lighting fixtures and lamps. This operation is being expanded from 50 trained workers to 100 or more individuals. Each quality inspector supervises a line of 6 to 13 workers to insure customer quality specifications. At first, individuals are trained on a specific task. As they become more proficient, they take on another step of the operation. Quality inspectors also rotate the positions of the workers so that absenteeism never effects the production rate or quality of the fixture assemblies. Linda Campbell added, "We celebrate Employ the Handicapped Week every day at Manu-Corp."



Fulton ARC President, Judy Schelle, discusses Children's Services with Program Director, Sue Lyons, who recently joined NYSARC Staff as Public Information Coordinator.

CHAPTER NEWS Continued....

CLINTON COUNTY

The Plattsburgh Rotary Club has donated \$1,000 to the CLINTON COUNTY ASSOCIATION FOR RETIRED CHILDREN (ARC) for its summer recreation program.

The special program will run July 16 through August 17 at four sites in Clinton County, for developmentally disabled youngsters. The \$1,000 gift goes towards a total of \$3,200 that ARC must raise to match a \$15,000 grant from the Developmental Disabilities Planning Council.

The money will be used for equipment, transportation and staffing this new summer program.

In addition to the donation from Rotary, ARC has also received donations from the Ellenburg Kiwanis Club, the Morrisonville Knights of Columbus and the Lyon Mountain Knights of Columbus.

But according to Michael Conine, Assistant Executive Director of ARC, the agency still needs to raise about \$2,000.

The agency is now taking referrals for this summer program, and by July 4, should have everything "ready to roll," Conine said. The program is open to all developmentally disabled youngsters in Clinton County; however, because of limited resources in its first year, only a certain number will be chosen.

PERFECT ATTENDANCE RECORDS CONTINUE TO SOAR!

The Work Activity Center of NIAGARA COUNTY ARC had initiated "perfect attendance" incentive program, which has become extremely successful. "In the past several months the number of individuals who have achieved perfect attendance in the workshop have far surpassed our initial objectives" said Don Propeck, Vocational Rehabilitation Coordinator. "We are now preparing for a quarterly report and I am sure we will be equally amazed at the results," Mr. Propeck said.

The program works like this: every month individuals with perfect attendance are awarded a small prize and a certificate.

These individuals became eligible for a quarterly prize based on their attendance for the remaining months of the quarter. The first quarterly prizes are to be awarded this month. The enthusiasm and attentiveness that the program has generated continue to be remarkable.

ONEIDA ARC

ONEIDA ARC reports that Progress Industries is flourishing and had made employing the handicapped a focus of their energies. This Utica affiliate of Oneida ARC feels that when you see the happy wage-earner employees leaving their facilities each day you know the program is successful.

DO YOU KNOW SOMEONE WHO IS NOT RECEIVING OUR CHILDREN'S VOICE?

Please tell that person to send a postal card with name and address to:
Computer Membership Listings
St. Lawrence Chapter ARC
Herkon, New York 13652

MONTGOMERY ARC

MONTGOMERY COUNTY ARC will probably be the final tenant in the new Theodore Roosevelt Apartments in Amsterdam, New York.

A proposal by ARC Executive Director, Frank M. Capone, calls for the leasing of the one remaining handicapped apartment in the 68-unit building for use as a respite center.

Capone presented his idea to the Amsterdam Housing Authority, the organization which manages the apartment building located on Wall Street.

Capone said the one-bedroom apartment would be used by his organization to provide a supervised temporary living space

for handicapped people who are normally cared for by their family. The temporary arrangement would allow the family members to vacation or participate in other activities that would be hampered because of the needs of the handicapped family member, he said.

The apartment, which is specially built to provide access for wheelchair-bound individuals, would be staffed on an as-needed basis, Capone said. The ARC would rent the apartment on a full-time basis, and would pay the full \$448 per month rent, he said.

The ARC currently has only one respite facility available, and the additional apartment would be "a big stopgap," Capone said.



This year's Membership Luncheon, held by Nassau AHRC, was attended by about a thousand women who enjoyed a box lunch and a fashion show previewing winter styles. In the photo, Helen Kaplan, Executive Director and a founding member of the Nassau Chapter, addresses the group. Mrs. Kaplan has announced that she is planning to retire at the end of the Nassau AHRC fiscal year in June.

RENSSELAER CHAPTER

ARC Chapters around our state have claimed for years that community residences can be an asset to their neighborhood. In October the Rensselaer County Chapter ARC received formal recognition of this fact, when its new community residence at 4 Biscayne Boulevard in Troy was presented a Beautification Award by the Greater Troy Chamber of Commerce.

The new ARC residence was opened in February, 1984 and was constructed with funding from the Section 202 Program of the Department of Housing and Urban Development (HUD) and Community Facilities funds from OMRDD. Even though the program will operate as a community residence, the facility meets the more stringent building codes required for residents who are not able to pass a "self-preservation" test. The building was also designed without architectural barriers to accommodate residents who are non-ambulatory and takes advantage of a number of solar heating features.

In commenting on the award, Rensselaer ARC Executive Director James Flanigan stated: "this recognition by the Chamber of Commerce is well deserved by a number of parties. Our architect, Jim Sidford, designed the residence to meet the various building code requirements we face and still provide our residents with an attractive home atmosphere. Our builder, Zandri construction, and our clerk of the works, Ernie Mssier, brought the project in on time without any costly change orders. Finally, the Board of Directors and staff of the Rensselaer ARC deserve a lot of credit for sticking with the project through years of red tape and frustration. Karen Myers, who was our Director of Residential Services during most of the project, and Mark Pattison, who took over when Karen joined the State ARC staff, deserve particular credit for countless hours of extra effort in addition to their day-to-day duties with the agency. To all of us the real reward came in seeing the residence become home for eight mentally retarded adults. The award from the Chamber of Commerce was like icing on the cake."

SENECA COUNTY

SENECA COUNTY CHAPTER this year was host for the Second Annual Five County ARC Dinner Dance in the Finger Lakes, the other participating chapters being those of Ontario, Schuyler, Wayne and Yates counties.

The evening's keynote speaker was NYSARC's immediate past president, Irene L. Platt, Esq., who now serves as a Commissioner on the NYS Commission on the Quality of Care for the Mentally Disabled. Commissioner Platt spoke on the vital role played by parents and other family member / advocates in the establishment and development of services for their disabled relatives; she stressed the need to remain actively committed in order to insure the continuation of needed services.

Seneca Chapter has added a vocational training program in food service support at the Seneca Army Depot, a service administered through the National Industries for the Severely Handicapped (NISH). The chapter is also negotiating to open a sheltered workcenter in January 1986, a critically needed program which does not currently exist within the county. The pressing need for this service was well documented by results of the Identification Program of DD persons in Seneca County, a survey of individuals and their needs conducted by the Seneca ARC earlier this year.

SARATOGA COUNTY

SARATOGA COUNTY ARC was recently granted a Certificate of Qualification from the National Industries for the Severely Handicapped (NISH). Deborah Kinderman, Director of Facility Operations, explains that the certification qualifies the A.R.C.'s sheltered workshop program, Alpha Industries, as a non-profit agency for the severely handicapped under the provisions of Public Law 92-28 and, therefore, eligible to participate in the Javits-Wagner-O'Day Program.

The Javits-Wagner-O'Day Act created, as part of the Executive Branch, the Committee for Purchase from the Blind and other Severely Handicapped. According to Irene Dembo, Director of Commercial Operations, the purpose of the Committee is to direct the procurement of selected commodities and services by the Federal Government to qualified workshops.

Presently, more than half of the Public Buildings Service regions have one or more

contracts with sheltered workshops. The objective of the Act is to increase employment opportunities for handicapped persons, thus preparing them for competitive employment.

NISH is a central non-profit agency which assists workshops seeking contracts with the Federal Government. Two major services are provided by NISH. One is technical assistance to any workshop trying to develop its contract production capabilities. The other is liaison to Government procurement groups for identifying contract possibilities for workshops and then developing them.

Alpha Industries strives to train and place handicapped individuals into competitive jobs. The Javits-Wagner-O'Day Act certification should assist placement by providing more jobs for training. When given the opportunity, handicapped individuals can lead productive, self-supporting lives.

Employer Of The Year 1984

**Kay Nogaj, Chairperson
Scholarship & Awards
Committee**

One of the highlights of each convention is the awarding of a plaque to the NYSARC Employer of the Year selected with difficulty (because of the close competition) by the NYSARC Scholarship and Awards Committee.

1984 Employer of the Year was nominated from Westchester ARC. He is Jack Danenberg, Food Service Director of the Westchester Community College Cafeteria. In awarding Mr. Danenberg, Kay Nogaj, Chairperson of the Scholarship and Awards Committee commented "Mr. Danenberg was nominated by the Westchester County Chapter and selected by NYSARC for his meritorious and outstanding efforts on behalf of persons who are mentally retarded and employed by the college.

The Westchester Community College has been used as a successful work experience site for preparing clients for competitive employment. Jack Danenberg has been instrumental in developing and nurturing the necessary work skills in the workers.

Mr. Danenberg has been and continues to be involved in community affairs and has demonstrated a strong and vital commitment to the mentally retarded. His caring, unselfishness and willingness to work cooperatively with the staff and clientele at the Westchester Chapter has earned him the respect and recognition he deserves."

Other nominees who received certificates of appreciation were: Holiday Inn of Auburn — Nominated by Cayuga County Chapter, Auburn, N.Y."

Holiday Inn presently employs 100 people including 7 workers who are mentally retarded and working as dishwashers, night porters and banquet assistants. In addition to the affirmative posture, the Holiday Inn has assumed regarding hiring practices. This company has consistently demonstrated a willingness to "go the extra mile" when working with the chapter staff and clientele.

The Holiday Inn allows for advancement into more challenging positions and restructuring of job responsibilities wherever necessary. Accepting the certificate was Anthony J. Terranova, Executive Director of Cayuga Chapter, ARC.

Also Ward Lumber Company — Nominated by Clinton County Chapter, Plattsburgh, N.Y. This firm presently employs a total of 80 people including one worker who is mentally retarded from the Chapter. This individual is currently engaged as a carpenter's assistant whose duties include: assisting carpenters, operating a circular saw and performing maintenance duties. This employer has assisted the worker in developing appropriate work habits and attitudes in addition to promoting positive relationships with co-workers.

With guidance and much time and effort in the part of the Ward Lumber Company, this individual who is mentally retarded has established himself as a self-supporting employed member of his community. Accepting the certificate: Janet Calkins, Board of Governor Representative from Clinton ARC.

Garcia's Irish Pub was nominated by Erie County Chapter, Buffalo, N.Y. This establishment presently employs 70 people including six workers who are mentally retarded and employed as dishwashers, building maintenance mechanics and assistant stock supervisor.

Garcia's Irish Pub, has displayed a desire to further develop and increase

competitive work skills for its employees in order to promote positive self images regarding competencies.

All restaurant personnel seem to demonstrate a genuine interest in the Chapter's clientele. This is evidenced by the encouragement they receive in order to be more productive and learn quality job skills that may facilitate their potential for further employment growth. Accepting the certificate was Winifred H. Morrison, PH. D., Executive Director of Erie Chapter.

A. J. Swift L.T.D. was nominated by Monroe County Chapter, Rochester, N.Y. This business employs 11 people including three individuals who are mentally retarded and working as floral arrangers. A.J. Swift, Wholesale Distributors Corporation has been an ongoing contractor with the Monroe Chapter's Sheltered Workshop Program and continues to offer opportunities for employees to increase their work skills. The Chapter and A.J. Swift have developed a mutually cooperative and positive relationship which has benefited both clientele and staff. Accepting the certificate of A.J. Swift L.T.D. was Gidget Hopf, Assistant Executive Director of Monroe ARC.

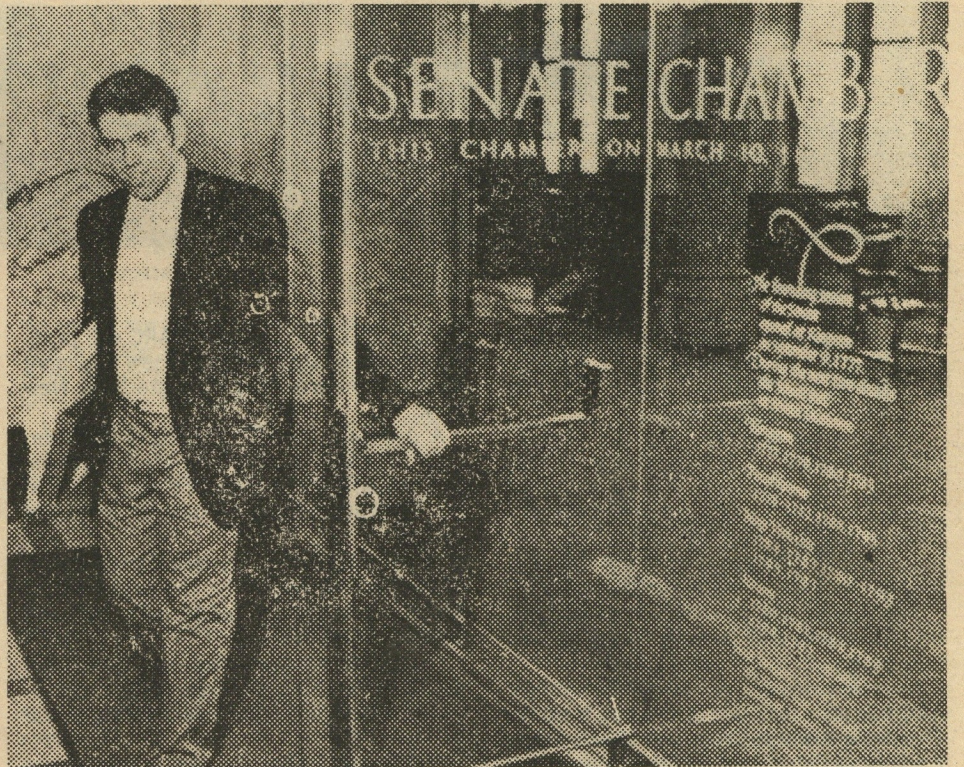
Mr. Henry Kalfas, Niagara Falls Chamber of Commerce was nominated by Niagara County Chapter, Niagara Falls, N.Y. In his role as chief executive officer of the Niagara Falls area Chamber of Commerce, Mr. Kalfas has been instrumental in the development of numerous job openings for the Chapter's clients with other employers in the community. Mr. Kalfas has been a strong client advocate and has been instrumental in developing workshop sub-contracts, assisting in fund raising, promoting public awareness of the mentally retarded and the goals and objectives of the Niagara County Chapter. Accepting the certificate was Kenneth Ford, President.

Ramada Renaissance Hotel — nominated by Saratoga County Chapter, Ballston Spa, N.Y. The hotel employs four workers who are mentally retarded in the capacity as dishwashers, a porter and laundry worker. The personnel at the recently opened hotel and convention center have worked closely and cooperatively with the Chapter staff in finding jobs for the clientele and they have consistently offered their support. Accepting the certificate was Barbara Sherwood, Director of Vocational Services, ARC.

Rual Manufacturing, Inc. was nominated by Columbia County Chapter, Mellenville, N.Y. This firm presently employs 100 individuals including four workers who are mentally retarded and working as bench assemblers. Description of some of the required duties consists of assembling electric vaporizers and humidifiers.

Rual Manufacturing, Inc. has consistently displayed a positive attitude towards its workers and has demonstrated its commitment in working cooperatively with the Chapter staff and clientele.

McDonalds of Delhi-Sidney was nominated by Delaware County Chapter, Wilton, N.Y. This business currently employs 20 people including one worker who is mentally retarded and engaged in preparing various foods, cleaning and stocking supplies for this food operation. Through these work station arrangements, these individuals have received valuable training experiences and have greatly benefited from the opportunity to secure regular employment. Accepting the certificate was Michael Morgan, Board of Governor Representative.



Messenger Richard McDonald leaves the New York State Senate lobby at the Capitol in Albany. The state legislature's messenger service employs 17 retarded and five physically handicapped people. Syracuse Herald American

1984 Retarded And Handicapped People Work For Legislature

**By David Egner
Associated Press Writer**

ALBANY — They are the workers few employers want, suffering from mental retardation or physical handicaps that can make job junting a nightmare.

But sometimes even nightmares have happy endings. At least that's been the experience of the 17 retarded and five physically handicapped people who work for the New York State Legislature's messenger service.

"There's nothing to do if you don't have a job, and this is a good job, interesting," said Richard McDonald, 32, a mildly retarded messenger who said he's proud to be able to work.

"This is an opportunity of a lifetime," said Robert Pollock, 33, also mildly retarded. "You meet different people and you learn different things every day, and you can support yourself."

No other state legislature runs a messenger service staffed by the retarded and handicapped, "but others should because it could work well elsewhere," said Michael Stumbaugh, job training director for the national office of the Association for Retarded Citizens.

There are about 3.6 million mildly retarded adults in the United States "and the vast majority of them want to work hard and get a job, and are capable of working," Stumbaugh said in a telephone interview from his office in Arlington, Texas.

However, he said the unemployment rate among the mildly retarded is about 25 percent.

Some of those who work hold jobs in

workshops for the retarded that pay less than minimum wage. The rest earn about \$7,000 a year as janitors, dishwashers, maids and in similar service positions, Stumbaugh said.

In contrast, the 18 messengers and four dispatchers who send them on their rounds for the New York Legislature earn \$9,100 to \$13,000 a year, said Louis Russo, who directs the messenger service.

The New York messengers, two of whom are deaf mutes, carry reports, memos and legislative bills across the more than 10.4 million square feet of state office space in the Capitol and the adjacent Empire State Plaza complex, linking the 211 state legislators with their staffs and other state officials.

In 1983, the messengers carried 83,795 items, Russo said.

"These people are terrific workers. They don't take days off unless they're really sick. They can learn and excel if they're supervised properly and given work not beyond their ability," Russo said.

The messengers are given assignment slips that tell them where to pick up an item and a code name for the building, such as 423 LOB for the Legislative Office Building. People sending and receiving such item must sign the routing slip.

One employee who has cerebral palsy and two wheelchair-bound employees work in the office as dispatchers.

"Once you hire these people, they're loyal and they stay with the job for a long time," Russo said. "The people find these jobs enjoyable and interesting."

Syracuse Herald American

Keynote Speaker Familiar To NYSARC

Robert Perske, novelist and commentator well known to disability rights advocates gave the keynote address and set the stage for considering the challenges and benefits of an America where all citizens have a means of participation at the Eleventh Annual Conference of the Association for Persons with Severe Handicaps (TASH) in July.

Perske, a well known author of books dealing with the many ways parents, families and friends can overcome their fears and inhibitions in regard to persons with disabilities and his wife, Martha Perske, a free lance artist whose work has appeared in several books dealing with the mentally retarded has recently published two new paperbacks.

The first titled "New Life in the Neighborhood" is filled with actual, documented cases of cities where persons with handicaps have moved into neighborhoods and have helped these good communities to become ever better.

The second "Hope For the Families" looks at various practical topics such as changing world views, theology, human dignity, sexual development and family systems.

Both books may be purchased at your local bookstore or ordered directly from Abingdon Press, 201 Eighth Ave., South, P.O. Box 801, Nashville, TN 37202 at a cost of \$4.95 for "Hope For the Families" and 15.95 for "New Life in the Neighborhood".

CHAPTER HAPPENINGS



NIAGARA COUNTY ARC VISITS HARRISON RADIATOR

Several clients from the Niagara County ARC were invited to tour the Harrison Radiator Company. Pictured above are Jackie McGrath, Mike Setlik, (Case Manager), John Andropolis, Anthony Cafaro and Harrison employee.

Presidential Commendation Presented To Madison ARC

By Representative George C. Wortley
THE WHITE HOUSE
Washington

Dear George:
August 16, 1984

I want to commend the Madison County Association for Retarded Citizens and all the people of Madison County for organizing the World's First Onion Olympics.

I'm sorry that I can't be with you for this event, but some of my advisers just didn't like the idea of my attending a competition that includes such breathtaking sports as raw onion-eating and breath throwing.

Thank you for sending me the Onion Olympics shirts, and please convey my deep appreciation to all who have worked so hard in organizing this event. Their compassion

for others, creativity in meeting challenges, and determination to accomplish their goals exemplify the greatness of the American spirit. Because of their efforts, the retarded citizens of Madison County will know that they are welcome as friends and neighbors in the community.

Nancy and I send you and everyone participating in the Onion Olympics our best wishes for every success.

Sincerely,
Ronald Reagan

The Honorable George C. Wortley
House of Representatives
Washington, D.C. 20515

Little Change For Handicapped Youth

Little has changed for Joey DeLillo in the past few months.

The 21-year-old Great Kills resident, who suffers from a rare behavior disorder, graduated from the Richmond Occupational Training Center in June and is now employed at a workshop for the handicapped. But he is still in temporary housing at Staten Island Developmental Center awaiting permanent placement in a group home.

His mother still cries at night wondering what will happen to her son.

Anne Seery, an aide to state Assemblyman Robert Stranieri and an advocate for the DeLillos, is still frustrated in her attempts to resolve Joey's plight.

Joey's story was chronicled by the Staten Island Advance in a three-part series published in April. The series told about Joey's disorder, Prader-Willi Syndrome, a rare dysfunction of the central nervous system which causes mental retardation, physical immaturity, emotional disturbances and an insatiable appetite.

Prader-Willi victims have a tendency toward gross obesity and problems like diabetes and heart disease. Their life expectancy is very short. People who have had experience with the syndrome say the only hope for Prader-Willi victims is to put them in a controlled environment which limits their access to food.

Joey's parents have spent several years trying to find such an environment for their son, but because of the unique problems posed by the syndrome, there are few options available.

Moreover, the state agencies involved — the state Office of Mental Retardation and

Developmental Disabilities (OMRDD) and the Committee on the Handicapped, a division of the Board of Education — could not come to agreement on the proper place for Joey, and that prevented his placement in a special school for Prader-Willi victims. Now that Joey has passed his 21st birthday, he is too old to enter the school.

When the series was published in April, Joey had been living at SIDC's repite center for six months, although the center usually takes clients for a maximum of two weeks. This spring, officials said they were discussing where Joey was to go. One OMRDD official optimistically predicted that Joey would be in a group home by summer.

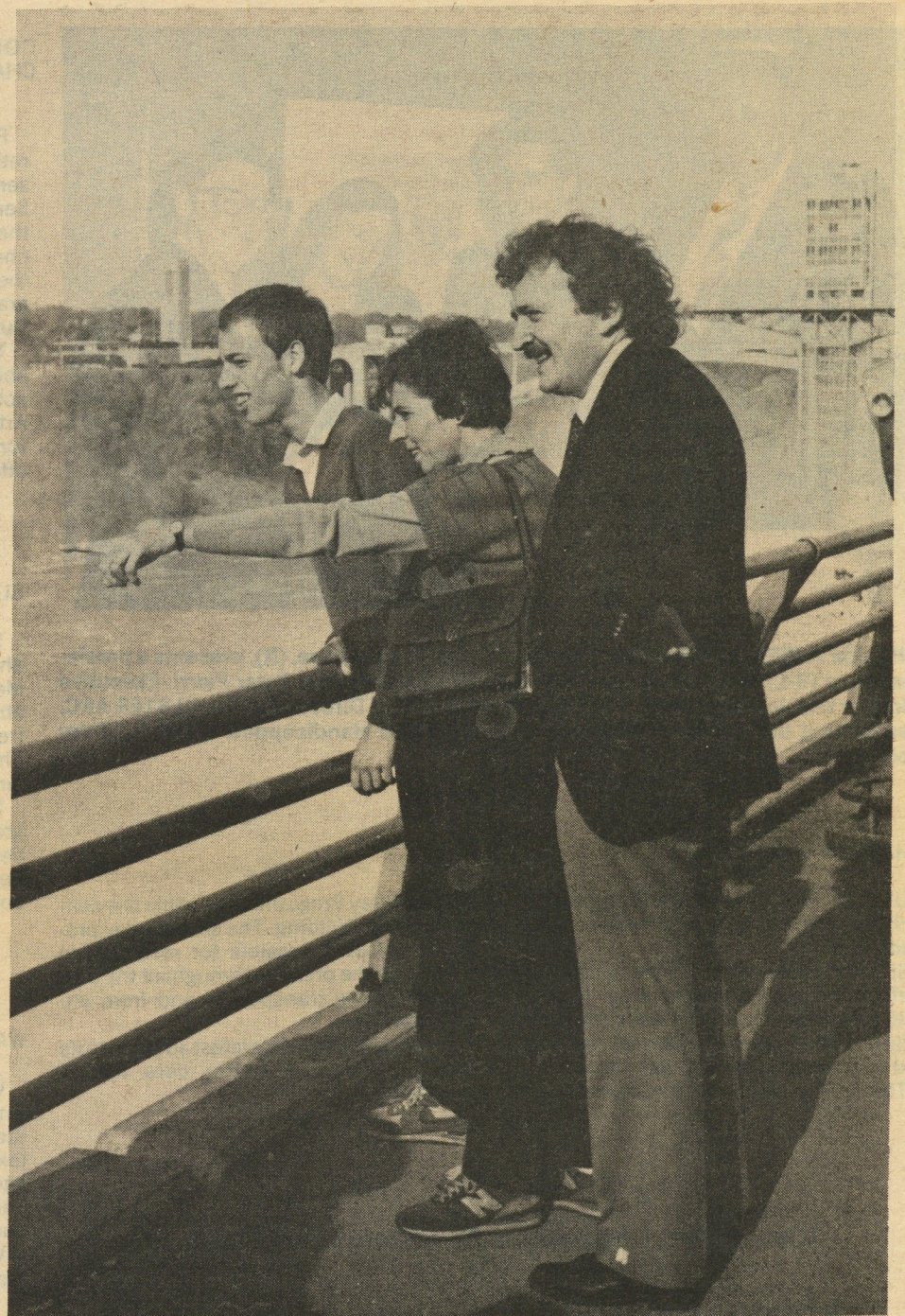
That hasn't happened. Joey is still at SIDC. His mother and Anne Seery say there has been no word on Joey's permanent placement for several months. "I just wrote a letter to (OMRDD Commissioner) Arthur Webb, asking him what's going on," Ms. Seery said. "You really have to keep after them. I've been batted around from one person in the agency to another."

Mrs. DeLillo says Joey is happy at SIDC. "They are very good to him," she said. "I really can't complain."

She would like to see Joey stay there, although that is not an option. The lack of other options worries her. "I still cry," she said. "I get so upset about this. I think about Joey constantly."

— Staten Island Advance

Editor's Note: At this time (November 1984) it is reported that Joey is still residing at the Staten Island Developmental Center.



RETARDED RUNNER CAPTURES SPIRIT OF MARATHON

Martin Tester, Maria Goddard (his trainer), and Paul Cesana, Executive Director, Niagara County Chapter, Association for Retarded Children, Inc.)

London Runner Visits Niagara Falls

The winners of the New York City Marathon may have captured all the glory, but Martin Tester has undoubtedly captured the spirit of running. The 18-year-old British youth completed the grueling 26-mile-plus course in just over five hours. Nothing is special about the time. Smoothing is special about the runner.

Martin Tester is mentally retarded.

IN Nagara Falls on October 30th, with the cooperation of the New York City Chapter and the Niagara County Chapter of New York State Association for Retarded Children, Inc., a day visit was arranged for Martin, his mother, June, his trainer, Mrs. Maria Goodard, and her husband, Peter. Before flying home to London, Tester spoke of his love for running and his impressions of America while showing off the medal given to every marathon competitor. "I like running, I enjoy it," he said. "It's good and it exercises me as well." His mother was more specific. "Running has tremendously improved his concentration," she said. "Martin has a nice disposition and most people who meet him say that. He really enjoys life to the fullest."

Part of the enjoyment stems from running, which he began over two years ago under guidance of his trainer, running partner and former teacher Maria Goddard, who competed with Martin in New York.

The other part comes from his college classes at Southeast Technical College in London, where he studies subjects like wood and metal working.

Before competing in New York, Martin ran in the London Marathon and several half-marathons in England. His first race was a sprint run to raise money for a new swimming pool at his old school, Mazehill, where he met Maria Goddard.

"After that sprint, we noticed he had potential," his mother said. "So Maria, who had never run marathons before either, began training him and in 1983 ran in the London Marathon. He's won a lot of gold medals."

And the most important thing," Maria Goddard added, "is that this love for running comes from him."

CHAPTER NEWS — FULL REPORT



WILLIAM R. WEST, Chairman of the Ulster County Legislature, (R), presents a proclamation to (R-L) Mary Brady, Director of Vocational Services; Peter Pierri, Executive Director and Joseph Pecora, President of the Board of Directors of the ULSTER ARC, designating the week of October 7 as Employ The Handicapped Week in Ulster County.

A HUDSON VALLEY FIRST

ULSTER ARC opened the first Geriatric facility for the elderly and infirm in the Hudson Valley.

Situated on five acres of open terrain just north of Kingston, the building formerly housed a private school. It was completely refurbished to accommodate 26 residents and to provide all the comforts of home.

The facility combines a residential set-

ting with Day Programming within the confines of one building. The six hour day program makes it possible for residents to remain on the premise throughout the day, hereby saving transport to and from another facility.

UARC is proud of this latest addition to its ongoing policy of better care for all retarded.

Ulster ARC Charting A New Course In Therapy

By Nicholas J. Genna, M.A.
DTP Psychologist

ULSTER ARC has recently partaken in a pioneer programming venture bridging the gap between mental illness and mental retardation. The program is a sub-division of the Day Treatment Program, representing months of research and planning in a relatively uncharted area. Our target population are those clients currently receiving Day Treatment services who have combined diagnoses and/or symptoms, a major challenge and responsibility to us as mental health workers.

This population is not a new phenomenon but one that has gained recognition in the wake of the national deinstitutionalization movement when our understanding of the personalities and behavioral characteristics of the developmentally disabled has taken on a new urgency. It is a little known fact that the mentally retarded individuals experience mental illness at a higher rate than the general public, and can have all forms of mental illness, just as the non-retarded. Concomitantly, the professional community is ceasing to view client's behavior patterns and personality characteristics as solely symptoms of some genetically fixed disposition. Rather, clinicians are beginning to be convinced that our clients possess individualized personalities, strengths and weaknesses, that they have a distinct emotional life with many and varied pleasures, frustrations and problems, again just like the non-retarded. This new and vital perception of our target population is an integral part of the Co-existing Diagnosis Program.

We see these clients are possibly having a central nervous system impairment inherent in mental retardation but also as people who have a relative inability to understand the complex demands of their

culture, who have diminished opportunities to develop interpersonal coping skills and who not surprisingly have a rather low self esteem and a sense of "differentness." Such vulnerabilities as these equate with a higher risk of mental illness.

The focus of our programming has had to adjust to these perceptions. We continue to teach our clients the necessary adaptive skills they will need in society but our intervention strategy is more convert than a direct behavioral change. We wish to offer our clients some of the emotional opportunities they may have been deprived of in the past, we wish to listen to their fears and their fantasies. It is hoped that we might in this way increase their sense of their own worth and in so doing ease the route to normalization and adaptation.

The program offers challenge tempered by support. Our expectations are individualized for each client's individual pace. In a generalized sense we would be more than pleased if our clients got along reasonably well with their peers, if they had fewer overt manifestations of emotional disturbance, if they get close to utilizing their intellectual potential and if they were content for a reasonable portion of the time.

The program represents a young and developing concept which has not yet gained full support of many of my colleagues who hang on to the conviction that a dynamic therapeutic approach is not effective with the mentally retarded. I hope our success will challenge these reactionary beliefs; I invite them to come and see the laughter and tears of a client who is beginning to discover his own emotional life. It is hoped that the availability of such programming will expand to a greater number of clients in the future.

FROM ARC LIGHT, ULSTER CHAPTER

COMMUNITY LEAGUE — WASSAIC CHAPTER

President, Florence Siegel reports that retirement is anything but dull for the 23 senior citizens who attend the Whitehall Senior Citizens Program. Operated under the auspices of the Wassaic DDSO, Dutchess County Community Services Office, the program is the first senior citizens program for the developmentally disabled in Dutchess County.

The program offers developmentally disabled senior citizens an impressive array of activities: Exercise programs, Ceramics, Arts & Crafts, Photography and a Horticulture Program. Of all the program modules offered, the most visible is the horticulture

program. Initiated in 1982 with the assistance of a Developmental Disabilities Grant, the clients have learned how to grow plants from seeds and have nurtured an expansive vegetable garden.

At the 1982 - 1983 Dutchess County Fair, clients enrolled in the program won a total of six ribbons for vegetables they grew. Plants have also been used to produce craft items such as sachets, herbal wreaths, etc., which have been sold at the Whitehall annual Christmas Boutique.

The program currently has a maximum capacity of 30 clients.

SUFFOLK

SUFFOLK CHAPTER was issued the go ahead this September from the Office of Mental Retardation and Developmental Disabilities (OMRDD) to build a second barrier-free 48-bed intermediate care facility (ICF). The facility will be built on a 5-acre parcel of land in West Yaphank.

Executive Director indicated, "There is a great need for more of these types of facilities. The size of our waiting list clearly demonstrates this." Of the 98, 71 children and adults are from the community and

Long Island Developmental Center. At present they "attend day programs offered by AHRC, B.O.C.E.S. I, II and III and other providers. The remaining 27 applicants are in private residential schools, most located outside of New York State. As with the first ICF, the West Yaphank program will serve 48 children and adults who are severely and multiply-disabled, many of whom will be non-ambulatory.

The new facility is expected to be completed in the winter of 1985.

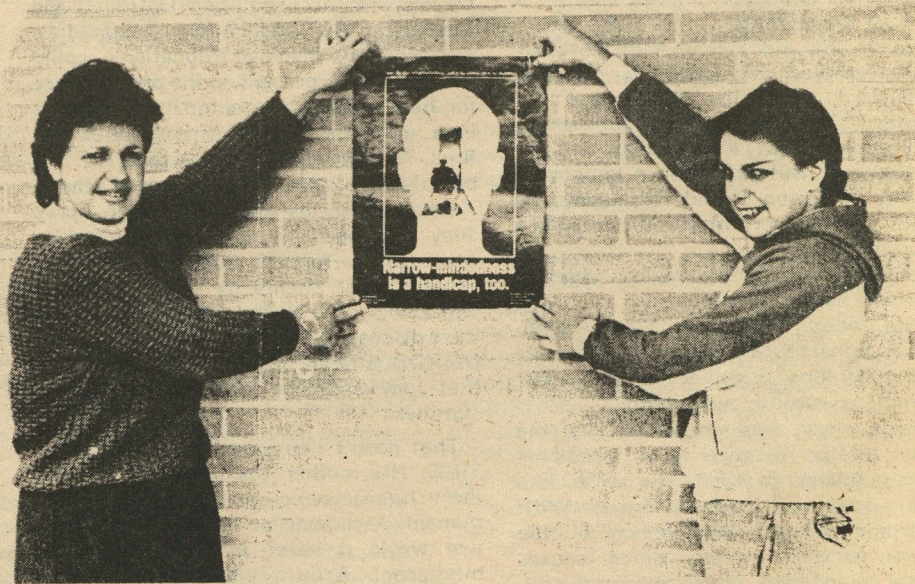
WARREN — WASHINGTON CHAPTER

WARREN-WASHINGTON CHAPTER has a new Executive Director, Stephen Holmes. Stephen replaced John Kemmer, who has taken a position with the State ARC management staff. John was toasted at several parties during the last week of September and will be missed by all.

WARREN-WASHINGTON CHAPTER also reports the opening of two new residences:

an ICF program for eight men and women in Ft. Ann and a barrier-free community residence for eight men and women in Hudson Falls.

The Chapter currently provides residential services for 55 individuals. In addition to all these above changes, the administrative offices have moved to a newly renovated space at 250 Ridge Street in Glens Falls.



To make the beginning of National Employ The Handicapped Week, St. Lawrence County ARC Placement Specialist Angela Fee, (above left), and ARC workshop client Judy Foster place a poster in front of the Ogdensburg ARC proclaiming that "Narrow-mindedness is a handicap, too." Photo by Ogdensburg Advance News

Gamma Delta Chapter of Sigma Alpha Iota music fraternity at the Crane School of Music at Potsdam College has become the most honored Chapter in the history of SAI. The Crane Chapter took three award including community action, outstanding musicale, and fraternity action.

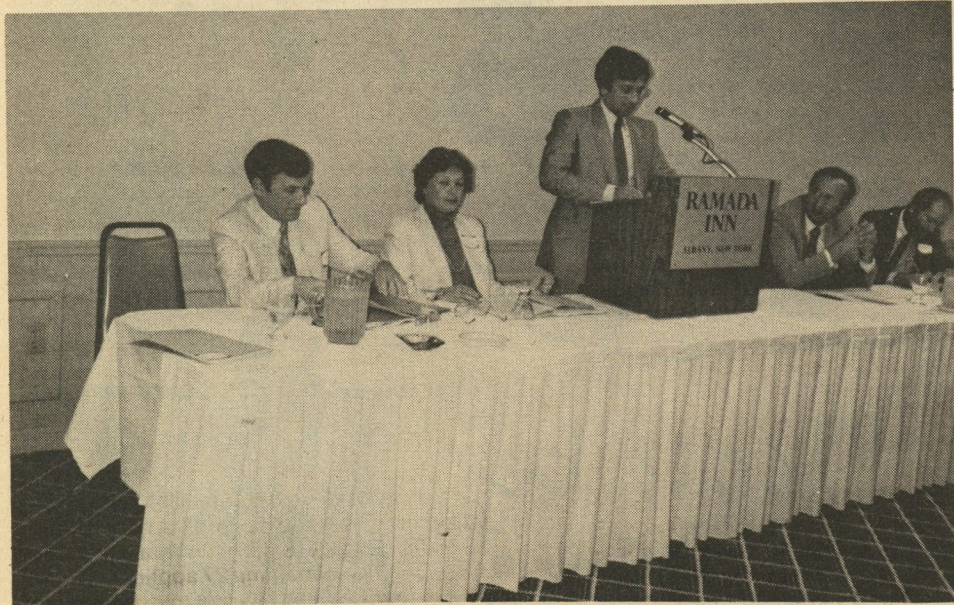
SAI President Helga Bodnar, a senior

voice major for Commack, N.Y., said that special commendation came for the community action program.

Each week SAI women visit the State Street Community Residence run by St. Lawrence ARC where they perform for residents and teach them about music, instruments and singing.

September Conference On Parents Effecting Change Stressed Positive Action To Erase Feelings Of Helplessness

An Airing Of Parental Issues Sponsored By NYSARC Developmental Center's Committee Focused On Parents And Professionals Working Together To Guarantee Least Restrictive Environment



Commissioner, NYS Quality of Care, Clarence Sundram advises parents and professionals on pitfalls in advocacy. Marc Brandt, NYSARC Executive Director, Bernice Volaski - Chairperson Developmental Center Committee, Chairman Clarence Sundram, speaking, and Kenneth Skrivancck, Human Services Consultant, (far right), Ira Gelinson, Schoharie ARC Director.

COMMISSION ON QUALITY OF CARE

Clarence Sundram, Chairman of the NYS Commission on Quality of Care amplified the role of the commission as he told the conference that "Most of the critical insights about the system have come from conversations with parents." Effective change in a system is the result of informed advocacy, the Commissioner said. Advocacy has its own procedures which define the role of the complainant and the role of the system responding to the complaint.

"Get and keep the respect of the people in the system by having your facts right" Commissioner Sundram warned "and make sure you are both talking about the same thing. This is most important."

There is a stereotype of parents as "too emotional to be objective" Commissioner

Sundram said. Parents have an obligation for the sake of effective advocacy to negate this stereotype. Define the problem with clarity and with facts to support your complaint. It is certainly true that parents have had difficulty in getting the facts but there the Commission can be of help. It is our stated goal to access facts through the procedures agreed upon. But parents should always remember that they are not supplicants asking favors but they are people endeavoring to live under a system with flaws — hence advocacy. Of severe importance, after registering a complaint, is the follow-up.

Never assume that because you have complained, you are done with the advocacy. In any interchange, confirm by letter what was agreed upon. If you don't, tomorrow's prices may undo today's promises.

past. Your allies in the system are other parents, outsiders, laypeople, clergy, groups which deal with rights. But the reality is that sometimes we must settle for half a loaf in impacting a large system. But this half a loaf is the plank to negotiate for future betterment, Commissioner Sundram summarized.

In his opening remarks Marc Brandt, Executive Director of NYSARC outlined past and present NYSARC impact on life in Developmental Centers. This impact is the result of an advocacy organization of over 40,000 members in New York State, Brandt said, including 1,000 Board Members at the Local level in Chapters around the state plus 7,000 employees supervised by NYSARC. This parent organization has a leadership role in legislation advancing the quality of care of residents in developmental centers and after they leave to go into the community. NYSARC analyzes for parents the monetary and staffing decisions which relate to this care.

NYSARC as an organization should assure society that developmental centers have an important place in the continuum of care of the mentally retarded.

DEVELOPMENTAL CENTER COMMITTEE ROLE

Chairperson Bernice Volaski told the conference that the NYSARC Developmental Center Committee had taken the responsibility to prioritize both the legislative goals (with reference to DCs) and the continuing update of quality of care issues and concerns as they emerge.

Currently the Committee will continue legislative action against co-location of prisons on the grounds of Developmental Centers. She related conditions in various developmental centers which have been documented. There is still a staffing shortage in some centers, she said, and that staff is not properly trained. There is lack of appropriate medical care and of proper supervision. The reporting of incidents, the very heartbeat of quality of care and its improvement is poor. Some centers do not yet have six hours of programming for each individual resident. There is an increase in gastric tube feeding; safety hazards still exist in the buildings and enormous amounts of paperwork interfere with the time given to actual client care, Volaski pointed out.

THE CHAFEE BILL

The Developmental Center Committee has reviewed in depth the popular Chafee bill which has received national recognition as a means of guaranteeing community placement for all institutionalized people in DCs. NYSARC supports this bill in part. We have some reservations, important changes to be recommended, having to do with funding and follow up support care.

Key To Recognizing Systems Flaws Is The Depersonalization Of The System Of Care. This Is Institutionalism

What any parent learns in confronting flaws in the health system is that an institution is not necessarily engaged in the flaws characterized by institutionalism —

Kenneth V. Skrivaneck, former Director for Citizen Participation Dept. Mental Hygiene and presently consultant in human services with occupational consultant services.

Advising parents about the roles they can take on to effect change as they deal with the problems such efforts present, Kenneth Skrivaneck asked for a commitment to an open system and participatory management. When institutions suffer from institutionalism, he said, the opposite of an open system and participatory management is in place. It is important to understand the difference. In an institutionalized developmental center the service is delivered in a depersonalized, even de-humanized way. Recognize that a developmental center is technically a removal from community life. Institutionalism can be harmful to those who receive the care and those who give it. Institutionalism is not limited to large systems, he added.

RECOGNIZING INSTITUTIONALISM

When the health system is the "Big Daddy" and you are looking at big, office, big car, big buildings, big home and closed social structure which feeds upon itself, analyzes itself for the outside world, is not subject to public scrutiny . . . with no decentralization of operations and a high investment in control of power — with no effective means to open the closed social system — you are looking at institutionalism.

When people in the system spend enormous amounts of time producing reports

which show they deserve outstanding ratings rather than giving their energies to client care — you are looking at institutionalism.

The opposite of this is the open system and participatory management. In this kind of institution, parents, families and even clients, where practical, have access to all levels of direct and indirect services. Councils, Advocacy Groups (like Developmental Chapters for instance) public hearings and public meetings describing changes being considered are all in place and functioning regularly. Parents and professionals work together in a partnership relationship to accomplish necessary changes.

It is very important for parents to take part in public hearings and public meetings. This kind of participation shows you are concerned and you will be on record as having said so. Then allow you to be a part of the decision making process in budgets, legislation and provision of services.

This kind of give and take gets results. It recognizes that people working in a bad situation are not going to have the means to change it — advocacy must be the structure to effect change. Parents must be the agents for change. You should ever recognize that your presence makes a difference.



All delighted with the interest shown at the "Parents Effecting Change Conference". Bernice Volaski, Chairperson of Developmental Center Committee (NYSARC), Joan Taylor, Rome Developmental Center, Julia Roberts, Syracuse Developmental Center and Karen Myers, Assistant Executive Director for Quality Assurance, NYSARC.

You Are Not Alone

For Parents When They Learn Their Child Has A Handicap

By Patty McGill Smith
National Information Center
for the Handicapped Children
and Youth

ON learning that their child may have a handicap, most parents react in ways that have been shared by all parents before them. One of the first reactions is that of denial — "this cannot be happening to me, to my child, to our family." Denial rapidly merges with anger, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Fear is another immediate response.

People often fear the unknown more than they fear the known. Having the complete diagnosis and future prospects can be easier than uncertainty. Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst that it possibly could be. There is also fear of society's rejection, fears about how brothers and sisters will be affected.

These fears can almost immobilize some parents. Then there is a guilt - guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for having done this? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?"

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?", many parents are also saying, "Why has God done this to me?". Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload.

Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's handicap. Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child is handicapped, yet parents want to feel competent and capable of handling their own life situations.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person. During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

SEEK THE ASSISTANCE OF ANOTHER PARENT

The first recommendation is to try to find another parent of a handicapped child, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent - Helping - Parent Programs. (Local chapters of NYSARC offer these support systems.)

TALK WITH YOUR MATE

Over the years, it has been discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life — your best friends, your own parents.

RELY ON POSITIVE SOURCES IN YOUR LIFE

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another might be a good friend or counselor. Go to those who have been a strength before in your life. Find the new sources that you need now. Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain.

TAKE ONE DAY AT A TIME

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Good things continue to happen each day. Take time to "smell the roses."

LEARN THE TERMINOLOGY

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the meaning.

SEEK INFORMATION

Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request accurate information. You should not be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child.

DO NOT BE INTIMIDATED

Many parents feel inadequate in the presence of people from the medical or educational professions because of their



High schools in Nassau County participated in the Nassau AHRC's fifth annual art/poster contest which had as this year's theme, "My World Is Small, Please Be My Friend." "Teach Me, So I Can Do It Myself" and "I Can Be A Good Neighbor, If You Will Let Me." One of the outstanding entries was submitted by Kim Leonardo from Massapequa, who tied for second place.

credentials. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is your child!

DO NOT BE AFRAID TO SHOW EMOTION

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how badly they are feeling. The strongest fathers of handicapped children whom I know are not afraid to show their emotions.

MAINTAIN A POSITIVE OUTLOOK

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is truly always a positive side to whatever is occurring.

KEEP IN TOUCH WITH REALTY

To stay in touch with reality is to accept

life the way it is. To stay in touch with reality is also to recognize that there are some things that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then to set about doing that.

AVOID PITY

Self-pity, the experience of pity from others, or pity for your child are **actually disabling**. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

RECOGNIZE THAT YOU ARE NOT ALONE

The feeling of isolation at the time of diagnosis is almost a universal feeling among parents. In this paper, there are many recommendations to help diminish those feelings of separateness and isolation. You can diminish these feelings by recognizing that they have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone!

— Reprint from Newsline,
Nevada, Utah

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