

# Our Children's Voice

Retarded Children Can Be Helped

VOL. XXXIII NO. 3

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

OCTOBER 1981

## Looking Back - Moving Forward

## 1981 Convention Set For Albany, October 15-18

The Convention Committee for the 1981 annual meeting of the New York State ARC has selected the theme "Looking Back - Moving Forward" for this year's meeting. Knowing full well that every wag from Riverhead to Niagara Falls would assure them that following such a theme is a great way to walk into a wall, they nevertheless have gone at their task with great enthusiasm and promise us a nostalgic look at things gone by, while at the same time an in-depth look at what is yet to come.

Hosted by our three close working capitol district Chapters, Albany, Schenectady and Rensselaer, this year's edition of the Convention promises to be an event no one should miss.

The Best Western Turf Inn, on Wolf Road, in Albany, New York, will be the host hotel and many members have expressed an interest not only in the newly constructed addition and fine restaurant at The Turf, but also in its renowned nightlife.

In any case, we hope to see all of you at the State Convention, October 15-18, Turf Inn, Albany, New York:

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN  
1981 CONVENTION  
OCTOBER 15 - 18, TURF INN, COLONIE, N.Y.

8:00 pm	Wednesday, October 14 Executive Directors Meeting	Stonehenge B
9:30 am	Thursday, October 15 Executive Directors Meeting Continues	Stonehenge B
2:00 pm - 7:00 pm	Registration #10	Main Lobby
8:00 pm	Board of Governors Meeting	Stonehenge B & C
11:00 pm	Hospitality Suite Open	
9:00 am - 7:00 pm	Friday, October 16 Registration	Main Lobby
9:30 am - 1:00 pm	Board of Governors Meeting cont.	Stonehenge B & C

10:00 am - 2:00 pm	Tours of ARC locals and Albany area
12:00 noon - 2:00 pm	Lunch - open
2:00 pm - 3:30 pm	Open Workshop: Fiscal Monitoring of an ARC Chapter by its Board of Directors - Mr. Robert Horn, Chemical Bank, Syracuse; Cornell University Rehab Management Training Staff.
3:30 pm - 5:00 pm	Open Workshop: Crisis Intervention for Board Members and Executive Directors - Ms. Helen T. Madden, PhD, Vice President & Senior Consultant, Madden & Madden Assoc., Schenectady, NY
5:00 pm - 8:00 pm	Dinner - open
8:00 pm - 11:30 pm	Opening General Session Greetings: Mark McDermott - Convention Chairperson I Rollcall of Chapters II Report of President, Executive Director and Committee Chairman III Report of Board of Governors Meeting IV Designation of Committees: Resolutions, 1983 Convention site, etc. V Election of 1982 Nominating Committee VI Election of State Officers and Governors

Continued on Page 5



## State City Clash

## Infant Screening Lab Closed

Over the vigorous protest of this Association, joined by concerned parents, physicians and other professionals, the Inborn Metabolic Screening Lab (IMSL) in New York City was ordered closed by the State Department of Health after negotiations between the heads of both state and city health departments had deteriorated into a stalemate, attributed by many close to the scene to an irreconcilable clash between discordant top-level personalities.

Since the inception, in 1965, of the state-mandated screening program, the N.Y.C. Inborn Metabolic Disease Screening Lab, located in one of the most populous areas of this state, has carried the heaviest screening assignment, being responsible for 45 percent of all births which occur annually in our state. Screening of the remaining 55 percent is dispersed, according to population centers, among the three other regional labs located in Buffalo, Syracuse, and Albany, each responsible for 16 percent, 10 percent and 29 percent respectively.

### LAB TESTS FOR METABOLIC ERRORS

The NYCIMS Lab is an integral part of a statewide mandated service to identify and treat infants who are healthy at birth but, upon testing, are found to have errors in metabolism. If left untreated, or if not treated within days after birth, these infants risk life-long disabilities, severe mental retardation and, in some cases, death.

In order for the regional concept of screening to work optimally, it is based upon a density figure of births in a given geographic area, taking into consideration the maximum number of tests which can be efficiently and cost-effectively handled by lab staff, while still insuring the shortest turn-around response time to initiate follow-up and treatments as soon as possible where indicated.

To produce accurate and reliable tests it is recommended that a Newborn Screening Lab operate within a range of 50,000 at the minimum level to a maximum level of 150,000 samples. Labs serving numbers outside this range are considered non-efficient.

The increased number of samples being diverted from the New York City Lab and sent to Albany places its current work load far in excess of standards, at approximately 185,000 - 190,000, which exceeds by 35,000 to 40,000 the prescribed quota for cost-effective testing. It also increases not only the turn-around time, but affects the efficiency and proficiency level of the Lab as well.

One must question the logic of absorbing the larger New York City Lab, where 45 percent of births occur yearly, into the smaller Albany Lab, where 25 percent of births occur yearly, when to do so requires not only the transferral of Albany Lab staff from other projects but the recruitment and training of additional staff to compensate for the increased work-load.

### ADVOCATE APPEALS UNHEEDED

Appeals by some of the most prominent prevention advocates in the field of infant medicine, including Dr. Robert Guthrie, (Professor of Microbiology, at Buffalo University School of Medicine and inventor of the several important infant screening tests), and Dr. Jessica Davis, (chair of the Governor's Genetic Task Force), have gone unheeded.

This summer, Ruth Messinger, N.Y.C. Council Member, had secured a commitment from Mayor Koch's office to provide needed funding for the Lab through January 1, 1982, which the State Department of Health rejected as it had done with earlier proposals. Senior officials of the Koch administration claimed that, while the brunt of the responsibility for the closing rested with the state, part of the blame also rested with Dr. Ferrer, of New York City Department of Health, for the attitude he adopted with commissioner Alexrod of the New York State Department of Health.

Any alleged savings in screening costs claimed by those advocating a single screening laboratory would be far offset not only by the tragic cost to the infants and affected families, but by the cost of medical care and other rehabilitative costs that would have been averted. Further, the cost of a malpractice suit on behalf of a single infant would be greater than any alleged savings.

### CAREY IGNORES INTERVENTION PLEAS

To date, pleas for intervention by Governor Carey have gone unanswered. By ignoring this important issue, silence is interpreted as a tacit acceptance and acquiescence to the misuse of power which ultimately and negatively impacts upon critically important and established services to the newborn infants of our city. Such an act of omission is viewed as tantamount to a giant step backward for all of us who have worked relentlessly to prevent unnecessary life-long developmental disabilities.

We are neither willing nor ready to accept the fact that irresponsible behavior on the part of discordant personalities should be tolerated, let alone be permitted to culminate in a gross tactical blunder which, in the end, does damage to the newborn children of this city whom we have pledged to serve.

It is the belief of many informed individuals that "accidents are in the making," and that tragedy looms in the background. Sooner or later, it is feared, notification of positive screens with concomitant immediate treatment will be delayed, thereby setting into motion a chain of events that will lead to irreversible and permanent damage to infants born in New York City.

What price "regionalization" which every official has been prating? At stake, here, is the very essence of timely discovery and PREVENTION!

# Meetings, Meetings, Meetings

We have recently been contacted by a number of groups, asking our assistance with publicity of upcoming meetings. To oblige, here are excerpts from each:

**October 15 - 17, 1981**

For those of you who won't be at our State Convention in Albany, The Association for Severely Handicapped sends the following:

## TASH EIGHTH ANNUAL CONFERENCE

"The Association for the Severely Handicapped (TASH) is pleased to announce its Eighth Annual Conference, "Bringing It All Back Home," October 15-17 at New York City's Statler Hotel.

The TASH Conference serves as a nationwide forum in the field of education and services for severely - profoundly handicapped individuals. Here professionals, parents, and advocates join together to share observations, expertise, and experience in an atmosphere of mutual concern.

This year's program will include over 200 presentations and symposia, a Keynote address by Jean Tufts, Assistant Secretary Designate of the Office of Special Education and Rehabilitation Services, and three special programs continuing throughout the three-day gathering: "The Community Imperative," sponsored by the Center on Human Policy; "Growing Powerful and Political," sponsored by Metro-TASH, the New York metropolitan area chapter; and "Engineering for a Better Way of Life: State of the Art Technology for the Severely Handicapped," also sponsored by Metro-TASH. A job service, media room, and exhibit area are also featured.

The Conference will begin with registration at 7:30 p.m. Wednesday, October 14, and end at 5:30 p.m. on October 17. For more information contact:

Dueretha Williams, Conference Coordinator  
TASH  
7010 Roosevelt Way N.E.  
Seattle, WA 98115  
(206) 523-8446

**November 9 - 11, 1981**

## NEW YORK STATE ASSOCIATION OF REHABILITATION FACILITIES

"The New York State Association of Rehabilitation Facilities is preparing for "Rehab '81", our 1981 Annual Conference and Trade Show. This outstanding rehabilitation event includes over 40 training sessions, as well as an unparalleled opportunity to view first-hand the latest rehabilitation equipment and services available.

The theme of the conference will be "Sharing Strategies to Not Only Survive - But Thrive - in a Cooling Economy." Held at the Americana Inn, Rochester, NY on November 9-11, the conference offers three exciting days of new ideas, technology, resources and experiences to interest all members of the rehabilitation community. Specially arranged chartered transportation service will greatly reduce travel costs from all areas of the state.

If you have any questions please call us for details. We expect our conference to appeal to a wide variety of rehabilitation professionals, and hope you will help us."

**November 20-21, 1981**

## NEW YORK ASSOCIATION FOR LEARNING DISABLED

"The New York Association for the Learning Disabled will hold their Annual State Conference on November 20 and 21, 1981, at the Hotel Syracuse, Syracuse, New York. This is the first time the Conference has been held upstate and we have planned an exciting program for our new audience.

We would appreciate your assistance in advertising the Conference through your newsletter. Interested persons will receive Conference - Hotel registration forms and the preliminary Conference Program.

## NEW YORK ASSOCIATION FOR THE LEARNING DISABLED 1981 STATE CONFERENCE November 20 & 21, 1981

Hotel Syracuse Syracuse, N.Y.

### KEYNOTE SPEAKERS

Dr. Drake Duane, MD

Neurology Consultant

Mayo Clinic

Rochester, Minn.

Dr. Sol Gordon, Ch.

Dept. of Child and

Family Studies

Syracuse University

— 30 Workshops covering: Diagnosis, Evaluation, Teaching Strategies, Mainstreaming, Services for Adults, Special Sessions for Parents, and more.

— Commercial Exhibits

— Film Theater

— Book Store

For more information, contact:

NYALD Conference

217 Lark Street

Albany, NY 12210

518-436-4633"

**August 22 - 26, 1982**

## INTERNATIONAL ASSOCIATION FOR THE SCIENTIFIC STUDY OF MENTAL DEFICIENCY "THE 1982 WORLD CONGRESS ON MENTAL RETARDATION IN TORONTO, CANADA

This Congress comes at a time when the field of mental retardation is entering a decade of change and challenge. The choices and decisions made during the '80s will set the direction of change and establish the range of opportunities for the balance of the century.

In panels, speeches, workshops and training events of the Congress, distinguished scientists, educators, practitioners, consumers and administrators will concentrate on major theme areas in order to assess the present state of research, practice, planning and policy-making — and explore the potential for future growth, change and local action for various areas of the world.

Information about study tours, special symposia, presentation of papers, training events, (including accreditation), program visitations, accommodation and tourism will be made available in future to those who request to be placed on the mailing list. The address to write to is IASSMD, Kinsmen Building, York University Campus, 4700 Keele Street, Downsview, Ontario, M3J 1P3.

Plans call for two streams at the Congress to provide for both scientific and technical groups, and for service workers, parents and volunteers.

## Hank, We Apologize!

After our last issue of Our Children's Voice was sent out, we received the following irate letter from Ferne Vanderhoof, a member of the State Board from Genesee County. It had to do with our omission of the name of Henry Valerych, Membership Chairman of the Chapter from our membership story. Her letter reads:

"To: Editor of OCV & Ass't. Editors  
For: Genesee County Chapter

This is the second or third time I've sent in this criticism - on the subject of membership. Henry Valerych is our man and has been for many years!

Please do not leave Genesee County Chairperson Blank. He has done a tremendous job. He has increased our membership by 200 in the year 1980, enabling us to have another Board of Governors Representative."

Ferne, you're absolutely correct. Henry has been doing a grand job for years, and for the record, we apologize, Hank.

## President's Message

By Elinor Pattison

It is said that as one gets older, time passes more quickly. If that's true, the swift passage of the months since the Spring meeting either prove the maxim, or I'm aging prematurely.

Certainly the increased activity on all levels generated by the state budget impasse and the federal budget cuts translated into numerous coalitions which tried to negate or diffuse cash flow problems and the spectre of vastly decreased funding. Although there is no accurate assessment of the future budget picture yet available, there is no doubt in the minds of those closely involved with direct service that there are "dark clouds on the horizon."

In addition, the State ARC level of activity reached an all time summer high. Many issues, both positive and negative, have been thoroughly addressed.

Convention time offers the opportunity to anyone who is interested and can attend to discuss, ask questions, garner information, criticize or praise all aspects of our activity. The Tri-County Convention Committee (Albany, Rensselaer and Schenectady) have expended enormous time and effort to provide an exciting forum that offers opportunity for participation.

I look forward to joining with you in what promises to be an exciting and rewarding venture.



## Disabled Doesn't Mean Unable

In issuing the 18-cent Disabled Persons stamp, the United States joins other nations in the worldwide effort to promote education for the prevention of impairments and the encouragement of rehabilitation efforts.

The above stamp was designed by Martha Perske of Darien, Connecticut. This is her first stamp design effort. Mrs.

Perske and her husband, Robert, have produced the art and narrative for two national and two international reports on disabled persons published since 1976.

The theme for the stamp design depicts an individual who is disabled in a wheelchair, working alone and unaided with a sophisticated microscope.

## 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.

Editor: John Bertrand, Executive Director  
Assistant Editors: Geraldine Sherwood

Donald Westervelt

Contributing Editor: Joseph T. Weingold

Editorial Assistant: Adele Osinski

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

Please address all inquiries to:

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

# Order ARC Christmas Cards TODAY!

## 1981 AWARD WINNERS

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

25 cards for \$7.75  
Add \$3.75 for each 25 cards imprinted



Card No. AG 1882 W3

A charming design featuring two children on a sled enjoying holiday fun by Jennie Strother, Stamford, New York. Reproduced in rich pastel color and framed by blue border. White envelope. Inside: Wishing you all the Joys of the Season and Happiness in the Coming Year.

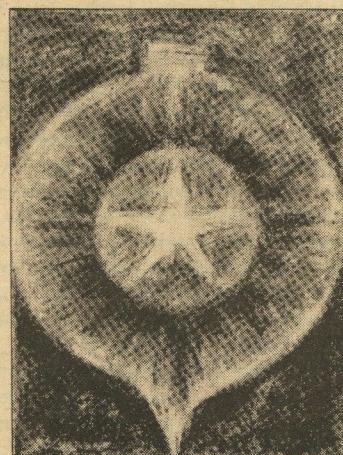


Card No. AG 1881 W3

A delightful snow family celebrates the holiday season, designed by Stanley Popielarz, Fulton, New York. Reproduced with bright color and a red border on a white background. White envelope.

Inside: Warmest thoughts and Best Wishes for a Wonderful Holiday and a Very Happy New Year.

## PREVIOUS AWARD WINNERS



Card No. AG-837W3

A glorious and beautiful multi-colored ornament by Thomas McComb, Wassaic, New York, reproduced in full brilliant colors against a blue background. White envelope. Inside: Wishing you all the Joys of the Season and Happiness in the Coming Year.



Card No. AG9822W3

"Tree and Gifts" by Joseph Spencer of Wassaic. Reproduced in full colors of Christmas on white, textured paper. White envelope. Inside: "May your home be merrie and bright with the joys of the Season"

25 cards for \$6.75  
Add \$3.25 for each 25 cards imprinted

## SPECIAL ASSORTMENT

Our own Special Assortment Box of 50 cards featuring original award-winning and best selling designs by retarded persons.

Box of 50 Cards and envelopes for \$9.00. Imprinting not available for this assortment.

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

Please send me the following cards by mentally retarded artists:

No. Boxes	Style, Price & Message	Amt. Enclosed
—	AG1881W3: 25 cards at \$7.75 — Warmest thoughts and best wishes for a wonderful holiday and a very happy New Year.	
—	AG1882W3: 25 cards at \$7.75 — Wishing you all the Joys of the Season and Happiness in the Coming Year.	
		Add \$3.75 for each 25 of the above two cards imprinted.

## ORDER FORM

No. Boxes	Style, Price & Message	Amt. Enclosed	No. Boxes	Style, Price & Message	Amt. Enclosed
—	AG736W3: 25 cards at \$6.75 — Wishing you all the Joys of the Season and Happiness in the Coming Year.		—	ARC: 50 cards at \$9.00 — Special assortment featuring the best selling designs by mentally retarded persons. Imprinting not available for this assortment.	
—	AG9821W3: 25 cards at \$6.00 — May your home be merrie and bright with the joys of the Season.		Specify Imprint: _____		
Add \$3.25 for each 25 of the above two cards imprinted.			TOTAL ENCLOSED: _____		

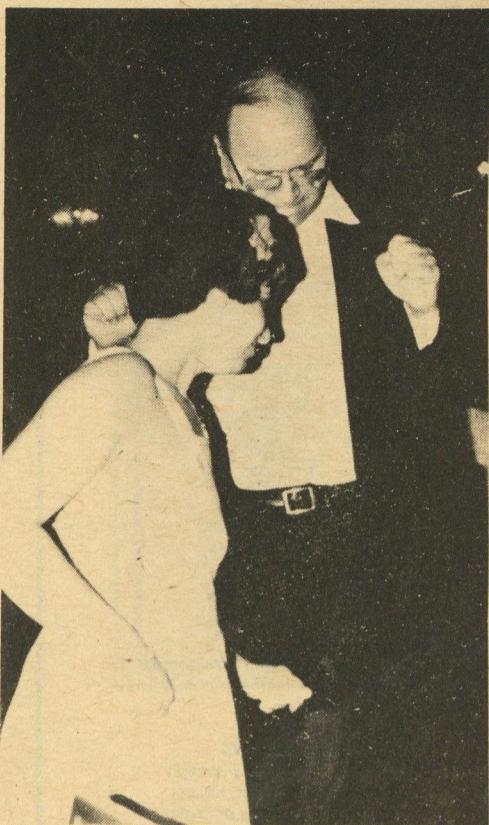
Your Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

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

# CHAPTER NEWS



It looks as if Marcia Buzzelli, President of Niagara County Chapter, is about to land a hard right to the unguarded mid-section of State Executive Director, John Bertrand, however, the photographer assures us it was only a dance and not a prize fight in connection with Niagara County Chapter's Annual Awards Dinner on June 10th.

This edition of Chapter News will start off with success story from DUTCHESS County Chapter. DUTCHESS now leads the way in total cash-back Lottery ticket collections, having edged past our previous leader after the August tallies... While in other parts of the State, NIAGARA County Chapter held its 14th Annual Awards Dinner on June 10th. It

was a gala occasion and a good time was had by all who attended... And in ONTARIO County Chapter, summer bowling was a major attraction. Bowling is just one of ONTARIO'S many ongoing recreation program activities... SCHOHARIE County Chapter held its annual summer Food and Bake Sale in July. One way to raise money and have fun at the same time... COLUMBIA County Chapter was the recipient of the proceeds from a soft-ball game played between the H. A. Rogers Fire Company and the Hudson Police Benevolent Association. It's great when groups like these get together and focus their efforts towards helping a local ARC Chapter... An open house was conducted by BROOME-TIoga County Chapter at their Country Valley Industries Workshop. The open house was attended by local businessmen. A good way to get those much needed work contracts... MONTGOMERY County Chapter is lucky to have the support of people like Jack McGary. This 22 year old Villanova graduate is intending to raise a minimum of \$10,000 for MONTGOMERY Chapter by bike-riding 3,000 miles across the country, from San Diego to Staten Island. He dipped his rear wheel in the Pacific Ocean and will dip the front wheel of his bike into the Atlantic Ocean. Jack intends to enter Medical School this fall. Best of Luck, Jack

... HERKIMER County Chapter sponsored its first Annual Slo-Pitch Soft-ball Tournament in June. They had 16 teams enter this first contest... Our own, Ellie Pattison, President NYSARC, was the guest speaker at GENESEE County Chapters' annual Banquet held at the Batavia Party House. Awards to Staff, Clients and Industry were made during the program... ORANGE County Chapter conducted its annual awards outing. This outing was sponsored by the Newburgh Council, of the Order of United Commercial Travelers of America. This group has been working with ORANGE Chapter for over 15 years... The Jacob J. Karl Memorial Scholarship



Ellie Pattison (l.) President of the State Association, accepts an award presented by Marcia Buzzelli, President of Niagara County Chapter at the 14th Annual Awards of the Chapter. State Executive Director, John Bertrand, who was Master of Ceremonies looks on.

has been established by the CAT-TARAGUS County Chapter. This scholarship is intended to aid either the academic or the professional advancement of a staff member of CAT-TARAGUS Rehabilitation Center... Every dollar counts and ERIE County Chapter was happy to receive the \$764 check from Bee Publications to help with ERIE Chapter's share for the cost of their new building project... Our WEST-CHESTER County Chapter honored its 163 volunteers in July. This group of volunteers contributed 14,997 hours of their time to the various programs. With people like these on our side, how can we do anything but succeed... A two year wait has ended now that SCHUYLER County Chapter has

received its U.M.P.T.A. Grant bus. It always makes life seem a little better when we have a new vehicle... SUFFOLK County Chapter was the recipient of almost \$5,000 netted by the Babylon Tuna Club's 25th. Annual Invitational Tournament, and that's no "fish story"!... Getting back to dry land, the "Great A.H.R.C. Horse Show" took place at NASSAU County Chapter in August. This is the annual equine fund-raiser that offers \$45,000 in prize money. It is part of the Grand Prix National Tour... We will end this edition of Chapter News with a recent Buffalo Evening News Article that said of CHAUTAUQUA County Chapter, "They build tent pins and dome lights and life and hope." One more acknowledgement that CHAUTAUQUA'S doing it right!...

## NCLH Files Pennhurst Brief On Community Settings

The National Center for Law and the Handicapped has filed a brief, *amici curiae*, before the United States Supreme Court in this critical case, on behalf of itself, the State of Indiana Protection and Advocacy Service Commission for the Developmentally Disabled, and the Ohio Protection and Advocacy Association. Pennhurst is before the Court on a writ of certiorari seeking to overturn the Third Circuit's ruling that the Developmentally Disabled Assistance and Bill of Rights Act (D.D. Act) provides affirmative and enforceable rights to habilitation in community settings.

The NCLH *amici* brief challenges the attempt by other *amici* parties (who support the Commonwealth of Pennsylvania's desire to reverse the Third Circuit decision), to portray mentally retarded persons, specifically severely and profoundly retarded persons, in grossly abusive and inaccurate terms. The *amici* brief filed by Congress of Advocates for the Retarded, for example, on behalf of numerous organizations and parental groups in support of institutions, argues to the Court that many of those residing in institutions have little hope of progressing and will need to remain in protective and segregated institutional settings forever. Believing this information to be highly misleading and prejudicial, NCLH has in contrast presented the Court with substantive data which illustrates the possibilities and the realities of integrating the mentally retarded into society and which places the whole issue of segregation in its proper perspective.

The brief first argues that Congress had before it extensive information concerning the harms associated with institutionalization. Though similar to the circumstances of *Brown v. Board of Education*, 374 U.S. 483 (1954), involving segregation by race, this case involves a plea by appellants not only to uphold the widespread use of institutional segregation but also to overturn deliberate findings made by Congress. The literature documents the developmental harms, which include decrease in such significant areas as intelligence quotient, motor skills, social competence and verbal skills. A multitude of federal court cases document the highly abusive conditions within institutions, resulting in gross physical harms. Institutions, the brief asserts, can in no conceivable manner be viewed as protective, pleasant or stimulating environments. Rather, the real existence behind institution walls is one of hopelessness, helplessness and abuse.

Furthermore, NCLH contends that it is absurd to justify institutions on the basis of selective failings and deficiencies within community settings when the stark horrors of life in institutions remain after a century of operation. The hearings on the D.D. Act reflect that Congress was well aware of this as it determined its appropriate legislative response, and they were especially aware that "such abuses are too commonplace to point at a single institution or a single abuse, and say that it is an anomaly." 121 Cong. Rec. 16,516 (June 2, 1975) (remarks of Sen. Williams).

**LONG HISTORY OF ABUSE**  
NCLH submits that it is extremely important for the Supreme Court to recognize the historical perspective in the treatment of mentally retarded persons in this society. Mentally retarded persons have consistently been viewed as "deviants," and treated harshly throughout history.

Highly prejudicial and erroneous conceptions of the nature of mental retardation served to further isolate them from society, either purportedly to protect them from society or to protect society from them. In an attempt to limit the procreation of mentally retarded persons, which was viewed in early 20th century as a grave threat to society, isolated and massive institutions grew and expanded.

Not until the last few decades, long after those earlier prejudicial rationales for segregation were discredited, has society begun to rectify the past injustices and to initiate a process of reintegration of the mentally retarded into society. Based upon increased scientific knowledge and social science developments, illustrating the importance and the successes of education and training procedures, mentally retarded persons, no matter how severe their handicaps, have a reasonable expectation to achieve like all other individuals, their maximum growth potential.

The brief then examines the newly emerging justifications for institutionalization which shift back to the earlier protective rationale. NCLH refutes this approach by initially explaining how mental retardation is a developmental

disability, necessitating the provision of education and training. NCLH focuses upon the learning process, an educative approach broader than traditional schooling and applying to all aspects of an individual's development.

The brief urges the Court to recognize that what appellants urge via institutionalization is merely a segregated education approach as well as a weakening of the structure of family and home life. The institution cannot provide needed socialization and human activities which are key to an individual's development, rather, it necessarily provides a degenerative and depersonalizing environment.

In the final section of the brief, NCLH summarizes and expands upon the existing social science data on habilitation and community services for severely and profoundly retarded individuals (See also *Amicus*, 5, No. 2, p. 73). In contrast to the presentation to the severely and profoundly retarded as basically non-functioning, NCLH describes the results from numerous successful educational and training programs. The documentation of the effectiveness of behavioral techniques employed by professionals includes such areas as reduction of undesirable behaviors; self-help skills; language, social and vocational skills. The important factor in achieving these successful results is clearly the program employed. Furthermore the data illustrates that these programs can be successfully carried out in various en-

# Looking Back — Moving Forward

Continued from Page 1

11:30 pm

9:00 am - 2:30 pm  
8:00 am - 9:30 am  
9:30 am - 12:30 pm  
12:30 pm - 2:00 pm  
2:00 pm - 3:00 pm

VII Old Business  
VIII New Business  
IX Good & Welfare  
Hospitality Suite Open

**Saturday, October 17**  
Registration  
Buffet Breakfast (\$5.25)  
General Session, cont.  
Luncheon (\$8.00)  
Workshop sessions:  
I Exerting Political Clout at State & National Levels  
Ned Pattison, former United States Congressman  
Larry Malone, Former NYS Assembly Majority Staff  
II Residential Services for Children & Adults  
NYS ARC, Executive Directors Assn.  
III Day Programming Services  
NYS ARC, Executive Directors Assn.  
IV Sexuality and Mentally Retarded People  
Heidi Ruefli, Niagara County Chapter, NYS ARC  
V Education: Moving Back? Looking Ahead!  
Main Speaker — to be announced, NYS Office of Education for Children with Handicapping Conditions  
Panel Discussion  
Betty Pendler — Chairperson, Education Committee, NYS ARC  
James Campbell — Assembly Task Force for the Disabled  
Marilyn Wessels — NYS ARC  
Shirley Reynolds — NYS ARC  
Edward Cunningham — NYS Department of Education  
VI Quality Assurance on Developmental Centers  
Presentations describing the newly organized Quality Assurance functions in these centers; their role & expectations.  
Bernice Volaski, Chairperson, Institutions comm. NYS ARC  
Dr. Stanley Slawinski, DDQA, SUFFOLK CO. DDSO  
Mrs. Patricia Bertrand, DDQA, BRONX, DDSO

Main Lobby  
Courtyard  
Stonehenge B & C  
Courtyard

Stonehenge

Stonehenge B

Stonehenge C

Phoenix Room

State Room

Board Room

3:00 pm - 3:15 pm  
3:15 pm - 4:15 pm  
4:15 pm - 5:30 pm

Coffee Break  
Repeat Workshop Sessions  
CRACKERBARREL SESSIONS

Board Room  
Courtyard

1. HUD 202 — Mr. Joseph Mastrianni, Consultant, City Planning & Development, Ms. Helen Forman, Community Facilities Planner, OMR/DD
2. SSI Appeals
3. OMR/DD — Kevin Travis, Director of Quality Assurance, Zygmund Sezak — 1st Deputy Commissioner  
Sam Kowala — Director of Program Operations
4. Public Relations/Membership — KATE KLEIN, CO CHAIRPERSON Public Information Committee
5. Guardianship — Hon. Warren Travers, Surrogate Court Judge, Rensselaer County
6. Labor Unions — Melvin Osterman, Attorney at Law
7. Insurance — Bernard Weinstein, Sobel Affiliates
8. Prevention — JOAN EDWARDS, Chairperson, Ad Hoc Prevention Committee — NYS ARC
9. Advocacy — Dr. Eugene Keeler, Client Advocate, Columbia County, ARC
10. Vocational Rehabilitation — Dave Essrow, Chairman, and members of Voc. Rehab. Committee
11. Speakers from Earlier Sessions  
Cocktail Reception — Cash Bar  
Annual Banquet (\$15.00)  
Invocation — Bishop Howard J. Hubbard, Diocese of Albany  
Master of Ceremonies — Mr. John McLaughlin — WTEN TV, Albany

Courtyard  
Stonehenge-A,B & C

6:30 pm

9:15 pm

10:00 pm

9:30 am - 12:00 noon

Meeting of New Board of Governors

Stonehenge A

COMPLETE AND MAIL RESERVATION FORMS ON PAGE 8 TODAY!

## NCLH Files Pennhurst Brief

Continued from Page 4

vironments and by professionals or non-professionals.

Responding to the attempt to disparage the viability of community programs by discussing the problems of specific instances of inappropriate community living arrangements, NCLH stresses the obvious point that it is the inadequacy of the services provided and not the inadequacy of the mentally retarded residents which have caused problems. No single variable such as IQ has been shown to be reliable predictor of successful community placement. Rather, it is the provision of appropriate services, individualized as the Third Circuit interpreted Congressional intent, which is the critical factor.

### SUCCESSFUL COMMUNITY PLACEMENTS DOCUMENTED

After reviewing general data on community placement, the brief focuses specifically on the state of Nebraska, from which several groups supporting institutionalization emerged. The examination of data from Nebraska provides a strikingly different picture of severely and profoundly retarded persons from that portrayed by appellants. In fact, over 25 percent of all mentally retarded persons being served in Nebraska community-based mental retardation programs are severely and profoundly retarded. Many of those served are non-ambulatory or ambulatory only in barrier-free environments. Many have behavior disorders serious enough to require special intervention and intensive behavioral programming.

The success rate of these community programs has also been documented. Prior to their creation in 1972-73, 25 percent of placements out of the institution were into the community, while 40 percent were into nursing homes; since 1972-73, 74.4 percent of placements have been in the community while only 7.2 percent have been into nursing homes. Yet of 479 individuals placed into the community, under 10 percent have needed to return to the institution.

Particularly relevant is the data on individuals with medical problems, a group claimed by Congress of Advocates for the Retarded to be of significant size and necessitating care only in an institution. In a study commissioned by the Nebraska Department of Public Welfare and Department of Public Institutions, Touche Ross & Co., reported on August 15, 1980, that "of approximately 335 BSDC (Beatrice State Developmental Center) clients identified with special medical needs, in the opinion of the BSDC medical staff only 8 require intense medical services not typically provided in the residential programs." The overall cost of serving large numbers of these individuals was found to be the same or significantly less than the cost of institutional services.

To stress the reality of community services, NCLH then describes a few additional settings. In the Macomb-Oakland Regional Center program in Michigan, for example, 60 percent of persons served in group homes and community training homes are severely or profoundly retarded and, of these, 70

## Boudov, Brandt Chair

### N.Y.S. Provider Council

Last year, the Legislature created a special Provider Council. The council's main objective is to design and recommend fee policies for residential care facilities serving those who are mentally retarded and developmentally disabled in

percent have serious secondary handicaps and many are considered medically fragile.

A National Survey of Community Residential Facilities in 1977 found that 32 percent of all residents of community facilities were severely and profoundly retarded and more than half had at least one additional handicap. Pennsylvania itself, has repeatedly recognized the ability to serve all mentally retarded persons in the community and the record of the case is replete with acknowledgements by state officials and state experts as to this fact.

NCLH, thus, concludes its brief by requesting the Court to affirm the Third Circuit's individualized approach with its presumption in favor of community placement. NCLH submits that all congressional actions have moved toward accomplishing this integration into the community. The data exists and is clear in support of the feasibility and actual success of community placement for all mentally retarded individuals. Congress merely acted, based upon existing information to spur and implement those goals.

New York State.

We are pleased to note Governor Carey has appointed many outstanding individuals representing provider agencies with a long and dependable history of service to the disabled. Donald Boudov and Marc Brandt, executive directors respectively of our Onondaga and Sullivan chapters, co-chair this important council. Participating in the Council are Helen Kaplan, Marilyn Zahler and Harold Hopkins, executive directors of our Nassau, Niagara, and Jefferson Chapters. Ed Reitman of United Cerebral Palsy; Henry A. Coley, of the Federation of Puerto Rican Organizations of Brownsville; Kathleen Lukens, of Venture Inn; and Alan Krafchin of Residential Opportunities Inc. have also been named as participants on the Council.

Don Boudov has indicated the Council has been meeting frequently and regularly in Albany to discuss issues relating to the new fee-for-service project and he hopes that, by Fall, a pilot project will be ready for trial implementation. Joseph Kovler, of OMRDD, and his staff have been working very closely with the Council composed of diversified agencies which provide a wide range of services as well as those that specialize in residential alternatives only.

The next Provider Council meeting scheduled for September 10th and 11th in Albany will discuss plans for the final draft of the Pilot Project.

# Albany's libraries are open to all

More than 100 clients of the Albany County Association for Retarded Children are using the Albany Public Library. This program for the developmentally disabled is committed to the belief that every person in the area has a right to quality library service.

The first program of its kind in New York State, it stems from a grant given to the Albany Public Library by the State Library for the Blind and Visually Handicapped. The funds are to adapt and modify library services to make all of the facilities accessible to the handicapped and disabled. The aim is to get people with disabilities into the mainstream of library services, and to break attitudinal barriers of the staff and public.

"Any library can do this," explained Gloria Freedman, special services librarian. "Books containing a lot of photographs with just captions are popular. They enjoy realism. Cookbooks and easy how-to-books are in great demand."

Mrs. Freedman and Sharon Barten, an intern, have developed a series of tours,

exhibits and films as well as books and magazine loans for the developmentally disabled. Mrs. Barten, a graduate student from the State University of New York at Albany, spends about 120 hours each semester on the project.

Mrs. Freedman said, "Clients are alert and aware and very proud to enter the library. When they come in they greet us and ask 'What's today?' Most, conscious of where they are, helping straighten up the chairs and pick up magazines before leaving."

When the ARC people first came to the library the public and staff became disgruntled and upset. Now, nobody notices them. Edgar Tompkins, library director, and the library staff are very supportive. For example, the periodical librarian gives them surplus magazines and publications the library gets as gifts.

Clients in the program are at least 18 years of age and have developmental disabilities. About 40 have library cards and are borrowing easy, adult level, books.

Story and photos by Julian A. Belin.



Sharon Barten, an intern and graduate student in library science from SUNY at Albany, helps return books that have been read.



Kurt Staub, a developmental specialist with the Albany Association for Retarded Children, shows some of the library's users how to make a selection from the records.

## Down's Syndrome Symposium planned

Dr. Jessica Davis, Director of the Child Development Center of North Shore University Hospital, and Dr. Alice Hayden, Director of Model Preschool Center for Handicapped children at the College of Education and Child Development and Mental Retardation Center of the University of Washington, have been invited by the Association For Children With Downs Syndrome, Inc., to speak at its first symposium.

The Down's Syndrome Symposium will focus on current intervention strategies with the goal of providing participants

with information and programming techniques to better meet the needs of young children with Downs Syndrome and their families.

The symposium will take place on October 21, 1981, from 8:45 to 3:30 p.m. at the Salesbury Parks Restaurant in East Meadow, New York. For further information regarding registration contact:

The Down's Syndrome Association  
2616 Martin Avenue  
Bellmore, N.Y. 11710  
(516) 221-4700.

## Fetal treatment versus abortion

The abortion debate may take a poignant twist as medical advances increasingly enable doctors to treat defective human fetuses still in the womb, a medical journal says. In deciding whether to abort a defective but treatable fetus, doctors will have to struggle with the fact that the fetus could also be a patient.

This dilemma is one of the ethical problems anticipated by Dr. John C. Fletcher in an editorial in the Aug. 24 issue of the Journal of the American Medical Association. Dr. Fletcher said that, ethical dilemmas aside, new treatments for fetuses present the possibility of eliminating or reducing "a lifetime of physical suffering and economic burdens."

### SURGERY USED FOR FETAL TREATMENT

The editorial accompanies an article detailing the ways, including delicate surgery, in which physicians can now treat fetuses.

Dr. Fletcher writes that difficult moral questions may arise in regard to borderline fetuses, those for whom doctors and parents must choose between life and death.

Dr. Fletcher, assistant for bioethics in the Clinical Center of the National Institutes of Health, writes that, in practice, high-risk fetuses old enough to survive birth are now usually given the benefit of the doubt when problems arise. Maternal

and family concerns, however, get priority over the fetus's life if doctors determine it is not yet viable.

But in these borderline situations, improvements in fetal therapy could establish stronger grounds for protecting the fetus, thus conflicting with parents' rights to decide on an abortion, Dr. Fletcher writes. He suggests that when such conflicts arise, a second physician may someday act as advocate for the fetus.

"A really interesting problem in the long run," Dr. Fletcher said in a telephone interview, "is, if a disease was perfectly treatable and yet the mother didn't want to undergo therapy, whether society would be interested in coercing her to go to term. Based on the values that have developed in society so far, that would not be the case."

### IS A FETUS A PATIENT?

Dr. Fletcher says doctors can escape the dilemma for the time being not by considering the fetus a patient until it is born and separate from the mother. However, he said that advances in so-called test-tube births may force physicians to re-evaluate the notion that "separateness from the mother is the most important morally relevant difference between the fetus and the newborn."

"The criteria of separateness is weaker as a morally relevant category than it used to be," Dr. Fletcher said, noting that infants born prematurely and weighing less than a pound can be saved through medical treatment.

## Protection, advocacy agencies listed

The Commission on Quality of Care has announced the establishment of protection and advocacy outreach offices and developmental disabilities legal service units following a review of responses to the requests for proposals issued in November, 1980.

These regional offices will serve as the primary contact for persons requesting assistance in the protection of rights of developmentally disabled individuals. The offices will provide assistance in resolving individual problems, information and referral services, and training and technical assistance to advocacy groups and organizations.

If you know a person with a developmental disability who needs help in protecting his/her legal rights, you can reach these agencies at these addresses or phone numbers:

Monroe County Coordinating Group on  
Developmental Disabilities, Inc.  
Executive Office Bldg.  
36 West Main St., Suite 490  
Rochester, NY 14614  
(716) 454-6560 Patricia Willis, Exec. Dir.

**Oct. 4-11**

## National Employ The Handicapped Week

The theme for National Employ the Handicapped Week (NETH) October 4-11, 1981, is a call to action to all communities to insure that disabled people share fully in all the many opportunities this country offers. The call to action is actually a "Community Challenge." In order to have an effective NETH week, we will need to identify resources available within our community for those who are disabled.

Local chapters of NYSARC are in a position to play an important part in helping to identify the strengths and weaknesses currently existing in local resources. Participation in NETH week

provides ideal opportunities to focus on the progress disabled people are making within their communities; to honor employers, labor leaders, and professionals who are actively contributing to the advancement of disabled people; to identify community resources, as well as community problems; as they affect disabled people.

A resource packet has been distributed to chapters through the NYSARC STATE OFFICE to assist them in making National Employ the Handicapped Week a success in their communities.

## Introne Reassigned

# Slezak New Acting OMR-DD Commissioner



ZYGMUND SLEZAK

In a brief release, dated August 26, James E. Introne, Commissioner of OMR-DD for the past 1 1/4 years announced his temporary reassignment:

As the attached announcement explains, the Governor has asked me to assume temporary duty as a member of the Executive Chamber Staff.

I have a special commitment to the successful achievement of the goals of the Office of Mental Retardation and Developmental Disabilities but I am also aware that this agency along with all others, has a stake in government as a whole. I take seriously my own obligation to do what I can to assist the Governor's Office and thus willingly accept the challenging responsibilities Governor Carey has given me.

I am able to make this decision in great part because of the confidence I have in the capabilities of our management team. I see no disruption in our operations and in our progress toward our goals.

As he has done before, Zygmund Slezak, First Deputy Commissioner, will assume responsibility for the duties of the Commissioner in my absence. He will have every authority to act in my behalf.

I look forward to rejoining all of you when my temporary assignments are concluded.

## Private School Funds Extended

A source of state funds for the care of mentally retarded adults housed in private residential schools has been extended by the State Legislature.

Chapter 720 of the Laws of New York, due to expire at the end of state fiscal year 1981, has been extended for the next two years and \$2.725 million appropriated. Chapter 720 monies are available to participating facilities certified by the Office of Mental Retardation and Developmental Disabilities for clients over the age of 21 and no longer eligible for educational funding.

Its renewal will guarantee that SSI level-3 payments of approximately \$700 will be supplemented by state funds, in lieu of parental contributions.

A total funding package of SSI and state supplementation provides up to \$1,100 a month per client in certified programs. OMRDD will establish the rate of reimbursement based on actual costs and limited to the \$2.725 million appropriation established.

As an added provision, the extension provides \$175,000 for certification audits and to assist the development of an equitable "fee-for-service" system.



JAMES E. INTRONE

### GOVERNOR CAREY NAMES INTRONE AS DIRECTOR OF STATE OPERATIONS

Governor Hugh L. Carey today announced the appointment of James E. Introne as Director of State Operations.

Mr. Introne will be on leave of absence from the Office of Mental Retardation and Developmental Disabilities where he has served as Commissioner since November, 1979.

"Jim will be on temporary reassignment from the Office of Mental Retardation to assist in the upcoming special session, the development of next year's legislative program, the State of the State and the 1982-83 State Budget," said Governor Carey.

Mr. Introne will also effect a reorganization of the management and program development responsibilities in the Executive Chamber.

"After these tasks have been accomplished," said the Governor, "we'll reassess where Jim's talents can best serve the Administration and the State."

Mr. Introne has a breadth of experience in the State government having served in the Executive Chamber from January 1975 through December 1977 as Assistant Secretary to the Governor for Human Resources, where he directed the reorganization of the Department of Mental Hygiene and the creation of a separate Office of Mental Retardation and Development Disabilities (OMRDD).

From January 1978 until July 1979, Mr. Introne served as Deputy Director of the Division of the Budget. In July 1979, he was appointed First Deputy Commissioner of OMRDD, and Acting Commissioner on August 1, 1979. Prior to joining the Executive Chamber in 1975 after Governor Carey assumed office, Mr. Introne had worked in the New York State Division of the Budget since 1969. He is a graduate of St. Lawrence University and holds a master's degree in public administration from Pennsylvania State University's Institute of Public Administration.

Mr. Introne's salary will be \$63,600 — his present salary as Commissioner of Mental Retardation and Developmental Disabilities.

In a letter to Mr. Introne the Association wished him well in his new position, but hope he would return to work with us in the future.

## Site Selection To Be Coordinated

One of the major needs in New York State has been the development of residential community care facilities in the appropriate types, numbers and locations for physically and mentally disabled persons, the elderly and youth with various service needs. In recent years, the number and types of facilities have expanded, as well as the number and type of public and private agencies involved in the development of such facilities. This has led to problems of planning and site coordination and inadequate local involvement in the site development process.

In the last two years, there has been a growing concern in the Legislature and Executive Chamber about ways to address the site coordination issues in a planned, integrated and comprehensive way both on the state and local levels. There have been numerous pieces of legislation related to site selection and housing issues that have been introduced in the Legislature in the past couple of years.

In an attempt to respond to these concerns, the Executive Chamber established an interagency site coordination committee. The Commission on Quality of Care, which had urged the formation of

such a committee, now actively serves on it as one of the representative agencies. There are 14 agencies participating in the "clearinghouse-site coordination project." The New York State Division of Housing and Community Renewal was designated the lead agency in the site coordination effort.

In a progress report of the first three months of activities, 39 requests were recorded followed by responses providing information on existing facilities, prospective sites, others actively searching in the same area and community issues. In addition the clearinghouse has supplied information to legislators, local and regional planning departments, county executive offices, New York City community boards, neighborhood and rural preservation companies, and has developed forms, procedures and mechanisms for reporting closing facilities available for alternative use. The clearinghouse has become a central point of information on sites and potential problem areas and is serving as a focal point for the State's effort to work with local communities towards the coordinated development of residential community care facilities.

## Maurer Appointed Executive

The Board of Regents unanimously appointed Robert J. Maurer, Deputy Commissioner for Cultural Education, as Executive Deputy Commissioner of Education effective July 30, 1981. The appointment to the second ranking position in the Education Department was made at the recommendation of Commissioner Gordon M. Ambach.

As Executive Deputy Commissioner, Maurer will have responsibility for preparing the budget and legislative proposals for both State and Federal education programs. He will have administrative responsibility for nearly \$5 billion of annual State and Federal funds for education. Maurer will serve as Acting Commissioner of Education during any absence of Commissioner Ambach.

Commenting on Maurer's appointment, Commissioner Ambach said: "Bob Maurer has demonstrated outstanding leadership as Deputy Commissioner for Cultural Education. During the past three years, he has developed the Cultural Education Center as a focal point of cultural activity in the Capital District and guided major changes in the State Library, archives, historical and television programs. He has a superb background in government administration and policy development. He will be a strong partner in his expanded role as Executive Deputy Commissioner of Education."

Prior to his appointment as Deputy Commissioner for Cultural Education in 1978, Maurer served as Director of the Senate Special Committee on the Culture Industry and as Executive Assistant to the Senate Deputy Majority Leader. Maurer first became involved in State government in 1967 as a research assistant in the Office of Information and Research for the State Senate. He was Assistant Director of that office and later was Director of Special Projects for the State Senate.

Maurer, 38, has extensive experience with budget and legislative matters in both New York State and in Minnesota where he served as an Assistant to Governor Karl Rolvagg in 1966. Maurer has specialized in developing legislation, including the reorganization of the Department of Mental Hygiene, newborn infant mortality, lobbying regulations and ethics in government, neighborhood preservation and the lottery aid program to support education. He received the Better Life Award from the New York State Association of Retarded Children in 1977 and was a Fulbright Scholar to Yugoslavia in October 1980. He received his bachelor of science degree from the State University College at New Paltz in education and his master of public affairs degree in state and urban government from the Graduate School of Public Affairs at SUNY Albany.

## Mainstreaming Decision

A recent decision by State Education Commissioner Gordon Ambach has affirmed the rights of children with handicapping conditions to receive their education with non-handicapped pupils according to their individual needs.

The ruling by the Commissioner overturned an earlier determination by a hearing officer who found that the New Hartford Central School District did not have to allow eighteen year old Jeffrey Gillette to participate in the district's regular school program. Jeffrey, who was born with Down's Syndrome, had progressed to the intermediate level in a summer instructional program approved by the Red Cross which included both handicapped and non-handicapped persons. The hearing officer, James Walsh, in upholding the recommendation of the

Committee on the Handicapped and the ruling by the Board of Education, determined that it was in Jeffrey's best interest to continue receiving instruction in the BOCES swimming program for handicapped children.

In overturning the hearing officer's determination, Commissioner Ambach noted that State and Federal law "create a clear preference for mainstream programs which are appropriate to a student's needs," and that preference for mainstream programs includes "non-academic programs as well as academic instruction."

Robert G. Wakeman, Esq., was retained by Parent Advocates for the Retarded to represent Mr. and Mrs. Edmund Gillette in the hearing before the Commissioner.

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

October 15 - 18,  
1981



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TO: Turf Inn  
205 Wolf Road  
Albany, N.Y. 12205

Gentlemen:

Please reserve the following accommodations for me at the Convention of the New York State ARC, October, 1981:

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Albany, N.Y. 12210  
Attn.: Convention Registration Chairperson

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Buffet Breakfast	\$ 5.25
Luncheon	\$8.00
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