

# Our Children's Voice

Retarded Children Can Be Helped

VOL. XXXIV NO. 1

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

JANUARY 1982

## Pattison re-elected at State Convention



Officially installed, and able to relax, State President Eleanor Pattison smiles as John McLoughlin, Senator William T. Conklin, Sherri Messier and Billy Conklin look on.

### PRESIDENT'S MESSAGE

Although I have attempted to personally contact many members of the Association since our Fall Convention in Albany, this column is the only way I know how to say thank you to everyone! Thank you for the confidence you have expressed for my past interpretation of the presidency and for my capabilities in the year ahead.

I am the first person to recognize this in no way means there were no deficits or weaknesses in my role. Instead, I, and I hope all of us, have learned and grown in the job, thus building on positives and correcting where necessary.

There are some difficult months ahead — transition of office staff, healing of wounds, and renewal of energy, to name a few. Even in recognizing these activities as an important part of a process, our

sights must be above and beyond our immediate needs.

Steps are being taken to assure a smooth transition. A Search Committee is already formulating its procedures so the identification of an Executive Director is accomplished with careful, concerned expediency.

Most important of all, however, is that everyone recognizes that this Association has emerged and will continue to emerge stronger, more united, and undaunted in its unswerving basic purpose of speaking with one voice on behalf of those citizens of this state who are developmentally disabled and mentally retarded.

Join with me in rededication to that purpose, for only together will we succeed.

Eleanor Pattison

### Sherwood named Acting Director

On December 5, 1981, the Executive Committee of the New York State Association for Retarded Children appointed Geraldine L. Sherwood as Acting Executive Director until a permanent Executive Director is named. Mrs. Sherwood serves as Assistant Executive Director of the State ARC.

In commenting on the appointment, President Eleanor Pattison said, "we feel confident that those of you who already know Gerry as we do, share the same high regard for her competency, commitment to the principles of our Association and concern for Chapter needs. Knowing Gerry is part of our team makes our work as a Board in the difficult times ahead, a little bit easier."



GERALDINE L. SHERWOOD

The 31st Annual NYS ARC Convention held at the Turf Inn in Albany saw a record number of Board of Governor representatives in attendance with almost 90 percent of our chapters responding to roll call.

The event planned and hosted by our three capital district chapters provided a diversified program consisting of workshops and cracker barrel sessions which presented opportunities for information sharing among members, governors and staff of our chapters. The collaborative efforts of Mark McDermott, Ken Bromley and Howard Church with Irene Haines, representing Albany, Schenectady and Rensselaer chapters, respectively, culminated in an innovative format which met with enthusiastic response from those who attended.

Traditionally one of the Highlights of our annual convention is the election of officers. This year saw the return of Ellie Pattison to the presidency for a fourth consecutive term. Joining Ellie in her governance role for 1982 are fellow officers, Irene Platt (New York City) as Senior and Southeast region Vice President; Shirley Valachovic (Schenectady), as Northeast Vice-President; William Ingraham (Cortland) as central Vice President; David Lettman (Erie), as Western Vice President; Shirley Reynolds (West Seneca) as Secretary; George Hirsch (NYC) as Treasurer; and Irving Caminsky (Rockland) as Assistant Treasurer.

The election, by the delegate assembly on Sunday morning, of Al Turk (Benevolent Society), Richard Marcil (Broome) and Robert Horn (Onondaga) completed the Executive Committee Roster for 1982.

Bill Conklin, retired N.Y.S. Senator, long-time friend of the Association, and outstanding legislative advocate for those who are retarded, affiliated at the Installation Ceremony where officers and representatives to the Board of Governors were installed.

These resolutions were adopted by the Delegate Assembly:

**RESOLVED:** That the New York State Association for Retarded Children, Inc. assembled in convention at the Turf Inn, Albany, New York on October 15-18, 1981, express its appreciation to the Albany, Rensselaer and Schenectady County Chapters of the Association, their Officers and Directors and their Committees for their excellent arrangements, organization and hospitality.

**RESOLVED:** That this Association and Board of Governors support, through their legislators, the request, now in the Supplemental Budget, for OVR Case Service Fees of 16.4 percent.

**RESOLVED:** That the New York State Association for Retarded Children, Inc., recognizing there has been no increase in the per diem reimbursement rates for Day Treatment programs since 1978, support the need for legislation to increase this rate on an interim basis until OMR-DD can develop and implement an adequate fee structure.

**RESOLVED:** That this Association endorses the creation and funding, by the State Legislature, of a permanent Commission on the Prevention of Mental Retardation and Developmental Disabilities.

**RESOLVED:** Whereas, newborn screening has already been documented to be strongly cost beneficial to the tax payers, but continues to be underfunded even though mandated, we recommend that legislation be passed to create and fund a statewide regional system of newborn screening for preventable causes of mental retardation and developmental disabilities. This legislation should provide necessary funding for the follow-up, confirmation and treatment, as well as development of new screening methods to improve the programs.

**RESOLVED:** That legislation is necessary to mandate screening of all preschool children on at least an annual basis for lead poisoning in view of the recent findings that children are at risk in rural and suburban areas where no screening programs exist, and where there are no plans for such programs.

**RESOLVED:** That legislation is necessary to require that a label be placed on all containers of alcoholic beverages sold in New York State. Wording of the message should read as follows:

**WARNING!** Consumption of alcohol during pregnancy has been shown to be hazardous to the development of the unborn infant.

**RESOLVED:** Inasmuch as the 1981 proposed legislation has not been completed or implemented, be it resolved that we reaffirm the 1981 legislative proposals:

#### A. STATE INSTITUTIONS AND SERVICES

##### Admissions and Discharge (Institutions)

1. It is recommended that a bill be introduced to give the Commissioner of OMR-DD, in consultation with an independent body, the authority to make decisions on admissions and discharges to and from developmental centers.

#### B. COMMUNITY MENTAL RETARDATION

##### SERVICES

##### 100 Percent Funding

1. Provision that funding of community services for the non-institutionalized mentally retarded be on a basis of parity with the funding of such services for those de-institutionalized - 100 percent funding by the state.

##### Interest on Loans

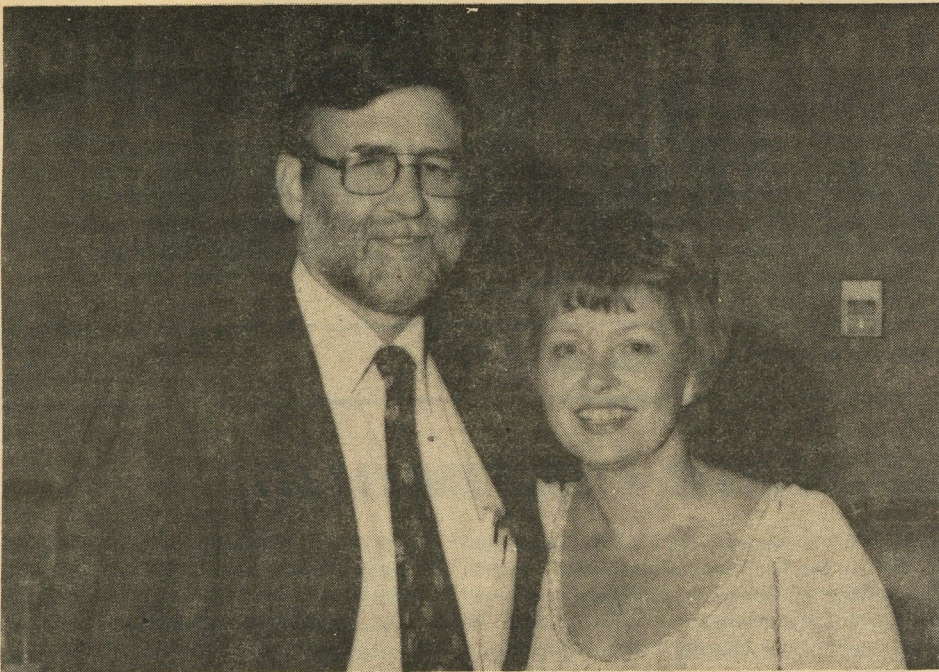
2. Provision that interest on loans necessarily obtained by volunteer agencies because of failure of the state to make payments on time by reimbursable items included in budget costs.

##### Interest on Mortgage Loans

3. Provision that interest on mortgage loans made by voluntary agencies for acquisition, construction or remodeling

Continued on Page 10





For all those who have really wondered — YES! there is a Ned Pattison. Our roving photographer caught him in a rare ARC appearance with our President.

## How to exert political clout

Former Congressman Ned Pattison chaired a well-attended NYSARC Convention workshop which focused on helping members and staff develop political influence to further goals for those who are retarded. The following summarizes the cogent points covered in his timely and effective presentation.

Ned emphasized that the greatest single impediment to exercising political influence with those who represent you at every level of government, is the belief that there is something mysterious, sinister, or not-quite-on-the-level surrounding the whole business; that the only way things are accomplished where politicians are involved is by special favors to shadowy types who know how to put in the fix as a result of some kind of special influence. As long as honest people believe that, the extent to which it is actually the case will continue and expand.

The truth, and he spoke from many years as an active observer of, and participant in, the legislative process, is quite to the contrary in the vast majority of cases. Indeed, one of the best kept secrets of the American legislative process is that it is by and large on the level.

Once you understand that, if you do not read beyond the end of this sentence, you have already learned most of what you need to know in order to influence the legislative process.

There are however some useful hints that may improve your effectiveness.

1. Try to remember that the basic currency of politics is votes. All politicians, from the most principled to the most depraved, are interested in pleasing as many constituents as possible. Some will go to any lengths, others only so far. In every case, a politician would rather please than anger. But if the politician is not even aware of your existence, he is not likely to be influenced by it. So make sure your representatives know who you are, what you do, and how many of you are involved in doing it. Invite him to meet with you and see your operation. Invite him to attend your annual dinner. Recognize his presence and ask him to "say a few words". And do it on an ongoing basis, before you need his vote on some issue.

2. Understand that most issues are not resolved by ideology of the left or the right. Most issues are matters of priority, not principle. This is a society of claimants, and the claims always exceed the resources available. As a result, decision makers are required to make choices, among competing claims, satisfying some and not satisfying others. It is the task of each claimant group to establish its claim as far up on the hierarchy of claims as possible, based both on merits of the claim and on the number of constituents who will be either pleased or disappointed.

3. Recognize the multiplicity of the issues that the representative has to deal with. Understand therefore that the representative may not be as familiar with the issues that concern you as you are. Give the man a break. Without insulting his intelligence, describe your problems and concerns in basic, not technical, terms. And briefly do it again each time so his recollection can be refreshed without embarrassment.

4. Never mislead your representative with exaggerated facts or bad information. If there is another side, tell him what it is even if you dispute it. Little is more damaging to your cause than putting your representative in a position where he gets blindsided by an argument that he is not even aware of, or by the reputation of some inaccurate fact or misleading statistic that you have given him.

5. Whenever you decide to embark on a short term campaign for support on some pending issue, understand that quantity weighs in more heavily than quality. Fifty short letters or calls will carry more influence than five long and thoughtful letters. And, by the way, only a minor percentage of your members will write or call as a result of an announcement at a meeting or a notice in the bulletin, in spite of their good intentions and assurances. If you need fifty letters, provide the pen and ink and do not let them out of the room until the letters are in hand.

By the way, there are many ways to communicate your ideas to your representative besides letters and calls. Find out what his schedule is when he is in his district so you can attend his town meetings if he has them, meet him on the street, call him when he is on the local talk show, and mention your concerns when you see him at the ribbon cutting ceremony or other civic event.

6. Do not ever write him off. Just because you did not vote for him, do not like his political party or philosophy, or generally dislike him, he is still your representative, he would still rather please than anger you; and, in spite of the fact that in general he does not support your positions, he will probably surprise you from time to time. But if you do not ask, you will not receive.

- 7, 8, 9 and 10. Respect his time, he only has a limited amount of it. Respect his memory. No matter what you have heard about the politician's memory for names and faces, its mostly myth and should not be tested. Introduce yourself every time or wear a name tag with large letters. Always be polite. It is possible to disagree without being disagreeable.

## Thank You Frances Reville

After many years of dedicated service to NYSARC, Frances Reville has resigned as treasurer of the association. Frances has effectively performed in this capacity for 12 years while simultaneously serving at the state level on the Budget and Finance Committee, the Institutions Committee and the Executive Committee of the Board.

In addition to her involvement with NYSARC, Frances serves on the Board of Visitors for Letchworth Village D.C. and Manhattan D.C. She was appointed by Governor Carey to the Advisory Council to

the Commissioner of OMR-DD and the Council on Developmental Disabilities, and has served as Chair of the Long Range Planning Sub-Committee.

Frances has a long and distinguished career of commitment to the voluntary sector and is recognized and respected as a staunch advocate for those who are disabled.

We take this opportunity to express our appreciation to Frances Reville for her many years of faithful service to the association.

### BOOK REVIEW

## In and out of mental retardation

"All people are equally valuable and deserve to be part of a normal world. . ." writes Burton Blatt, Dean of the School of Education at Syracuse University, in his latest book "In and Out of Mental Retardation: Essays on Educability, Disability, and Human Policy" (University Park Press, 1981, \$19.95).

The book is a compilation of 15 essays Blatt has written over a 30-year span in which he documents the horrors he has seen, and examines the fears and prejudices that foster segregation and dehumanization of the mentally retarded. In the book's preface Blatt writes: "We must try to change the world, else we contribute to its evil."

Blatt believes the mentally retarded must gain equal access to ordinary society. "For that to occur," he says, "it is not so much the task of the retarded to change, but the task of the world to change."

"Schools are ridden with the idea that people do not change. Mental retardation is viewed as irremediable and incurable.

However, there is a great deal of evidence that illustrates the potential for change. The mentally retarded are entitled to the opportunity to learn. All people can learn.

"For many generations, workers in the field of mental retardation have viewed retardation as a clinical problem — they have tried to help the retarded learn better, adjust better, learn to do a job. That is important, but if that is all that is done there will always be those who do not quite measure up. The greater task is for society to better understand that all human beings — be they severely retarded or college professors — are equally valuable."

Blatt is the author and editor of numerous books and articles on mental retardation including "Christmas in Purgatory: A Photographic Essay on Mental Retardation," "Exodus From Pandemonium: Human Abuse and a Reformation of Public Policy," "Souls in Extremis: An Anthology on Victims and Victimized", and "The Family Papers: A Return to Purgatory".

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NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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# Legislation - 1981, 1982

The 1981 legislative session ended without significant gains having been achieved in terms of specific NYSARC legislative goals. Most of the 1981 legislative platform, therefore, will be carried over with increased efforts to achieve passage of these bills.

These are among those bills enacted into law for those whom we serve:

## CHAPTER LAWS 1981

### Chapter Law 412 (S-4860A Padavan)

RE: Mental Hygiene Law, provides that, subject to regulations of commissioner, operating costs shall include part of rental costs paid to those community mental health or mental retardation service costs, which represents interest accrued after Jan. 1, 1981 and is paid on obligations incurred thereby, organized pursuant to Art. 75 hereof and which participated in mortgage financing in accordance with Chapt. 1034 of 1969.

### Chapter Law 434 (A-5161 Walsh)

RE: Civil Service Law, increases from 400 to 500, maximum number of positions which civil service commission may determine with duties such as can be performed by physically or mentally handicapped persons.

### Chapter Law 588 (S-6779A Padavan)

RE: Mental Hygiene Law, amends the mental hygiene law, in relation to the advisory council on mental retardation and developmental disabilities and to amend the executive law, in relation to establishment within the executive department of a developmental disabilities planning council.

### Chapter Law 611 (A-8056 Connelly) (S-6957 Padavan)

RE: Mental Hygiene Law, amends the mental hygiene law, in relation to appointing a receiver for the operation of residential facilities for the mentally retarded and developmentally disabled.

### Chapter Law 612 (A-9001 Comm. Rules)

RE: Mental Hygiene Law, amends the mental hygiene law, in relation to determining funding methods for sheltered workshops, work activity and day training services, and making an appropriation therefore.

## NYSARC LEGISLATION PROGRAM 1981

These bills represent carryover items from 1981 and some additional bills which will be the focus of our attention in the months ahead:

### A-1126 LIPSCHUTZ (See S-y49 Calandra)

An act to amend the family court act and the education law, in relation to authorizing certain handicapped persons over the age of twenty years to obtain educational services.

### A-1198 KREMER (see S852 - Padavan)

An act to amend the mental hygiene law, in relation to parental liability for fees.

### A-1553 SANDERS

(This bill could destroy existing sheltered workshops and any growth in the sheltered employment area for the disabled.)

To extend definition of employee for purposes of minimum wage to include person engaging in sheltered employment as defined in provision relating to sheltered workshops for mentally retarded, mentally ill and severely physically handicapped.

### A-333-A GOTTFRIED (see S-2570 Flynn)

An act to amend the insurance law, in relation to life insurance for mentally retarded persons.

### A-4355-A PILLITTERE

An act to amend the transportation law,

in relation to a transportation operating assistance pilot project for the transportation disadvantaged in nonurbanized areas and making appropriation therefore.

### A4509-A ROBACH (see S4966 Pisani)

An act to amend the workers' compensation law, in relation to insurance of not-for-profit corporations.

### A-4775-A GRABER (see S1027 Kremer)

An act to amend the vehicle and traffic law, in relation to providing for a non-operating driver's license.

### A-5628 GRANNIS

To require that public health commissioner conduct outreach and education program to inform pregnant women of benefits of prenatal care and sources of such care and to encourage them to seek prenatal care early in pregnancy, which shall be directed primarily at reaching pregnant women residing in designated high risk areas, especially those women who are adolescents or alcohol or drug abusers; makes provision for prenatal care demonstration program, eligibility for medical assistance for such care and reimbursement for prenatal care in high risk areas; fixes reporting requirement and describes period of effectiveness thereof.

### A-6054 KREMER (see S-4378 Levy)

An act to amend the mental hygiene law, in relation to including certain costs in the definition of costs of mental health, mental retardation and alcoholism services and making an appropriation therefore.

### A-6663-B HEVESI

An act to amend the civil rights law, the executive law, the labor law, the education law and the insurance law, in relation to prohibiting certain discriminatory practices and repealing certain provisions of article four and repealing article four-B of the civil rights law relating thereto.

### A-7387-A DUGAN

An act to amend the labor law, in relation to the definition of "employee" and minimum wage in certain cases.

### A-7943 McCABE

To appropriate \$50,000 to education department for establishing training program for impartial hearing officers to hear appeals from parents or guardians of handicapped children; requires that such officers be individuals who have completed approved training program as determined by regulations of commissioner, and if education board or trustees fail to effectuate recommendation of committee on handicapped within required period of time, education board shall appoint impartial hearing officer to hear appeal and make determination.

### A-8014 TALLON

To amend Pub. Health Law, to repeal provisions relative to state aid and to enact new provisions providing for state aid for basic services and additional services as set forth herein whereby municipalities are required to annually file public health services plan, employ full time local health commissioner or public health director to supervise same and appropriate and make funds available for such services, with state aid to be in form of base grant and reimbursement as set forth herein for such basic services; makes provisions as to state aid reimbursement for basic public health services and related provisions as to state aid for additional services and limitations thereon.

### A-8538 COMMITTEE ON RULES — CONNELLY

An act to amend the mental hygiene law, in relation to funding sheltered workshop,



Before the Convention Banquet Reverend Howard J. Hubbard, Bishop of the Albany Diocese, Albany Mayor Erastus Corning II, President Eleanor Pattison and Walter H. Johnson, Jr., President Quadrant Marketing Counselors Ltd., the main speaker get together.

day training and work activity services for the developmentally disabled and making an appropriation therefore.

### A-8768 COMMITTEE ON RULES — McCABE

An act to amend the mental hygiene law, in relation to community residential facilities.

### A-9227 (see S-7195)

### S376 FLYNN

An act to amend the executive law, in relation to recognizing and declaring equality of opportunity and freedom from discrimination because of a disability to be a civil right.

### S-749 CALANDRA (see A1126 Lipschutz)

An act to amend the family court act and the education law, in relation to authorizing certain handicapped persons over the age of twenty years to obtain educational services.

### S-852 PADAVAN (see A-1198 Kremer)

An act to amend the mental hygiene law, in relation to parental liability for fees.

### S-1027 GOODHUE (see A-4775-A Graber)

To require commissioner upon application of state resident at least 18 years of age, to issue non-operating driver's license if applicant submits required proof of name, age and address, and fee of \$3, with such license to be used by license for ID or other purposes, but not for vehicle operation.

### S-1302 LACK

To require education department to authorize board of education or trustees of school district to provide transportation to and from educational facilities for handicapped person who has attained age 21 who is not receiving instruction due to lack of transportation.

### S-2419 PISANI

To provide that special classes and programs for which board of education or trustees of school district are required to provide suitable transportation shall include continuing education schools and vocational rehabilitation facilities, including sheltered workshop programs, notwithstanding that such handicapped persons have attained age 21.

### S-2570-A FLYNN (see A-3333-A Gottfried)

An act to amend the insurance law, in relation to life insurance for mentally retarded persons.

### S-2885-A PADAVAN

To provide that schools under jurisdiction of mental retardation and developmental disability commissioner at Bernard Fineson developmental center shall have board of visitors consisting of at least 7, but not more than 10 members.

### S-4116 GOODHUE

To coordinate, cooperate with and stimulate public and private not-for-profit association and other agencies in promoting and implementing eligible programs and activities for reducing perinatal, infant and maternal mortality and morbidity and to promote health of people of childbearing age, infants, children and adolescents in certified areas. To provide grants to entities for programs satisfying eligibility requirements described herein for residents of certified geographical areas.

### S-4378 LEVY (see A6054 Kremer)

An act to amend the mental hygiene law, in relation to including certain costs in the definition of costs of mental health, mental retardation and alcoholism services and making an appropriation therefore.

### S-4966 PISANI (see A-4509 Robach)

An act to amend the workers' compensation law, in relation to insurance of not-for-profit corporations.

### S-7195 COMMITTEE ON RULES

An act authorizing the commissioner of mental retardation and developmental disabilities to conduct a study to assess the service needs of certain handicapped children, and to amend the family court act and the education law, in relation to handicapped children within the jurisdiction of the family court and repealing subdivision one of section forty-four hundred six of the education law relating thereto.

The above capsules are necessarily brief; however if you wish the complete text of any bill which is of particular interest to you, contact the following:

Senate Document Room 317  
State Capital  
Albany, New York 12224  
Telephone: (518) 455-2311

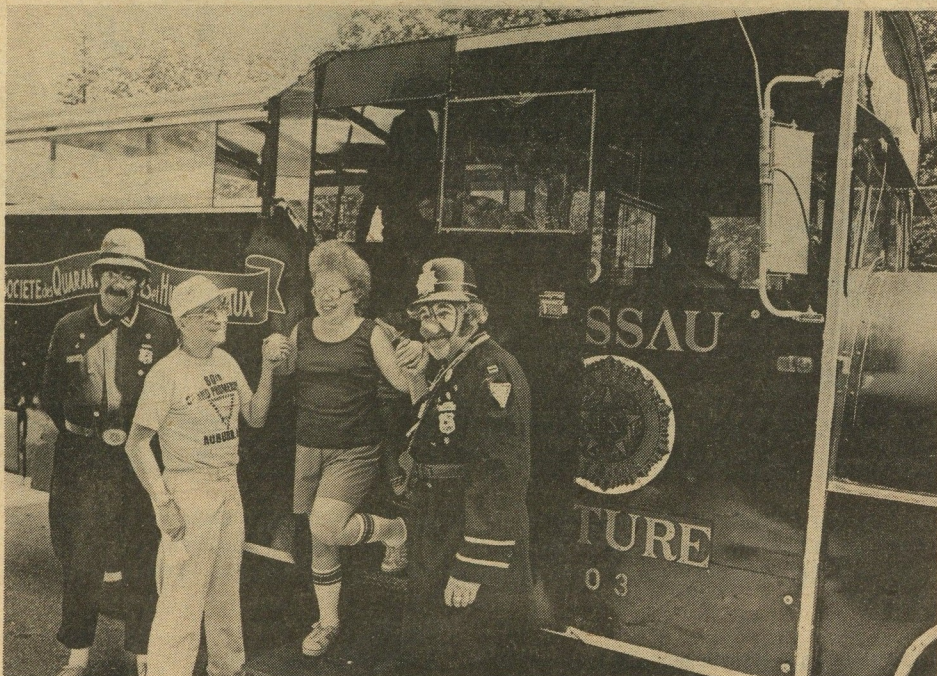
Assembly Document Room 305  
State Capitol  
Albany, New York 12224  
Telephone: (518) 455-5165

A status report on each bill can be obtained by dialing the legislative toll-free "Hot-Line", 1-800-342-9860.



# CHAPTER NEWS

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



The American Legion 40 and 8 was one of the attractions at the Policemen's Benevolent Association party which was held at the Brookville campus of the Nassau AHRC for the children in the AHRC summer day program. The off-duty policemen ran games, gave a barbecue, sounded their sirens and gave the children a real treat for the day.

Our leading Chapter in the October Cash-Back Lottery Ticket Collections was **SUFFOLK COUNTY CHAPTER** with a month's total of 21,812. That's the way to start off Phase III Suffolk. October also saw the opening of Suffolk Chapter's gift shop at their Bohemia Headquarters. The Grand Opening was scheduled for October 1st. This hop will be run by volunteers, and will stock a fine selection of gold, silver and costume jewelry, as well as a wide variety of boutique and gift items. The Babylon Auxiliary sponsored a Masquerade Ball on October 3rd at the Feustal Kurdt American Legion Hall. There was unlimited liquor, a hot buffet and live music. Need we say that everyone had a good time.

**ALBANY COUNTY CHAPTER** presented a "Dress for Work" fashion show. The show was intended to teach clients how to dress properly for work. Some of the fashions were provided by Macy's of Colonie and Hairstyles and make-up were the courtesy of Hair House Beauty Salon and the Austin and Colonie Beauty Schools. It was fun and educational too.

Our **ORLEANS COUNTY CHAPTER** scheduled a Ride-A-Bike. This fund raiser is similar to a walk-a-thon and the top prize of a 10 speed bike was the courtesy of the Medina Jaycees.

It was an honor to have Judge Edward Horey, surrogate of Cattaraugus County attend a meeting of the **CATTARAUGUS COUNTY CHAPTER** to discuss guardianships with all who were interested. The program was coordinated by St. Bonaventure University office of estate affairs and a film on the subject of "Financial Planning — Wills" was presented.

Congratulations to **ULSTER COUNTY CHAPTER** on its 25th anniversary. Celebrations included an open house at the new central Kingston site and a planned dinner - dance on November 6th at the Wiltwyck county club. Music was furnished by Papa Bear's Band and the dinner was filet mignon. Now that's the way to celebrate.

And speaking of celebrations, the **SCHUYLER COUNTY CHAPTER** held their annual Chicken Barbecue at Havanna Glen in Montour Falls. The barbecue is an annual get together for members and friends of the chapter.

Charles Mathews of Montour Falls won the 50-50 Raffle for \$40 and donated the money back to the chapter. The Handicapped, Boy Scout Troop 154 from Elmira Heights also attended. The event was a great success.

**WAYNE COUNTY CHAPTER** had an open house at the Roosevelt Center for Educational Activities for parents and board members. A slide show was presented followed by a tour of the facility. Viewed were the new renovations which included new shades, painting of all classrooms and the addition of new classroom. The program serves 38 full-day pre-schoolers and 14 children in the Infant Development Program. Wayne Chapter has come quite a way since its beginnings in 1964 when 12 parents met to discuss the lack of community services and educational programs for their retarded children. There are now over 180 members in the chapter servicing 367 individuals. Wayne Chapter can be proud of its accomplishments.

The **ST. LAWRENCE COUNTY CHAPTER** held a special meeting to discuss guardianships, trusts and rights of handicapped children and adults. Governor Attorney Charles Gardner was guest speaker. All aspects of guardianship, including emotional impact and financial affairs, trusts and rights were open to discussion.

**DUTCHESS COUNTY CHAPTER** GUEST SPEAKERS FOR October were Patricia Gilbert, Ph.D. a clinical psychologist who described programs offered at Wassaic D.C. and Mrs. Patricia Shanny who discussed Down's Syndrome and offered an update on medical information as well as a review of crisis intervention for parents of newborns with handicaps.

New housing for 12 geriatric clients is becoming a reality at **ORANGE COUNTY CHAPTER** with the awarding of a \$335,800 grant from the Department of Housing and Urban Development. Present plans call for the placement of 6 ambulatory and 6 non-ambulatory residents.

**MONTGOMERY COUNTY CHAPTER'S** Christopher Sollecito Memorial Scholarship has been increased this year to \$400 and in addition offers a summer internship to the recipient. Its purpose is to aid third and fourth year college students

from Montgomery County majoring in special education or a related field.

The **PUTNAM COUNTY CHAPTER** is proud and pleased with their acquisition of a new Vocational Rehabilitation property in Carmel, New York and which will be expanded utilizing combined OMR-DD, DDA and OVR funds by spring of 1982. Those grants, coupled with resale funds of the agency's Bower Road property in Kent, New York enable the Chapter to look forward to a 20,000 square foot facility fully equipped to accommodate it's expanding program.

The long-range goals for the Chapter are to endeavor to secure cash funds which would allow for consolidation of all programs at the above noted site by 1984 so as to curtail costs and to allow for a continuum of service and smoother administrative interaction between the multifaceted programs comprised of Day Treatment services, Vocational Rehabilitation, Clinical services, Preschool services, Clerical Training and our ten community residences.

**CHAUTAUQUA COUNTY CHAPTER** was fortunate to have Richard Huber, an estate and financial planning consultant, as their guest speaker to talk about "Estate Planning for Parents of the Mentally Retarded," during their October membership meeting.

It's not all work at **ONTARIO COUNTY CHAPTER**. At least not during Soccer season. Ontario Chapter had scheduled a two session soccer clinic which was open to all developmentally disabled residents of the county. That's a great way to stay in shape and have a lot of fun doing it! The Chapter also sponsors instruction in Disco Dancing and conducted a dinner - dance at the Phelps Hotel. The evening included a social hour and dinner, followed by dancing and was open to all developmentally disabled residents of Ontario County, 18 years of age or older.

**SENECA COUNTY CHAPTER'S** Day Training Program is flourishing and having fun with Saturday afternoon bowling and Thursday night Square Dancing. A Thanksgiving feast was held for friends and family.

A Residential Home is in the negotiating stage.

## Respite Manual available

For This Respite, Much Thanks. . . , a manual on Respite Care is the outcome of a two-year project, conducted jointly by UCPA and the Special Education Development Center of the City University of New York, funded by the Federal National Significance Developmental Disabilities Grant.

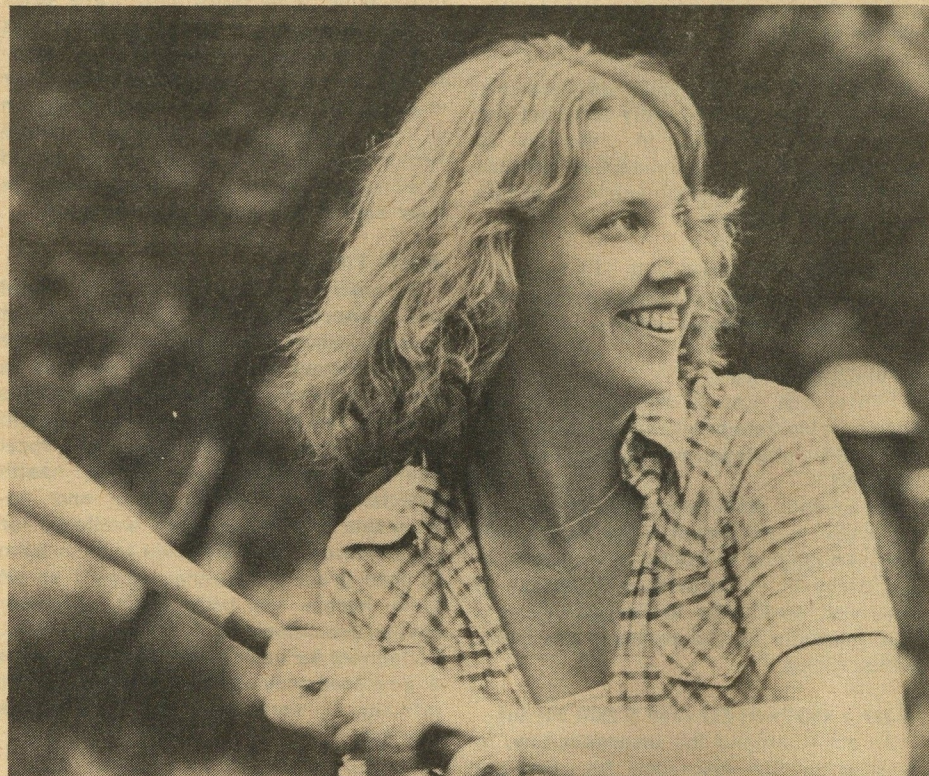
The purpose of the project was to demonstrate how effective service and education programs can increase the ability of families to care for their disabled members at home.

Samples of forms, guidelines for parents and respite workers, programs of parent education and other materials used by established respite care programs are included. There is also an extensive analysis, made by the UCPA Governmental Activities Office, Washington, D.C. of possible sources of government aid for respite care programs.

The manual may be ordered from the Professional Services Program Dept., UCPA, 66 East 34th Street, New York, New York 10016. The price is \$3 per copy.

## Teenage pregnancy grant received

Erie Chapter has recently been awarded a one-year grant through the Department of Social Services Teenage Pregnancy Program. This project will focus on the problems and risks of teenage pregnancy among the mentally retarded population. The staff person, who will be hired under the grant, will develop three curricular to address the issues of (1) parents who would like to learn how to more effectively teach sexual information to their retarded adolescents, (2) retarded adolescents who need to learn how to handle themselves in social and potentially sexual situations, and (3) very young and/or limited parents who need to further their parenting skills.



It was batter up as Valerie Zurbliis, editor of the Nassau Illustrated News and a member of the Press Club of Long Island, took her turn when her team played the Press Photographers Association of Long Island. The game was won by Valerie's team, the Press Club, but actually the real winners of the day were the retarded boys and girls who are served daily by the Nassau AHRC which was the recipient of the day's proceeds. The softball game was held at AHRC's Brookville center. Beer and ice for the event were donated by Budweiser.



## Governor's Conference directed to form Prevention Action Plan

Despite impressive reductions in infant mortality rates, approximately 3,200 infants die each year in New York State prior to their first birthday. Each year, about 10,000 children are born or become afflicted with mental or physical disabilities which may significantly affect their subsequent development.

In an effort to avert more of these tragic and costly happenings and to evaluate and bolster State efforts to prevention and early intervention, Governor Hugh L. Carey established the Governor's Conference for the Prevention of Developmental Disabilities and Infant Mortality. The Conference is composed of the Commissioners and Directors of 11 State agencies responsible for health and social services, together with twenty-seven representatives chosen by the Governor from the private and voluntary sectors.

The Governor's general charge to the Conference was to develop a Prevention Action Plan for consideration and use by the Legislature, State agencies, health educators, and social and health service providers, as well as the general public, with the goal of improving the health of future generations of New Yorkers. Specifically, the Conference was directed to:

1. gather and analyze data and information relating to the activities of preventive and early intervention programs;
2. establish goals with respect to the availability, accessibility, quality and cost of such programs;
3. review federal, state, and local preventive and early intervention programs and identify:
  - a. existing inadequacies;
  - b. possible modifications of programs, if appropriate;
  - c. new initiatives;
4. recommend strategies to improve the effectiveness of such programs, and
5. hold public meetings to solicit comments from interested parties for consideration in formulation of a final plan.

The end product of this process, which occupied the Conference members and staff throughout the winter, spring and summer of 1981, is a Prevention Action Plan which recommends the pursuit of seven basic goals which the Conference believes will enhance the prevention of developmental disabilities and infant mortality. The goals are:

- I. To offer information to residents of New York State on the factors which influence their reproductive health and the health of their unborn, and the physical and psychological development of their infants and children.
- II. To reduce the toll of infant death and disability in New York State, basic preventive and primary care services should be available and accessible to all in need regardless of geographic location, socio-economic status, marital status, or age.
- III. To ensure services to all New York State families at medical risk for atypical pregnancies, and to promote the optimum development of infants and children who are disabled and their families, appropriate services must be available, accessible, and acceptable.
- IV. New York State must encourage the prevention of developmental disabilities and infant mortality and also lessen the consequences of developmental disabilities when they occur, by ensuring educational and training services for school children and teens within or outside the school system and training services for parents and service providers.
- V. New York should have a system of human services that is available to all

families and children. A full range of continuous primary level preventive and therapeutic health care, social service education resources, as well as consultation, referral, transportation, and follow-up services, should be available in an appropriate and timely fashion.

- VI. The State of New York should ensure the continuation of research into the causes and effective means of prevention of developmental disabilities and infant mortality.
- VII. The State of New York should ensure the continuation of preventive efforts.

The Action Plan is organized into five sections with a separately bound volume of appendices and bibliography. Section I is an introduction which describes the Governor's charge to the Conference, presents a statement of conference objectives and provides important definitions to assist the reader. Section II provides an overview of the problem of infant mortality and developmental disabilities. Section III describes in more detail the causes of developmental disabilities and infant mortality. Section IV describes the wide range of prevention programs and services available in New York State and discusses significant issues raised in the deliberations of the Conference. Section V presents a detailed set of goals, objectives and private sector decision-making in reducing the incidence of developmental disabilities and infant mortality.

The entire plan covering recommendations formulated to implement dramatic changes in the way State governments work toward the prevention of developmental disabilities and infant mortality can be requested from Diane Smith, Project Coordinator, N.Y.S. Governor's Conference for the Prevention of Developmental Disabilities and Infant Mortality, Empire State Plaza, Tower Building, Room 1683, Albany 12237.

### Helping Hand

Greyhound's "Helping Hand" service, created in 1975, takes the handicaps out of travel for the handicapped. Practical incentives have stimulated increased use of this service which costs no more than for anyone else.

Companions travel without additional charge, both on a single adult-fare ticket. Travelling together the entire trip, the companion assists enroute, in boarding and alighting. Non-motorized wheelchairs and certain other aids and devices are carried as baggage without additional cost.

A letter from your doctor, on his letterhead, addressed to Greyhound Times, Inc. indicating that in his judgment the individual can travel by bus when accompanied by an attendant, and indicating whether the disability is permanent or temporary, constitutes the letter of eligibility required by Greyhound.

### Is Social Security system sound?

In response to a request by Governor Carey of upstate health and human services commissioners, a special task force conducted a study and prepared a report entitled, Keeping Social Security Strong, which refutes many of the myths currently circulating about the Social Security System.

If you would like a copy of this publication, write to:  
Public Information Office  
New York State Office for the Aging  
Agency Building 2  
Nelson A. Rockefeller  
Empire State Plaza  
Albany, New York 12223



Pictured with their award winning designs are Stan Popielarz and Elaine Fountaine of Oswego County Chapter, with Dorothy Gibbo, (r) the Work Activity Center Supervisor.

## Christmas card design winners

Oswego Industries has the honor of having two winners in the 1981 State Christmas Card Contest. Stan Popielarz won a \$100 Savings Bond for 1st place and Elaine Fountaine received a \$50 bond for third place. This was not Stan and Elaine's first time as winners. Stan won honorable mention in 1979 and in 1980 Elaine was awarded a \$25 Savings Bond.

Dorothy Gibbo, the Work Activity Center Supervisor recognized the art talents of the employees at Oswego Industries and encouraged everyone to enter the contest. She has organized the contest since 1978.

Needless to say everyone at Oswego Industries was excited and proud when we received the news about Stan and Elaine.

When Stan received the news he kept shaking his head and saying "I can't believe it", "I'm glad it happened. I won \$100". Stan uses his talent in other ways such as drawing on wood and using a jig saw to make articles to sell. His interests are bowling, going to movies, driving his own car and attending Adult Education classes at S.U.N.Y. at Oswego. Stan is an officer in the Oswego Industries Social Recreation Club — S.C.O.R.E.

"I was pretty happy" was Elaine's response when asked how she felt about winning third place. Elaine draws at home and sometimes gives her drawings away for gifts. Her interests are Math, needlework, visiting friends and she especially likes meeting with her literacy volunteer.

They both stated they will be entering the contest again next year.

Other Oswego Industries employees who participated in the 1981 contest were Dave Hart, Bob Arden, Bob Perry, and Ken Hughes.

Congratulations Stan and Elaine!!

Delaware Chapter is proud of its winning entry. Second prize in the annual Christmas Card Contest was awarded to Jennie Strother for her charming design featuring two children on a sled, enjoying the holiday fun.

Jennie was happily surprised to learn of her award. She never thought she could have won a prize in the contest. In fact, she had to be encouraged by her teacher, Mrs. Chichester, to even participate in the program. After much encouragement, Jennie and Mrs. Chichester sat down and discussed the theme for the card which later won the award.

Jennie is the daughter of Harold and Ella Strother of Gilboa. She is eleven years old and is the youngest of five children.

At the time she entered the contest, Jennie was a student in the BOCES Primary EMR class at the Stamford Central School. According to Mrs. Chichester, Jennie does well at gymnastics and art and has an extremely good sense of rhythm. She also does well in math. While in Mrs. Chichester's class, Jennie had been mainstreamed in music and gym and was being prepared for mainstreaming in math, too. Jennie was well liked by her peers and was considered a part of the family at school.

Within the last few weeks, Jennie's progress has been such that she has been advanced to the intermediate EMR class operated by the BOCES at the South Kortright Central Schools. Her new teacher is Mr. Stephen Peskin. Her current curriculum includes math, reading, social studies, home economics, art, gym, and music.

The second place prize, a seventy-five (\$75.00) dollar bond, was presented to Jennie by Thomas Banks, President of the Delaware County Chapter, at her class. The chapter provided refreshments for the entire class in honor of Jennie's success. According to Mr. Banks, "The smile on Jennie's face and the feeling of pride that she evidenced let us know that our efforts in supporting the contest were well worthwhile. We are truly pleased that Jennie has received this recognition for her fine art work."

## State committee to develop living programs

A State interagency committee has been established to develop supportive living programs for physically disabled persons. The committee, which meets with prospective sponsors of supportive housing for physically disabled persons to discuss transitional housing and to provide coordinated guidance and assistance, is composed of representatives of DHCR, Office of the Advocate for the Disabled, Office of Vocational Rehabilitation and the Department of Social Services: Commission for the Blind and Visually Handicapped, and the Divisions of Adult Services, Medical Assistance, and Income Maintenance. Organizations interested in developing programs should write to: William Jacobi, NYS Department of Social Services, 40 N. Pearl Street, Albany, N.Y. 12243, (518) 474-9383.



## What should be done?

In a recent article in **UPFRONT**, Dr. Harold E. Yunker discussed the problem of public attitudes toward Americans with disabilities stressing the importance of providing opportunities for those who are disabled to present themselves and to be portrayed in the most positive light possible.

This excerpt is from the New York State Consumer Advocacy Network Newsbulletin:

Americans have a variety of attitudes toward other Americans. Sometimes these attitudes are based on observable characteristics such as skin color or physical disability. At other times they are based on labels attached to a person, labels that indicate a person's religion, country of origin, physical or mental condition. In many cases they are based on stereotypes — beliefs that all people who are alike in one characteristic are alike in many characteristics.

Studies have shown that Americans tend to stereotype their fellow Americans who are disabled. These stereotypes are often negative and devaluing of disabled persons. They are perceived as not as good or not as competent as non-disabled individuals. Of course, since this is the United States, which emphasizes equality, these negative attitudes are frequently disguised, at least in polite interactions. Nevertheless, they do appear in such behaviors as a lack of willingness to have disabled people (especially those who are mentally ill or retarded), live in the neighborhood, an unwillingness to have disabled children attend school or associate with "normal" children, and an unwillingness to contribute tax monies toward making aspects of the physical environment adaptable so that physically disabled persons can achieve maximum possible participation in American Society.

These negative attitudes are in conflict with the laws passed in recent years that mandate such things as equal employment opportunities, mainstreaming in the schools, and the adaptability of both buildings and transportation systems. For these laws to be successfully implemented, public attitudes must change. How can this be accomplished?

The best way of changing attitudes toward people is through the process social psychologists refer to as interpersonal contact. In other words, "getting to know them". Many studies have demonstrated that individuals who become friendly with disabled persons and interact with them develop positive attitudes. They perceive the disabled person as an individual rather than as blind, or as a person in a wheelchair. Of course, this only works when the disabled person and the non-disabled person become involved with each other in ways that draw upon similar backgrounds and similar interests. It doesn't mean that every disabled person should try to become friendly with the next disabled person he or she sees. That wouldn't work.

A clear implication of the theory that attitude change is best effected by interpersonal contact is that we should conduct a campaign to facilitate interaction between nondisabled and disabled individuals with similar backgrounds and interests. The U.S. Council's Community Partnership Program of local goal-setting promotes this type of meaningful interaction. We should mainstream America, not just a limited number of schools.

Unfortunately, this leads to a Catch 22 situation: Mainstreaming America would be much easier if we already had mainstreamed schools and accessible buildings and transportation.

There are other things that can be done. We could make intelligent use of media, particularly television, in an attempt to emphasize the "normality" and capability of the disabled people. Unfortunately,

practically the only time disabled individuals are seen on TV is during fund-raising telethons, which are apt to feature cute children and try to play on people's sympathy. They give little, if any, emphasis to ability and normality. And I know of no evidence that such telethons change attitudes even though they succeed in raising money.

What is needed is the portrayal of "ordinary" disabled people on TV. Disabled persons do have jobs as doctors, lawyers, teachers, secretaries, and factory workers; but are seldom portrayed in these roles on TV. They can be seen in department stores, on city streets, on college campuses, at airports; but they are never seen in these places on TV. If TV were to include disabled persons in crowd scenes or as patrons in restaurants, bars and stores, or as characters in television series, or maybe even someday as newscasters or participants in talk shows, negative stereotypes would begin to break down.

Attitudes would also probably be improved if there were more emphasis on the achievements of disabled persons. A recent full-page advertisement by United Technology pointed out that:

"The light over your mirror was perfected by a deaf man.

While your morning radio plays, remember the hunchback who helped invent it.

If you listen to contemporary music, you may hear a symphony written by a composer who couldn't hear.

The President who set an unbeatable American political record could hardly walk.

A woman born unable to see, speak or hear stands as a great achiever in American history.

Anything you can do, they can do, too."

## The Language Barrier

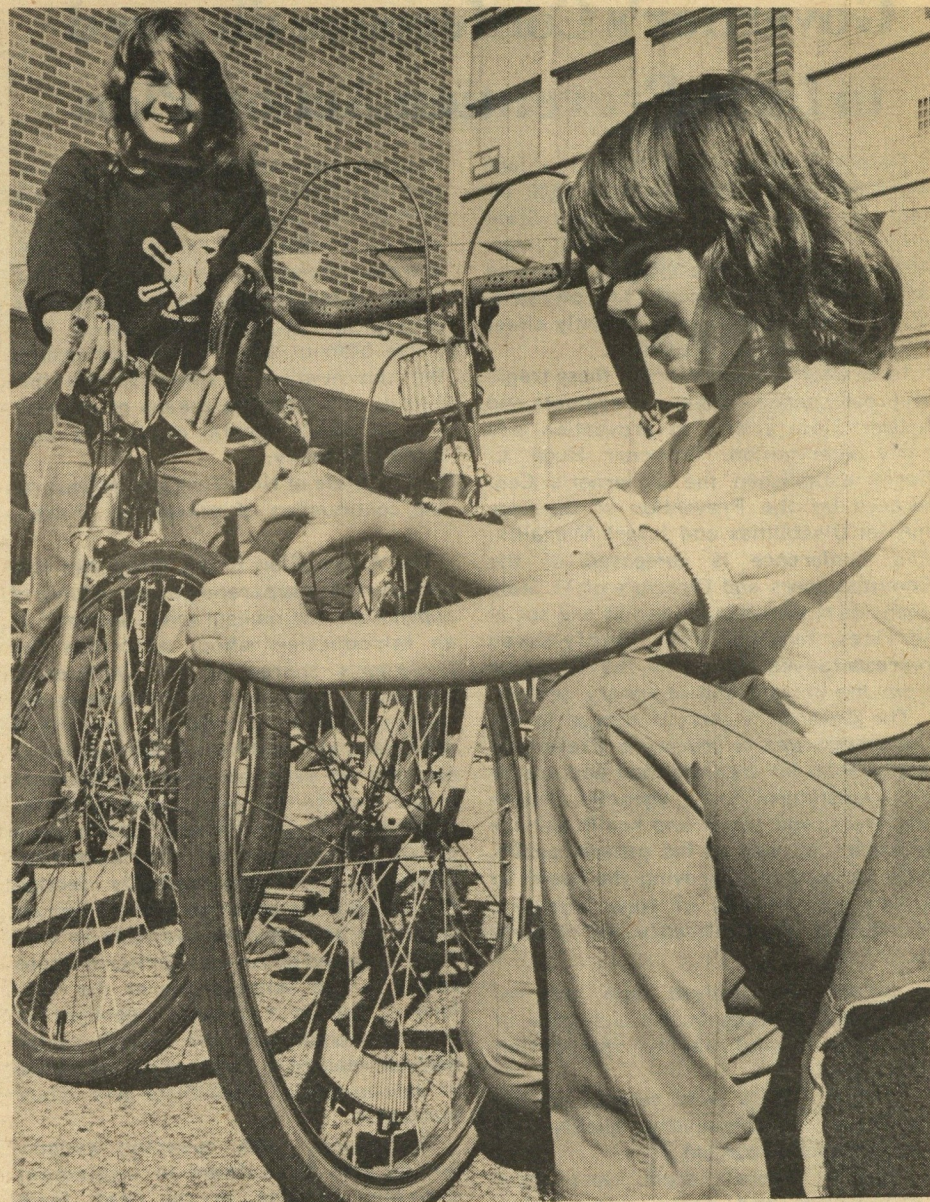
(From Research Institute on Attitudinal, Legal and Leisure Barriers)

Much is currently being made of the use of labeling language related to people with disabilities. While many of us are battling over use of words like "handicapped" "disabled," or "impaired," we forget that the mass media is still loaded with terms that are totally unacceptable to all disability groups. Rehabilitation professionals themselves are often guilty of using terminology that reduces the self-esteem of disabled people and perpetuates a negative image to the general public.

In the past 20 years, many people have learned to stop using the common pejorative terms applied to blacks, jews, women and other similarly repressed groups. Despite the fact that disabled citizens have recently come to be recognized as a repressed group, certain pejorative terms are still in popular media.

How often have we heard a medical case presentation begin with language such as "this unfortunate woman has been an arthritis sufferer since 1950, and is confined to crutches"; or "this stroke victim is afflicted with left hemiplegia and is restricted to special equipment for feeding and personal hygiene"? Patients are regularly described as being confined to crutches, or wheelchair bound.

Our language, as well as our written communication, reflects our attitudes: these terms convey a negative empathy or patronizing pity which reflects the speakers' personal reactions to how they imagine they would feel under the same circumstances. Use of such negative language serves to perpetuate the attitudinal barriers faced by our handicapped patients as they try to re-enter the abled-bodied world.



Two young supporters of the Nassau AHRC, Colleen Boyle (left) and Denise Kilday, pedaled for AHRC profits on October 4th when they participated in the annual AHRC Bike-A-Thon.

## Councils for the Disabled

Rehabilitation professionals know that crutches do not confine, but free one from a chair or bed. The wheelchair does not bind, but liberates its user to go into the world for work, play or travel. A wealth of other positive expressions are available to us. The patient is a person with arthritis, or a man who has recovered from a stroke and is handicapped by hemiplegia. The mobility-impaired person is a crutch-user or a wheelchair-ambulator. The ADL-impaired person is one who uses adaptive eating and toileting devices for independent self-care.

Both handicapped and disabled are acceptable as adjectives in written and verbal communication; the former is more commonly used in the U.S. Midwest and the latter tends to be preferred on the East coast. On the contrary, their use as nouns in expressions such as the disabled or the handicapped is not acceptable because it conveys a separate and inferior status. Handicapped individuals or persons with disabilities are positive alternatives which convey a sense of respect and equality.

The use of the term normal to describe non-handicapped persons tends to demean disabled persons by suggesting that they are abnormal or subnormal. The preferred term to describe the general public is abled-bodied (or nondisabled).

We in the rehabilitation professions should not hesitate to correct anyone who uses pejorative expressions toward disabled constituents. A friendly but firm explanation of why these terms are unacceptable will usually be accepted and appreciated.

Our goal should be an atmosphere where negative words such as sufferer, victim and afflicted are unacceptable in both civil conversations and media communications.

In 1980, the Governor signed into law a measure developed by the Task Force creating regional "Councils for the Disabled." These councils are vehicles for people around the state to assist localities in meeting the needs of the disabled.

Consisting of three to nine member bodies, the councils would:

- Develop community programs for the disabled;

- Evaluate the accessibility to the disabled of public places in the community;

- Advise and assist local governmental units and agencies on matters affecting disabled persons;

- Recruit, train and utilize volunteers to facilitate local programs;

- Refer disabled persons in need of services to appropriate agencies and service providers;

- Cooperate with local council and state and federal agencies regarding programs and services;
- Perform any other functions recommended by local governmental units.

Many localities in New York State have already begun implementing this concept. Thus communities can develop the expertise necessary to better employ existing services. Although the statute suggests a model for organizing the councils, local governments may determine the methods most appropriate for their needs.

For information concerning "Councils for the Disabled" and assistance in the establishment of such councils, please contact: Office of the Advocate for the Disabled, Empire State Plaza, Agency Bldg. 2, 6th Floor, Albany, New York 12223; (518) 474-2825.



# Federal Budget Cuts: Rounds 1 and 2

By James Flanigan,  
Executive Director  
Rensselaer ARC

The election of November, 1980 brought a major change in the direction of the Federal Government. Running on a platform calling for massive cuts in human and social services, increases in defense spending and tax cuts, Ronald Reagan overwhelmed then - President Jimmy Carter. The election sent a chill through most agencies offering services to mentally retarded children and adults. When pressed for specifics during his campaign, Ronald Reagan indicated that the cuts would come from a rather vague area called "waste, fraud and abuse."

This lack of specific information on the impact of proposed cuts would continue throughout the entire budget process. The best response reporters could get from President Reagan or his budget director, David Stockman, was a weak promise that the cuts would not hurt the "truly needy." What did become clear was that the attack on human service budgets would be two pronged, with decisions made in the already approved funding levels for the 1981 fiscal year as well as cuts for the 1982 fiscal year. In addition, a number of proposals were developed to combine various programs into "block grants." The stated purpose of going to block grants was to give the state and local governments more control over how federal funds were spent in their areas. However, block grants also had an interesting side effect of making it almost impossible for people to clearly determine what the impact of the President's budget policies would be.

The initial response from people most directly effected by social service cuts was slow in developing. While a well organized conservative lobby flooded Washington with letters and calls in support of budget cuts, many people whose funding or budgets would be cut waited for a clearer indication of just what the impact would be.

Gradually, a number of target areas began to emerge. One of the first to be identified was the Comprehensive Employment and Training Act (CETA). Cuts in this program had a double impact on ARCs in New York State. Not only did many chapters use CETA funding to hire agency staff, but the program had become one of the most effective tools in job placement for handicapped adults.

The Developmental Disabilities ACT (DDA) faced threats on two levels. First, the President had proposed cutting 25 percent from the program and rolling it into a block grant. Second, the Act itself was due to expire in mid-1981. Without a renewal of the Act its civil rights protections, as well as its funding, would disappear.

Other areas of federal activity in which cuts were being proposed included the Rehabilitation Services Administration (RSA), the Education for All Handicapped Children Act (P.L. 94-142), food stamps, Medicaid and the Section 8 program of the Department of Housing and Urban Development (HUD). In addition a number of trial balloons were floated proposing cuts in Social Security programs, including Supplemental Security Income (SSI) and Social Security for Disabled Individuals (SSDI).

In a number of areas efforts were made to blame the financial problems of the entire Social Security system on programs serving handicapped people. Even though a well organized senior citizen lobby was able to beat back most of the most devastating budget cuts in Social Security Administration programs, there has been an emerging trend of denials of benefits at the local office level. More and more, people are finding that they have to go through the hearings and appeals process to establish eligibility for benefits such as SSI and SSDI.

By April, morale in the human service community had reached an all-time low. Confusion and shock over proposed cuts was compounded by a feeling of powerlessness and the realization that our lobbying techniques were quite rusty and ineffective, when compared with the computerized efforts of the new right.

Gradually, the feeling that "somebody has to do something" about the situation was replaced by a realization that the somebody was us. Groups and individuals began to form coalitions in an effort to lobby against the budget cuts. Even though specific information on the exact impact on individual programs was not yet available, calls and letters began to pour into Washington on behalf of programs serving handicapped people. Many ARC chapters around New York State took time at Board meetings, staff meetings, committee meetings or general membership meetings to hold letter writing sessions. The word from Washington was that congress wanted to hear from people directly effected by the cuts at the grass roots level, rather than professional lobbyists. On May 7th, ARC chapters from around the state took part in demonstrations at Federal Buildings located throughout the state in support of a Washington demonstration by handicapped people protesting the cuts. The media began to provide some coverage to the anti-cut forces, although the President still was able to command the lion's share of the press, radio and television when he needed it.

During the spring congressional recess, many individuals and organizations representing mentally retarded and other handicapped citizens met with their congressmen in their home districts. While the impact of these meetings was not immediately evident, a number of congressmen and their staffs began to acquire a greater understanding of the federal role in services to handicapped people.

After the spring recess, we began to gain some ground, as the budget committees in both the House and Senate restored funding for programs such as RSA, P.L. 94-142 and DDA. From the New York congressional delegation Senator Daniel Moynihan and Congressmen Thomas Downey and Stephen Solarz played major roles in getting funding restored for these programs. In the Housing and Urban Development area Congressman Stanley Lundine led the fight for funding for programs for handicapped citizens.

A major break came in the Senate when three Republicans on a key committee, Orrin Hatch (Utah), Robert Stafford (Vermont) and Lowell Weicker (Conn.), came out publicly in support of restoring funding for programs such as P.L. 94-142 and the Rehabilitation Services Administration. As a result of these efforts and the support of many other congressmen, who had been in contact with home district constituents, funding for these programs was restored for 1982 to the same levels as 1981. While this would appear to be a major victory, it is important to keep in mind that the impact of inflation turns these appropriations into a 10 percent cut in actual spending ability.

The battle was not over, however, as the President's men turned to the budget reconciliation process (where House and Senate members meet to iron out differences in their budgets) as a vehicle to make further cuts. The tactic of keeping the public in the dark on where the cuts were to be made was carried to its extreme in the Reconciliation Act, where the actual 1,000 page bill to be voted on was not released to the House of Representatives until 2 hours before it was scheduled for voting. Once again, a coalition of Republicans and conservative Democrats prevailed and the Reconciliation Act passed.

Immediately after the Reconciliation Act vote, many organizations scrambled to find out where they stood. In some cases entire programs were eliminated without the knowledge of the people who voted for the bill. Fortunately, services for handicapped people fared relatively well. The Rehabilitation Services Administration and P.L. 94-142 actually came out with a 5 percent increase as a result of the efforts of supporters in Congress. The Developmental Disabilities Act has its funding for 1982 restored to 1981 levels.

Everyone breathed a sigh of relief, but it proved to be premature. On September 26th the President went on national television to announce that, based on new projections of the 1982 federal budget deficit, he was asking for 12 percent in additional cuts. People in the rehabilitation community were further shocked to learn that the 12 percent cut was actually 12 percent below the earlier 25 percent cut levels, rather than below the Reconciliation Act levels. For example the 1981 fiscal year appropriation for State Grants for rehabilitation services (which funds services such as vocational evaluation, personal adjustment training and job placement) was \$854 million. The President, in his March budget message, had proposed cutting this to \$640 million. The Reconciliation Act has provided a 5 percent increase to \$899 million. The President was now asking for a cut to \$563 million. Clearly, the impact of such a cut would be devastating.

Once again, individuals and organizations went to work asking congressmen to support the Reconciliation Act funding levels for the Appropriation Bill for Labor, Health, Human Services and Education, rather than the President's proposed funding level. In the House, victory was achieved as New York Congressman S. William Green led a group of Republicans in voting against the President. Other New York Republicans joining this revolt included William Carney, Hamilton Fish, Benjamin Gilman, Donald Mitchell and Frank Horton. Oddly enough, the national press devoted very little coverage to this defeat for the President, compared to the coverage given to his earlier victories on the budget and Reconciliation Act.

As this issue of Our Children's Voice goes to press, the Senate is meeting to mark-up the same appropriation bill. New York Senators Alfonse D'Amato and Daniel Moynihan have indicated opposition to the additional 12 percent cuts. However, the President has threatened to use his veto power if he does not get his way on this bill.

## Round 2

### WHAT TO EXPECT

Based on our first year's experience with "Reaganomics", we should be able to identify some patterns with the President's budget cutting techniques and some strategies we can employ to insure that the mentally retarded citizens of New York and the other 49 states are not asked to bear an unfair share of the burden when the cutting is done.

First, there should be no question that further cuts will be attempted. Paul Marchand of the Governmental Affairs Office of the National ARC commented at a recent seminar in Washington that there was no question in his mind that the President wants to eliminate federal funding for human services.

Second, we can expect that the cutting pressure will be constant. The President will most likely try to use rescissions, budgets, reconciliation, appropriations and vetoes, as well as a number of other mechanisms, to achieve his goals. This will require a constant response. We will not have the luxury of a number of months

between major battles.

A third pattern, which we can expect to see continue, will be the administration's efforts to push cuts through before the public is fully aware of their impact and has had time to react.

We can also expect that areas that survived 1981 without major cuts will be prime targets for the 1982 round of cuts. This should raise particular concern in areas such as the Rehabilitation Services Administration, PL 94-142 and the Developmental Disabilities Act.

Block Grants should also continue to be used as a means of making cuts and hiding their true impact.

Finally, we are going to have to expand our efforts at the state and county levels. The President has been saying that he wants to move the financing and administration of social and human services closer to the people. However, our Governor has already come out with a policy statement indicating that the state will not pick up the slack created by federal cuts. A number of County officials have also made similar statements. If we truly believe our services are needed we should not let these officials get off so easily. We should not let ourselves be bounced from level of government to level of government without demanding some accountability at each step along the way.

So, what do we do, as individuals and organizations, to insure the future of services to mentally retarded children and adults in our state. First, we must overcome some of our long-standing hang-ups that tend to get in the way of effective political action. ARC chapters can no longer afford the luxury of being apolitical. While our chapters can not become directly involved in partisan politics, we should recognize our role in educating legislators and governmental officials as to the services needed by the people we serve. The real experts in mental retardation are not the David Stockmans or the members of the House and Senate Budget Committees. They are the parents, Board members, staff and friends who work day in and day out with mentally retarded people.

We also can no longer afford the luxury of letting somebody else do it. To be effective, everybody must get involved. Parents can't say "let the staff take care of it" and staff can't say "let the Board do it." Everybody who cares about the services we provide has to make a personal commitment to do their part to see that those services are not lost.

Forming coalitions is also an important part of an effective strategy. We are much more effective when we can join forces with other groups from around our state and country in a unified effort. To accomplish this it may be necessary to forget some of the past differences that have come between our organizations.

In explaining our services we should not be ashamed about the fact we used federal funds. When one analyzes many of the services we offer, one finds that they have a great deal of conservative appeal. We often hear conservatives talking about "workfare" programs that take people, who are on welfare, and put them to work. The vocational rehabilitation programs run by ARCs around our state take people who receive public assistance (usually from SSI, SSK1 or home relief) and train them so they can move into competitive employment and become taxpayers. In doing this we have enjoyed a great deal of success. In fact, vocational rehabilitation programs in New York State in 1980 alone had more successes than the California "workfare" program did in all the years Ronald Reagan was Governor of that state.

Our community residences also have a great deal of appeal to traditional con-

Continued on Page 8



## Tax cuts could also cut giving

The "new federalism", among other things, means that social services will have to be financed increasingly by state, local, and private funds. In a recent article appearing in **Word From Washington** a cautionary note was issued to non-profit agencies with regard to the possible negative impact of the 1981 Tax Act.

The competition for these funds could become intense at the local level and to make matters worse, the "Economic Recovery Tax Act of 1981" inadvertently includes several provisions which reduce incentives for individual giving to charities. Charles T. Clotfelter and Lester M. Salamon have analysed the potential impact in a study for Independent Sector Titled "The Federal Government and the Non-profit Sector: The Impact of the 1981 Tax Act on Individual Charitable Giving."

Clotfelter and Salamon identify seven factors in the act which are likely to discourage giving:

- Reduction in the Maximum Tax Rate on Unearned Income from 70 percent to 50 percent.
- Across-the-Board 25 percent Reduction in Marginal Tax Rates Over Three Years
- Reduction in Capital Gains Tax Rate from 28 percent to 20 percent
- Liberalization of Estate Taxation
- Indexation of Tax Rates and the Standard Deduction Beginning in 1985
- Modification of Foundation Payout Requirements
- Reduction in Corporate Income Taxation through Liberalization of Depreciation Provisions.

They find but two factors which are likely to encourage giving:

- Charitable Deductions for Non-Itemizers
- Increase in Maximum Allowable Corporate Contributions

The authors conclude that:

1. "Private contributions to churches, universities, hospitals, service organizations and other nonprofit or charitable institutions will decline over the next four years by \$18.3 billion in current dollar terms, and \$9.9 billion in constant dollar terms, below what they would have been under prior law as a result of the recently enacted Economic Recovery Tax Act of 1981."
2. Because of the expected increase in overall income levels between 1981 and 1984, individual giving even under the new law will be higher in absolute terms than it was in 1980. However, the rate of growth under the 1981 law is projected to be considerably slower than it would have been under the previous law. As a result, private giving is projected to decline as a share of personal income."
3. In addition to aggregate impacts, the 1981 tax law will significantly redistribute the burden of giving from the rich to the middle and lower-middle classes. In particular, the share of individual giving provided by the top 15 percent of all taxpayers is projected to decline by 12 percent between 1981 and 1984 under the new law, while the shares accounted for by the bottom 30 percent of all taxpayers and the middle 55 percent will increase by two percent and 11 percent, respectively."
4. "Because taxpayers in different income groups allocate their charitable contributions differently among the various types of recipient organizations, the redistribution of charitable giving among income classes means that some types of organizations will be adversely affected by the 1981 tax law more than others. In particular, wide individual giving to religious organizations is expected to grow by 17 percent in constant dollar terms between 1980 and 1984, individual giving to educational in-

stitutions and hospitals is projected to fall more than three percent below actual 1980 levels."

The prospect of an \$18 billion shortfall in charitable contributions is coupled with a projected \$27 billion reduction in Federal revenues which would have gone to non-profit organizations between 1981 and 1984 under previous law. Thus the projected net impact of the Economic Recovery Program on the private, nonprofit organizations which are being asked to "pick up the slack" is a reduction of \$45 billion in actual dollars (calculated to be \$31 billion in constant 1980 dollars). The analysis here examines, however, only the 1981 law's impact on individual giving, not its impact on giving by foundations, corporations, or estates.

Independent Sector, an umbrella organization for private foundations and nonprofit organizations, which sponsored the study has made it clear that these projections may not come to pass. If the Economic Recovery program succeeds in stimulating the economy, and if donors respond to the call for increased support in spite of reduced tax incentives, then private donations could be far larger than projected by Clotfelter and Salamon.

Copies of this report are available from the Urban Institute, 2100 M Street, N.W., Washington, D.C. 20037 for \$5.00.

## Federal budget cuts

Continued from Page 7

servatives. We have been able to provide in community settings a higher quality of service, as a much lower cost, than the government did in its institutions. Also, we should keep in mind that it's the conservatives who are in the forefront of having the private sector perform jobs that the government has not been able to do in a cost effective manner. Take a look at the work being done by any ARC chapter in New York State and ask yourself what it would cost if those same functions were performed by the government.

Another often heard argument from conservatives deals with over-regulation by the government. When I talk with friends from the business community about this topic, I am mildly amused to see their reactions when I describe the kind of over-regulation we face. As justified as many small businesses may be in complaining about over-regulation, the volume of paperwork, time and energy they devote to meeting these regulations is relatively small when compared with that faced by the typical ARC chapter. We should be taking the lead in offering to help the appropriate legislators and government officials identify those areas of regulation that are not necessary. After all, as I said before, we're the real experts in this field.

In getting this message to our elected officials we should try to use more than letters, telegrams and telephone calls. Direct head-to-head meetings, preferably at a vocational training center where you can show your program in action, are extremely valuable. In setting-up and conducting these meetings try to utilize Board members, bankers, businessmen who do contract work with your agency, parents or elected officials from the local level. Ask yourself, "who will my congressman be most responsive to?" Chances are good that you can identify somebody connected with your ARC chapter who will be influential, regardless of whether your congressman is Republican, Democrat, liberal or conservative.

Many of our local ARC chapters publish very good monthly or quarterly newsletters. Put your legislators on the mailing list for those publications. In-

## Ulster Exec at State Convention



Shown with Richard Swierat, Executive Director of Ulster A.R.C. are Mayor Quick and Mrs. Quick.

## Disability and Communications Conference planned for April

The President's Committee on Employment of the Handicapped is hosting an international conference "Disability and Communications: A Global Perspective" in cooperation with the International Committee on Public Relations in Rehabilitation of Athens, Greece.

The conference will be held at Gallaudet College in Washington, D.C. from Sunday, April 25 to Friday, April 30, 1982.

The conference will explore the communications needs of disabled people in both developing and developed nations. Experts in communications from throughout the world will share experiences, program knowledge and recommend initiatives.

Topics of the conference include: rehabilitation - disability information centers and exchange; education and information; national advertising - information campaigns concerned with disability; developing nations communications needs and programs; publications concerned with disability; the international agency role in information about disability; national organizations for handicapped people; independent living; the integration of disabled people in developed and developing nations with case studies.

Suggested papers can be submitted with a one-page description to the Conference Organizer no later than February 1, 1982. Papers must be delivered in English, which is the language of the Conference. Papers are limited to 15 minutes in length, and will be selected on the basis of their potential contribution to the Conference.

The Conference will include site visits to organizations in Washington, D.C. concerned with information and disability. Conference participants will be afforded the opportunity to participate in the 1982 Annual Meeting of the President's Committee on Employment of the Handicapped at the Washington Hilton Hotel beginning Wednesday, April 28 and ending Friday, April 30 with a luncheon honoring the participants in the "Disability and Communications: A Global Perspective" Conference.

Request for further information should be addressed to Conference Coordinator, "Disability and Communications: A Global Perspective," The President's Committee on Employment of the Handicapped, Suite 600, 1111 20th Street, N.W., Washington, D.C. 20210, USA prior to February 1, 1982.

## Mothers lobby for baby formula standards

Before their infant sons became gravely ill, neither Carol Laskin of Washington nor Lynn Pilot of Arlington, Va., was unusually active in Government affairs. They became lobbyists for America's babies in 1979 after their children's sickness had been traced to a diet deficiency in two commercial baby formulas.

With the help of their husbands and Mrs. Pilot's training as a lawyer, the two women badgered the Federal Food and Drug Administration and members of Congress. In September 1980 a new law

was adopted setting infant formula standards and empowering the Government to enforce them.

Mrs. Laskin and Mrs. Pilot still haven't quit.

"The law is O.K.," Mrs. Laskin says. "Now what we're trying to do is make sure that the F.D.A. writes regulations that are stringent, that will supervise and monitor the manufacturing of baby formulas."

In addition, with expenses paid "all out of our own pockets," they are attempting to identify all babies who received the defective formulas — Neo-Mull-Soy and Cho-Free — in 1978-79, so the children can get "appropriate medical attention." They have asked parents to write to: Formulas, P.O. Box 39051, Washington, D.C. 20016.

One TV appearance by the two brought 65,000 letters, Mrs. Laskin says — "and they're still coming." She says that parents are reporting speech delays, convulsions and poor growth in children who were fed the formulas.

"Nobody knows what the long-term effects are," she says.

interview them for your newsletter; report on how they voted on key issues; copy letters received from them in your newsletter.

These are but a few of the strategies we should begin to follow if we are to maintain services as we know them. Perhaps future copies of Our Children's Voice would be a good forum for sharing other ideas and suggestions.



# Respite care co-op gives parents break

As parents of disabled children know all too well, appropriate respite services in New York City are few and far between. But Retarded Infants Services, a Manhattan-based organization serving developmentally disabled children and their families, is doing something to change that.

This new program, designed to give Mom and Dad "a break" from the tensions that arise in maintaining a disabled child at home, is known as Parents Helping Parents and is billed as a care co-op.

## SHORT-TERM RESPITE

According to Sheila Merolla, Project Coordinator, "this newly funded project was designed to meet the part-time or short-term respite care needs of disabled children and their families." Parents will provide respite care for other disabled children in their own homes, and, in turn, will be owed an equivalent amount of time by the co-op for respite care of their own child.

Ms. Merolla adds that "this cooperative would operate much like any co-op — service would be received in return for service given." While in the beginning a child might stay in the respite home for only several hours, Ms. Merolla envisions the length of the respite period expanding as the groups become more cohesive and parents get to know one another and their children better.

## GOAL TO IMPROVE FAMILY FUNCTIONING

The goals of Parents Helping Parents are varied, but focus on alleviating some of the stress which accompanies the ongoing care of a disabled child. Families may be feeling isolated. Siblings may be feeling overlooked. There may not be enough free time for spouses and other siblings to share together, away from the home.

The co-op, however, would provide much needed "time-out," thereby helping to strengthen the family through the prevention of internal strife. It would also create the opportunity for disabled family members to develop friendships with similarly situated families.

## EACH BOROUGH TO HAVE GROUP

Retarded Infants Services' initial objective is to bring together a core group of parents in each of the five boroughs. Each group would consist of five to seven families who are relatively homogeneous in terms of the child's age and disability, geographical location, socioeconomic background, and life style. Furthermore, all participating children will have to be ambulatory.

Respite providers are expected to be responsible for the normal care of the child they are tending. Thus if a child is in a program he/she will be expected to continue attending. Retarded Infants Services is exploring the possibility of using home aides to assist the parents, and Project Coordinator Sheila Merolla will be conducting monthly workshops to discuss techniques for caring for others' children as well as problem solving. Ms. Merolla notes that, in addition, physical disabilities will be thoroughly explored so that parents will have prior knowledge and understanding of a particular child's needs before taking him/her into their home.

Eventually, Ms. Merolla sees the groups as providing an opportunity for parents to share success and failures as well as information of mutual interest. It is also hoped that each group will begin to function autonomously as a self-help body and will no longer need the direct services of the facilitating social worker.

## FOR MORE INFORMATION...

Although the project is in the formative stage screening of applications has already begun. Interested families who live in the greater New York City area and have a physically or mentally disabled child are asked to contact Mrs. Merolla at: Retarded Infants Services, 386 Park Avenue South, New York, New York 10016 (phone 212-889-5464).

# Vitamins, minerals aid retarded

By Shirley Hoffman

Mentally retarded children now have new hope, thanks to an exciting study which shows that special doses of vitamins and minerals will raise their IQ's.

Dr. Ruth F. Harrell, a research professor at Old Dominion University in Norfolk, Va., who led the study, said the 15 children who received the treatment had IQ's ranging between 15 and 69 points.

"But after taking the supplements for eight months, all of them improved," she said, "showing an average increase of 16 IQ points."

The doctor also pointed out that the children became less hyperactive and thus increased their attention spans.

"They not only improved mentally, but physically as well," the researcher added, "as four of the children who had Down's Syndrome have more normal appearances since their treatment. That is, they do not have the puffy look they had before."

"Although the study was done on extremely retarded children, I feel quite sure that these vitamins and minerals will help children who are less retarded."

The theory behind the study is that retarded youngsters are born with a biochemical deficiency that keeps the brain from functioning normally. Thus, to counteract the abnormality, the brain must be nourished with additional supplements.

Those that were used were large amounts of Vitamins A, C, D and E, and small amounts of calcium, zinc, copper, iron, magnesium, manganese, and iodide.

Dr. Harrell, who has been aided in her work by the Nobel Prize winner, Dr. Linus Pauling, and the famous biochemist, Dr. Roger J. Williams, said one-fourth of the children were transferred from special education to normal classes.

She also noted that, when the treatment was discontinued, advances slowed down or reversed.

"There is every indication," she said, "that if these children continue to take these vitamins and minerals, they will continue to improve."

The researchers did a similar study on six epileptic children, and their seizures ceased as soon as they were given the vitamins and minerals.

Dr. Harrell is now starting her second study on this illness with 20 children who are retarded, normal, and superior, but who all have epilepsy.

The researchers are not the only ones who are excited about the results. Principals, teachers, and parents of the children are delighted with the improvements.

One of the parents, Joseph Briggs, of Portsmouth, Va., father of Joey Briggs, whose IQ increased by 20 points, calls his son's improvement "almost a miracle."

Dr. Harrell, whose investigations in this field began 10 years ago, said, "My colleagues and I have something so good we wanted to give it away. We just want to help all these afflicted children."



## License plates for disabled

On April 1, 1981, the New York Department of Motor Vehicles began to issue specially designed registration plates to qualified disabled drivers upon renewal of their current registration or when the disabled person applies for an original registration.

## State employees are asked for doctor's note

Upset at the amount of sick time taken by its employees, New York State says some employees will have to produce letters from their doctors to prove they are not playing hooky.

Meyer Frucher, head of the state's office of Employee Relations claims "notes from mothers will not do."

A study of state Department of Civil Service records shows that New York state workers take off an average of 10.4 days a year in sick time — 3.4 days a year more than workers in other states and 2.4 days a year more than federal employees.

Frucher said that as part of a state crackdown on the sick leave "problem," all supervisors and management level workers in the state will be sent a 37-page "handbook" telling them how to spot workers abusing sick leave.

In some cases, Frucher said, workers with suspicious illness excuses should be contacted at home by managers to make sure they are in fact nursing a sickness.

"We're not talking about spying," Frucher said. "We're talking about supervisors doing what they're hired for."

However, Frucher noted that the annual sick-day rate among the state's 10,500 supervisor level managers, the people charged with keeping state employees honest, is also above the national average at 8.3 days a year.

Perhaps not coincidentally, Frucher made public his report on sick leave by state employees at the same time he is beginning contract negotiations with the public employee unions representing most state workers.

## Social Security to simplify SSI forms

The Social Security Administration (SSA) announced proposed changes in the agency's Supplemental Security Income (SSI) forms for reconsideration and notification. The changes are in response to a study which found that "the current notice and appeal forms are beyond the reading and comprehension skills of most (approximately 70 percent) SSI recipients." Therefore, simplifying revisions have been proposed in order to increase SSI applicants' and recipients' awareness of administrative procedures so that they can make informed, knowledgeable and voluntary decisions in the critical area of SSI appeals. For further information contact: Philip Berge, Legal Assistant, Office of Regulations, Social Security Administration, 6401 Security Boulevard, Baltimore, Maryland 21235, (301-594-7452).

The plates will bear the International Symbol of Access followed by six numbers. No extra fee will be charged for these plates — the fee will be the usual registration fee for the vehicle.

The necessary forms are available at any local Motor Vehicle issuing office. A physician's statement attesting to the applicant's disability must be presented at the time of application.

These plates and existing permits are valid for parking in any space designated as handicapped parking anywhere in the state regardless of where the owner resides.

## Rehab Hotline established

A national telephone hotline providing information on Section 504 of the Rehabilitation Act of 1973 has been established.

The hotline will be staffed by specialists who will answer questions concerning Section 504 and its requirements of non-discrimination against handicapped individuals. Callers will be referred to sources of additional information and technical assistance programs.

It is offered through the Office for Civil Rights of the Department of Health and Human Services. The National Association of Social Workers also is involved in the operation of the hotline.

The toll-free number, with teletype (TTY) capability for the deaf, is 800-424-5068. In Washington, D.C., the number is 628-6800. Hours of operation are 9 a.m. - 5 p.m., Eastern Standard Time.

For additional valuable information on other timely issues OCV readers should be aware of Exceptional Parent Magazine, available for a subscription rate of \$14 per year. EPM carries articles by both parents and professionals, providing practical information covering such topics as psychological testing, curriculum, sex information, issues concerning siblings and much more.

## Federal funds for non traditional housing

A Working Group on Special User Housing, appointed by the National Association of Housing and Redevelopment Officials (NAHRO), met this month with HUD officials to discuss the use of federal funds to develop non-traditional housing: shared housing, congregate housing, group homes or shelters. The group requests information from local groups or State agencies on their experience trying to develop such non-traditional housing using federal funds (e.g. Section 8 for independent group residences and public housing or Section 202 for supervised residential programs). Send comments in writing to: Working Group on Special User Housing, NAHRO, 2600 Virginia Ave., N.W., Suite 404, Washington, D.C. 20037.



# Board, staff, committees can relate

The following excerpt is taken from a presentation by Irene Platt, senior vice president, as part of her southeast regional workshop hosted by the Rockland County Chapter:

The subject of separation of functions between a Board of Directors, Committees and Staff is a little like discussing the separation of church and state:

1. Some issues are clear cut and decisive;

2. Some issues are yet to be determined — either by history, preference or the law;

3. Some issues can only be determined by the particular parties involved;

4. And some issues probably will never be completely defined and determined.

How a Board operates within itself, and how it relates to its staff, is generally the result of a mixture of personalities, egos, ids, dedication, determination, philosophy, common sense, gut reactions, self interest, public interests and almost any other human quality or characteristic you can name or imagine.

The first thing to consider is what the law states with reference to Boards of Directors, individual Board members and their responsibilities, obligations and restrictions. These in general will determine the appropriate function of the Board as the policy initiator for the organization.

While the law sets out general guidelines for organizational operations, such as the number of Directors on a Board, terms of office, meeting and voting requirements, the law is relatively sketchy in setting forth standardized rules as to the appropriateness of particular agency acts. This must often be determined on a case by case basis. As a general rule, actions by directors are not disturbed when good faith and honest judgment dictate the decisions made.

Basically, a Board of Directors has the responsibility to "manage" the organization. How this is accomplished is determined by the mix of Board members and their personalities, the reality of the particular item under discussion, and by the powers given to or prohibited to the Board through the Certificate of Incorporation and/or the By-laws.

The general aims, goals, philosophy and attitude of this entity called a "Board" is to be determined by the collective will, the personal attitudes and the professional judgments of the individuals constituting the entire Board of Directors. As a group and individually, they are responsible for agency policy. Except in unusual and extraordinary cases, a single officer or individual should not be permitted to determine policy or action.

Directors are legally charged with the responsibility for the governance of the agency's internal affairs and the management and use of its assets.

Examples:

1. The Board should determine the nature and character of the agency's advertising and public relations, i.e. how it presents itself to the public;
2. The Board should determine the nature and character of the programs they will provide, their priorities and the groups they will serve. Shall a workshop, day treatment program or residence be established? This is a question for the Board to answer. Should the agency give priority to the aged, the very young, community or institutional clients? The Board makes these determinations. Staff is responsible for carrying them out.
3. The Board should determine the amount to be expended and the way it is to be used. Board members must study the budget, question income and expenditures and finally determine the shape of the budget.

Under the law, Directors are mandated to operate in a fiduciary capacity. They must:

1. Act in good faith, exercising diligence, care and prudence, prudence being the

judgment which ordinarily prudent men would exercise in similar circumstances;

2. Act with undivided and individual loyalty to the organization.

The paramount duty of a Director is to champion the cause of the agency. To do this, each must fully acquaint himself with the agency's programs, policies and procedures.

As a Board member, you are responsible for actions taken at meetings even if you are not there! You are legally presumed to have concurred in the action taken, unless, within a reasonable time after hearing of the action taken, you submit your dissent. This applies to Committee members also and to actions recommended and taken by the Committee in which they participate.

As an agency grows, and its problems become more complex, as financial matters seem to take priority in our Board discussions and determinations, I believe that it is all too easy for a Board to unintentionally lose sight of the basic principles on which the organization was founded, especially when all goes well. This may result in gradually turning policy decisions over to the professional staff.

The law mandates that the Board member has this responsibility and requires that he or she not abrogate this responsibility.

This raises the issue of the professional staff whose role is vital. I believe that effective agency management requires "balance" between Board and staff. I believe that the key to this balance is mutuality and respect. All, however, must be aware that the final determination and responsibility is that of the Board. Without this mutuality and respect, long range, successful operation of the agency cannot be accomplished. The staff is there to implement, on a day-to-day basis, the programs and philosophy as determined by the Board. Staff is not to be expected to create or carry out what they believe should be agency policy.

In arriving at any particular policy, comprehensive information must be gathered, digested and analyzed before a policy can be established. Thus, careful consideration must be given to what the professional staff has to say! Their input is invaluable, for they, through their training and experiences are able to determine if a "theory" is practical, realistic or valid and if it is in the best interests of those it is designed to serve. Board members must listen carefully, but must never be intimidated by the professional staff. They must carefully weigh the alternatives.

Every Board member, although not acting as a professional in this field, brings to the board some expertise from his or her life experience, common sense, professional or vocational background. All of this must be respected, considered and taken into account when the collective Board makes an agency determination. The word of one person or one group should never supercede the determination of all. If and when that happens, the members of the Board surrender their right to be a part of the organization, for they have failed to fulfill their legal and moral responsibility.

This relationship between Board and staff is, I believe, easy to state but most difficult to observe on a daily basis. Based on mutuality and respect, the Board makes the policy; staff executes that policy. The complexity of our operations, combined with the fact that we are a parent organization, often makes it difficult to determine where one begins and the other ends. I honestly believe that the simplicity of "Board sets policy, staff executes policy" must be the golden rule.

Our philosophy relates to a parent and client oriented organization. This does not mean parent domination and this does not mean professional domination. Rather this implies that the combination of two sectors

operating with mutuality and respect will result in what is most beneficial for those whom we serve.

The Executive Director is responsible for carrying out Board policy. It is not the function of Board members to see the daily administration of the agency. Board members should not personally interfere with staff. The Executive Director is responsible for the staff. If we question actions of our staff, we should address these questions to the Executive Director. This separation must be maintained if both sectors are to function effectively and properly.

The size and complexity of our Chapters require the use of Board Committees, which are created through the authority of our By-laws and Certificate of Incorporation. Committees have the authority of the Board to recommend policy and procedures. The law states what committees cannot do, such as amending By-laws or amending or repealing Board resolutions. However, the delegation of authority to a committee does not relieve any Director of his legal duty or responsibility to the Board.

Committees are the eyes and ears of the Board as a whole. Committees are the information-gathering and fact-finding arms of the Board, which, based on such information, recommends action to the Board which it is free to accept or reject. The use of committees enables Board members to know what is happening and to make informed judgments.

## CONTINUED FROM PAGE 1 — PATTISON RE-ELECTED

of facilities be a reimbursable item even when state has made a 1-3rd contribution for construction.

### Construction Aid

4. Provision that state funding of construction or acquisition of facilities for the mentally retarded by voluntary agencies be on the basis of 1/2 of the cost, instead of the present 1-3rd, or on parity with facilities for the de-institutionalized, whichever is greater.
- RESOLVED: Whereas in the United States accidents are the leading cause of death and disability to children under 16 years of age, and whereas the principal accidents occur to children as passengers in cars, we therefore urge that every Chapter of this Association become actively engaged in the New York State Buckle-Up Baby Program preparatory to the implementation date of April 1, 1982 for the recently passed Child Restraint Legislation.

RESOLVED: Whereas children from 5 to 12 years of age are entitled to a free and appropriate public education in the least restrictive environment regardless of residential setting; and whereas some children require the services found in an ICF-MR or ICF-DD in addition to their educational requirements; and whereas the right to this education is being selectively withheld from children residing in ICFs, pending the resolution of the meaning and intent of Chapter 721 of the New York State Education Law, be it therefore resolved that the New York State Association for Retarded Children insist that the State Education Department make provisions for educational services for children residing in ICFs as mandated in both Federal and State Law.

RESOLVED: Whereas this assembly is the governing body of the New York State Association for Retarded Children; and whereas this assembly requires up to date minutes of the preceding Convention, Board of Governors Meetings and Committee Meetings be it therefore resolved that these minutes and committee reports be mailed to each member of the Board of Governors at least 10 days prior to the next Board of Governors Meeting.

RESOLVED: That this Association ex-

## State Advocate chides

### President's Committee

State Advocate Frances Berko indicated her disappointment in the design selected for the 1982 PCEH calendar card by letter to the President's Committee as follows:

I am herewith returning the 18,000 PCEH 1982 calendar cards in protest of the picture on the back. In 1981, the International Year of Disabled Persons, the New York State Advocate for the Disabled used such cards extensively — in every possible context. However, we of the New York State take the goal of "full integration and participation of disabled citizens in daily community life" with utmost seriousness.

The unhealthy days when those with disabilities are portrayed as objects of abject pity have long passed. This nation's economy cannot afford its rebirth. Yet, this public awareness piece is reminiscent of the 1920's concept of charity. May I add that, viewing the 1982 calendar card gave me the first insight as to why 1981 has turned into the year of disaster for the disabled citizens of the United States. Is it any wonder that the present administration views meeting the needs of the disabled as expendable for the national welfare, if its professional advocacy staff accepts and circulates pictures such as this to demonstrate its work?

Your selection of this picture wipes out 40 years of efforts of the President's Committee on Employment of the Handicapped and all that those efforts have achieved.

press to Mr. Walter E. Scofield, Director of Sunmount DDSO, who has announced his retirement, its best wishes.

RESOLVED: That advocacy and guardianship are of vital importance to the mentally retarded in the State of New York, be it resolved that this Association urge all its Chapters to develop both guardianship and advocacy programs.

RESOLVED: That this Association record with deep sorrow the passing of Julian Banner of the New York City Chapter, Charter Member of this Association and Chairman of the Insurance Committee for many years. His many years of devoted service to the cause of mental retardation was greatly appreciated and will always be remembered.

RESOLVED: That this Association adjourn this meeting in the memory of Julian Banner and that the Secretary send a copy of the Resolution to the family.

And as one convention ends, planning for the next convention begins. Our Niagara Chapter has been designated as our host for the 1982 NYS ARC Convention at the Niagara Hilton, on October 7th through October 10th 1982. Keep these dates in mind; we look forward to seeing you in Buffalo.

## Sheltered Workshop Committee established

Management Update reports that, in a surprise move, the U.S. Department of Labor has announced it will reestablish the Advisory Committee on Sheltered Workshops. The committee was disbanded in 1977 along with numerous other such groups in Washington as a cost-cutting move. The move reflects what can be done when one key national leader (Norm Grunewald of National Easter Seal Society) took the initiative to establish a consortium of nine major organizations concerned with the workshop field. They battled for re-formation of the advisory committee and, against high odds, got it. The big role for this committee for the future will be advising DOL on issues concerning the sub-minimum wage program for handicapped workers.



## Information Committee's slate

The Crackerbarrel Session at convention was lively with a wide range of topics on public information needs according to Chairperson Kate Klein. Fielding questions and giving specific advice to participants were Mary Kallet, Gail Fishkind and Martha Smith who acted as recorder. Arthur Gassman, former member also provided spontaneous input.

Discussion concluded that in addition to program visibility, issues important to education of the public on aspects of mental retardation need repeated airing in the various media. A well-informed public will support the goals of NYSARC. Chairperson Kate Klein concluded, but a poorly informed public will be apathetic, even derogatory.

### POSTER CONTESTS ARE FUN

The Public Information Committee offers a kit which provides step-by-step procedure for the organization and publicizing of a chapter art-poster contest. This can be used again and again by merely changing the themes.

"See Me as a Person," the theme of International Year of the Disabled is suggested along with the theme of the recent State association contest themes. Chapters devising new themes for schools to use are encouraged to share these success stories with the PIC.

The art-poster contest is recommended for use by chapters to encourage awareness and understanding of the mentally retarded as well as to feature visibility of the local chapters.

### ADOPTION EXHIBIT

World Trade Center in New York was the background for the PIC's Adoption Resource exhibit November 23 and 24. The display featured the theme "Mentally Retarded Children Wait the Longest".

The exhibit, an effort by adoption organizations to encourage adoption of children with special needs displayed information materials on the financial and medical programs available to prospective parents. Many people contemplating adoption of handicapped children have been discouraged by learning of the costs of care.

The exhibit presented information to prospective parents on the assurance of special programs in facilities, schools and employment areas and showed how such help continues, particularly in later years.

### FUND RAISING A SKILL

Seminar leader Robert F. Katz covered a wide range of topics dealing with development techniques and skills at the November Fund Raising Seminar held at the Americana Inn in Albany.

President Eleanor Pattison prior to the seminar had urged ARC chapters to intensify their fund-raising capabilities to counter-act the budget deficits that will become a "way of life."

Mr. Katz, consultant on fund-raising and related management practices is a member of the Public Information Committee (Nassau Chapter) and has been associated with ARC as a consultant and staff member. He raised money and directed an HEW funded project which won the coveted New York Advertising Club's Andy Award. He holds an appointment as Director of the Institute of Adult Care Administration and has instructed at the C.W. Post Center of Long Island University.

Volunteers and staff members were the guests of the PIC for a continental breakfast and luncheon. During the evening Mr. Katz conducted a problem-solving workshop. Certificates were awarded to participants.

### REVISED PRAYER CIRCULATED

A rewording of the association prayer was presented to convention for distribution back at local chapters. Need

for such a change was approved at the May Board of Governors meeting in 1981.

The PIC recommended that during International Year of the Disabled such rewording would effectively highlight the accomplishments of NYSARC by eliminating the evoking of pity in the prayer. Stressing the aspect of the mentally retarded as people with needs the association has met and will continue to meet in the content of the change demonstrated below.

The Public Information Committee will ask members of the Board of Governors to vote on the change at the Spring meeting.

**PUBLIC INFORMATION COMMITTEE**  
In keeping with the theme of the 198 Convention... Looking Back... Looking Ahead...

### Present Association Prayer

Almighty and Merciful God,

We, who are the parents and friends of your little ones  
Ask for guidance and help in our effort to brighten their lives  
That we will become reconciled to their affliction.

Grant that we may not despair  
As those who have no hope  
But rather give us the grace to know your wisdom and the courage to accept it nobly.

Help this association to thrive and prosper  
So that we may bring into the lives of these children and their parents,  
Happiness and peace in saying,

"Thy will be Done."

AMEN.

### A Spontaneous Rewording Others Welcome

Dear God,

All life in your creation  
has a purpose

And while your eternal plan  
Is not known

We do reaffirm our role  
In helping those in need.

It is our prayer that we will be  
Ever mindful of our  
Responsibility

As parents, friends and neighbors  
Of the mentally retarded

Helping them to a full measure  
Of the precious life  
You have given.

Guide our Association

So that it may be ever strong  
And selfless

And bestow your blessing  
On our special children.

AMEN.

## Housing Development Fund provides seed money

Division of Housing and Community Renewal, Housing Development Fund (HDF) Program provides interest-free seed money to non-profit sponsors to build or rehabilitate housing for low and moderate-income families. These funds, also utilized by Section 202 sponsors, may be used for administrative and preliminary costs associated with the development of housing and are repaid when permanent financing is obtained. For further information, contact: Noel Harris, DHCR, (212) 488-7086.



Ira Gelinson, Executive Director of Schoharie County Chapter is flanked at the chapter's recent Ribbon Cutting by (l to r) Rev. Gerald Daniels, ARC Board Member, Assemblywoman Gail Shaffer, Eleanor Pattison, President of NYSARC and Rev. Franklyn Wright, President of ARC Board of Directors.

## Schoharie ribbon cutting

The Schoharie ARC has recently completed both an expansion and renovation program. The renovations were quite extensive and included the installation of a new insulated roof as well as providing for insulation to the existing facility. Further renovations included a new septic system and a new boiler room utilizing a high efficiency boiler.

The expansion included the construction of a brand new cafeteria as well as the

adding on of 5,000 sq. ft. for their workshop, Toe Path Industries.

The Schoharie ARC has experienced a rather large growth rate over the last 18 months. The numbers of clients being served through the workshop in the early part of 1980 was approximately 50. At this time, the Schoharie ARC provides residential, day treatment and workshop services to over 113 mentally retarded developmentally disabled clients.

## Accessible Fashions heightens clothing awareness for disabled

Clothing provides us with warmth, modesty and a means of personal expression. Along with these provisions are embedded some social and psychological benefits we have learned, to a lesser or greater degree, to manipulate. Through clothing we can enhance our attractiveness, and sometimes cover our shortcomings.

At an early age, we learn to manipulate clothing effectively and judge the results by the reactions of family and friends. By the time we reach adulthood we have formed fairly stabilized responses in clothing to a wide variety of social encounters, and the lifestyle that a person adopts is usually reflected in his or her clothing.

This pattern pertains to most non-disabled people, but not to many disabled people. The disabled person has traditionally been stigmatized or discredited because he or she is different, and social responses have placed them in an inferior position.

Clothing has been part of the problem because drab institutional-looking and ill-fitting garments draw attention to the different attributes of a disabled person. Hence, attractive, well-fitting clothing is an effective means of ameliorating the stigma.

Public attitudes toward the disabled community are slowly evolving from the recent 'dark ages' when disabled persons were not encouraged to become involved in the community and received very few of their rights to education, housing, employment and creative pursuits.

Behind this changed attitude lies a political stimulus organized by disabled people themselves which resulted in

legislation that changed the civil rights of all handicapped and disabled people in the country: Section 504 of the 1973 Rehabilitation Act (P.L. 93-112).

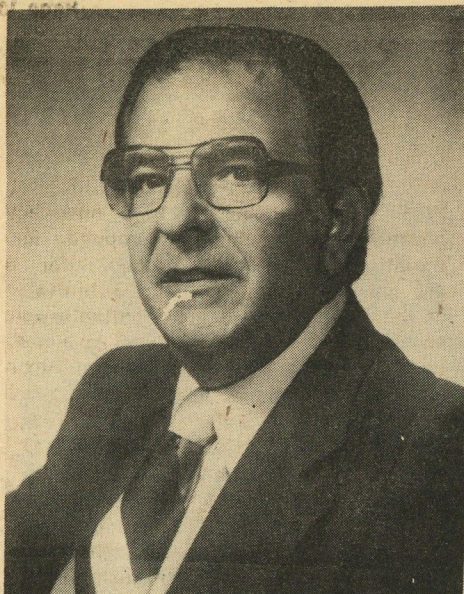
Now that disabled people have won the right to participate in all manner of work, educational, cultural and social situations that they were formerly dissuaded from, clothing becomes more important because they now need the same variety of clothes as non-disabled people have always taken for granted.

To encourage consumers, designers and manufacturers to create and fulfill a market for fashionable but accessible clothing for disabled people, the National Access Center, supported by grants from the Design Arts Program and the Office of Special Constituencies of the National Endowment for the Arts, commissioned a fashion publication which was researched and written by two women who have a professional interest in fashions. Because of their own disabilities, they have a personal interest in fashion for disabled people.

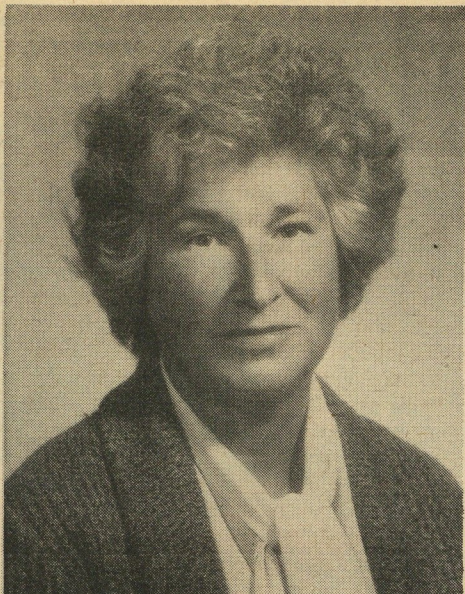
Angela Thompson and Susan Voorhees would like their work in Accessible Fashions to stimulate a heightened awareness of the issues involved with clothing worn by disabled people. They want to raise the level of excitement, ingenuity and creativity in fashion, designers, students of fashion and textiles, manufacturers and merchandisers, parents, home economists and rehabilitation specialists.

For additional information on this publication address inquiries to Larry Molloy, Director, National Access Center, 1419 27th Street NW, Washington, D.C. 20007.





Joseph Bernstein, a new Executive Director of Westchester County Chapter.



Mary Kallet, Assistant Executive Director.



Thomas Hughes, Assistant Executive Director.

## Staff changes for three ARC Chapters

Joseph B. Bernstein has been named Executive Director of the Westchester Association for Retarded Citizens, succeeding Eugene G. Laughery, upon his retirement.

Mr. Bernstein has held the post of Associate Executive Director of WARC for the past four and a half years. Nine years ago he joined the agency, which has its headquarters at 74 Westmoreland Avenue, White Plains, as Assistant Executive Director. As Associate Executive Director, he has been responsible for planning and operation of all agency programs for more than 800 retarded adults and children at three training centers, three pre-schools, twelve community residences and a sleepaway summer camp.

"Joe Bernstein has played a major role in the expansion that has made WARC the largest and most influential private agency in Westchester serving retarded people and their families. It is the Board of Directors' conviction that he will maintain our agency's leadership in the field, expanding and strengthening its services. He has our full confidence."

Mr. Bernstein came to Westchester from Mineola, where he served as Director of Training at the Rehabilitation Institute.

He is presently a technical consultant to the Rehabilitation Services Administration of the Department of Health and Human Services, Region II, and is on the faculty of Cornell University's School of Industrial and Labor Relations, teaching management training for rehabilitation personnel. He has served the New York State Association of Rehabilitation Facilities as Board Member, Treasurer and Chairman, and he is a member of the National Rehabilitation Counseling Association and the Administrative and Supervisory Practices division of the National Rehabilitation Association.

Mary Kallet, C.S.W., A.C.S.E.W. and Thomas Hughes have been appointed by Mr. Bernstein as Assistant Directors. Mrs. Kallet moves to her new position from the directorship of the Department of Community Education. She has been on the staff of WARC for 11 years, and served as Director of Social Services before heading the Community Education Department. She is an Adjunct Professor of Human Services at Westchester Community College and a member of the Advisory Committee of Westchester County Office for the Disabled. She will have supervisory responsibility for Day Treatment, Pre-

School, Community Education and Guardianship programs. Tom Hughes has been Director of Residential Services for the past two years, after serving successively as Residence Supervisor, Senior Residence Supervisor and Program Coordinator. He will be responsible for supervising Day Training, Residential Services and Recreation.

Suffolk County Chapter announced with pride that Norma Pitcher of Holbrook has been appointed Deputy Executive Director of the Suffolk Chapter of the Association for the Help of Retarded Children (AHRC).

Mrs. Pitcher has been involved in AHRC for over 25 years serving first as a volunteer, then as a member of the Board of Directors and for the past 13 years as Director of Adult Services.

Genesee County Chapter announced that Thomas Glair, formerly of Niagara County Chapter has been appointed as their Executive Director, of Genesee Chapter. Tom holds an M.S. in Vocational Counseling, has seven years experience in workshops and rehabilitation counseling. Prior to his involvement in the Human Service field, Tom was involved in marketing, construction and supervision functions for several major corporations.

## Messier receives Parent Award

On the evening of Thursday, October 15th the members of the Board of Governors of the New York State Association for Retarded Children were gathered in Albany to begin their work on an extensive agenda. However, one regular participant in these meetings was missing. Henrietta Messier, Chairperson of the State ARC Community Residence Committee, was in New York City at the banquet of the National Association for the Severely Handicapped. She was there to receive that Association's Distinguished Parent Award, in recognition of her years of dedication, enthusiasm and advocacy on behalf of people with handicapping conditions.

When the people in Henrietta's home community first learned that nominations were being accepted for this award, there was unanimous agreement that her name should be submitted. The nomination was made by the Rensselaer County Chapter of the ARC, with support letters coming from State ARC President Ellie Pattison, Rensselaer County Unified Services Commissioner Ara Baligian, Dr. Hugh LaFave, Executive Vice President of the Canadian Association for the Mentally Retarded, Rensselaer ARC President Joseph Lynch, Joni Fritz, Executive Director of the National Association of Private Residential Facilities for the Mentally Retarded, Susan Eisler, former Chief of Services for Eleanor Roosevelt Developmental Services and Dr. Carl Mindell, a child psychiatrist.

Rather than go over Henrietta's extensive background, which qualified her for this honor, we will let the excerpt from the nomination letter speak for themselves:

Mrs. Messier is the parent of six children. Her second oldest, Cheryl or Cherie to all who know her, has Down's Syndrome. In 1948 when Cherie was born the medical experts of the day advised Henrietta and Ernie Messier to place her in an institution. The Messiers rejected that suggestion and Henrietta set out to make the world a better place for her daughter and all the other mentally retarded and developmentally disabled people who could benefit from her efforts. For a person starting out with no experience in the field and no formal education beyond high school this would seem to be an almost unsurmountable task, but God knew what he was doing when he selected Henrietta Messier for this job. Today her advice and wisdom is sought by parents and professionals, with years of training and experience, not only in New York State, but throughout the United States and Canada.

It is hard for those of us who have had the privilege of working next to this extraordinary person to imagine what it would have been like without her. She has been the major force behind the development of our pre school, community residence and adult services programs. Without her efforts our agency would never have been able to acquire Pinewoods Center (where our pre school is located) and our work center. It is also hard to imagine how we would have been able to develop one of the most extensive networks of community residential services for a county of our size in New York State without Henrietta. Even more important than the mere opening of programs facilities, Henrietta Messier has set and maintained a standard of quality in programing that has achieved for our agency recognition and respect throughout the country.

As Chairperson of the Community Residence Committee of the New York State Association for Retarded Children, she was the primary catalyst in the writing and passage of legislation that provides a funding structure for community residence programs in our state.

## St. Lawrence holds "Positive" Rally

Dick Laurin, Executive Director of St. Lawrence Chapter, decided it was time to do something different, and which, in his words was long overdue!

Working in conjunction with the United Cerebral Palsy Association, Dick organized a "positive" rally in recognition of the work of local officials in bettering conditions for those who are disabled. In addition to the POSITIVE rally, on the courthouse steps, individual proclamations were issued to area businesses and industries that employed the handicapped and helped the chapter in its employment programs.

We think the chapter's idea of issuing a proclamation to the people is worthy of recognition and replication by others.

This is a model proclamation issued to Congressman David Martin of the 30th Congressional District!

### PROCLAMATION

Let it be known, that during the week of October 4-11, 1981 during National Employ the Handicapped Week in the International Year of Disabled Persons, that the St. Lawrence County Chapter of the New York State Association for Retarded Children, Inc. and United Cerebral Palsy Association of NYS, Inc. did hereby present this Proclamation of recognition and appreciation to the people of St. Lawrence County.

The Associations; members, parents, staff and clients offer this proclamation in symbolic thanks to the people of St. Lawrence County through the efforts of the St. Lawrence County Legislature, individuals, agencies, and industries throughout St. Lawrence County who in the past and present, have enabled the disabled of St. Lawrence County to pursue a high quality of life.

It is with heart-warming thanks that we welcome the opportunity to present this at this time:

to

Honorable David Martin, Congressman  
30th Congressional District



Sincerely,

Carolyn Smith, President  
St. Lawrence County Chapter  
of the N.Y.S. Association  
for Retarded Children, Inc.



## Epilepsy

# Old attitudes resist change

In 1951, Ronald Reagan made a movie called, "The Winning Team", which chronicled the struggle of baseball great Grover Cleveland Alexander to overcome his epilepsy and alcoholism. The odd thing about the movie was that although Alexander's drinking was openly discussed the word "epilepsy" was never mentioned and his physical condition was described merely as "a problem that will be with you for the rest of your life". President Reagan, reminiscing recently about that part, one of his favorites, said he regretted then and still does that the film could not have been more explicit. Apparently the film's producers felt mentioning "epilepsy" would be too shocking for the audience.

"Thirty years later, things haven't changed a whole lot," noted Laura Wagman, executive director, New York State Epilepsy Association. "While there have been sensitive television programs about epilepsy in recent years, there is still a general reluctance on the part of the American public to deal with epilepsy."

Epilepsy is a disorder of the brain caused by abnormal discharges of excess electrical energy in the brain. Depending on where in the brain this excess energy spreads, the result can be a convulsive or non-convulsive seizure. Epilepsy is an episodic disorder, which means that when the brain cells are functioning properly, the person is perfectly healthy and normal. But many people have the misconception that epilepsy renders every person who has it incapacitated or mentally ill.

"Too many people are still trapped by ancient fears and prejudices about epilepsy," Ms. Wagman continued. "It would be one thing if those prejudices didn't affect anyone else, but unfortunately, they show up in higher

unemployment rates for people with epilepsy, improper first aid techniques for those having seizures, and a tendency to regard someone who has epilepsy as 'different.'"

The New York State Epilepsy Association is conducting a public education campaign during November as part of National Epilepsy Month.

"We don't think it's fair to build walls of ignorance and fear around the more than two million Americans who have epilepsy. We know that once the American public learns the facts about epilepsy, they'll help us start tearing these walls down. That is what National Epilepsy Month is all about."

For more information, contact the New York State Epilepsy Association at 11 Broadway, Room 1157, (212) 344-5466 or one of its thirteen member chapters around the State.

— There are different kinds of epilepsy, ranging from convulsive seizures to brief periods where the person loses consciousness and appears to daydream. For persons severely disabled by epilepsy, some of them with other disabilities as well, a range of special support services are necessary.

— For the majority of people with epilepsy, medication can control their seizures.

"Because most people with epilepsy can control their seizures with medication it is people's reaction to epilepsy — not the epilepsy itself — which causes the disability," noted Laura Wagman, executive director of the New York State Epilepsy Association.

For more information, write the New York State Epilepsy Association at 11 Broadway, Room 1157, New York, New York 10004 (212) 344-5466.

## "Fragile X" chromosome causes male retardation

The second most common form of mental retardation has been found to be caused by a genetic disorder that afflicts mostly males and is transmitted in families by a defective chromosome dubbed the "fragile X."

A "rock-bottom minimum" of 2 or 3 percent of those in schools and hospitals, for the retarded suffer from this newly discovered form of genetically determined retardation, a Harvard geneticist said which would make it second only to Down's Syndrome, as a known cause of retardation.

Emboldened by recent research, doctors are beginning to look for the defective chromosome in retarded males, so they can counsel their parents about the chances of having another retarded child.

If a woman has had one retarded child with the fragile X trait, the chances are 50 percent that her next child will also be retarded if it is a boy, researchers say. The retarded child can be tested for the fragile X trait. And though no test is available to ascertain if a fetus is carrying the faulty chromosome, a standard test called amniocentesis can determine if a pregnant woman is carrying a male, and give the parents the choice of taking the 50 percent chance or terminating the pregnancy through abortion.

Dr. Park S. Gerald, chief of clinical genetics at the Children's Hospital Medical Center in Boston, said he considers it "grounds for malpractice" if a doctor does not do chromosome analysis on a boy suffering from no known cause of mental retardation to determine if he is carrying the fragile X. Not to do so, Gerald said, deprives the parents of information

about the risk of having another retarded child.

The fragile X syndrome was first discussed widely by scientists about two years ago, but researchers were uncertain then how common it was.

"The big thing now is that we know it really is as frequent as we were guessing," Gerald said. "It's not a guess any longer. Fragile X is the second most common known form of mental retardation."

## 3 publications tell OMRDD story

Three new publications tell the OMRDD story to the public in clear and sympathetic fashion.

Now available from the OMRDD Office of Public Education as well as Speakers Bureaus located at all Developmental Disabilities Services Offices are:

"Community Living for the Mentally Retarded," a brief but thorough explanation of recent history and current goals for the care of mentally retarded and developmentally disabled people in New York State.

"Right at Home, Right in the Neighborhood," a description of the various residential options now available to people who are retarded or developmentally disabled here.

"Facts About the Developmental Disabilities," which provides the best, most easily understood and most accepted definition of the developmental disabilities as well as the legal and philosophical approach to dealing with these disabilities in the State of New York.

# Preventive dentistry for the disabled

Availability and accessibility of preventive and therapeutic dental care is a significant need of disabled individuals. Preventive dental health education has generally not been extended to disabled individuals with the result that their oral hygiene is often very poor. The National Foundation of Dentistry for the Handicapped (NFDH) considers the disabled as presenting unique opportunities for preventive dentistry because of the nature of the educational and rehabilitation services provided to this population. Opportunities for organized oral hygiene and nutrition instruction on a daily basis are compatible with the basic living skills curriculum of special education centers. As adults, many developmentally disabled people attend sheltered workshops or reside in group homes where organized programs of daily oral hygiene are similarly compatible. Accordingly, NFDH has sought to build a system of dental care for developmentally disabled people by taking advantage of the unique preventive care opportunity accorded by their life style.

## N.J. PREVENTIVE PROGRAMS VISITED

At the invitation of Larry Coffee, D.D.S., Executive Director of NFDH — Chairman Sundram, Maxine Prescott, Director of the Protection and Advocacy Bureau, Bob Melby of Commission staff, and Dr. Robert Sapin, Medical Director of UCPA of New York State visited preventive dentistry programs in New Jersey assisted and fostered by NFDH. In New Jersey state appropriations have replaced grant support of pilot projects. Additional revenue is provided through Medicaid reimbursement since the New Jersey Medicaid program has approved the project as a Title XIX benefit.

Visits were made to Pensauken, New Jersey, outside Camden. One visit was to an elementary school based EMR class in which dental hygienists were teaching preventive procedures. Another visit was made to an adult activities program sponsored by the Camden County Association for Retarded Citizens in which preventive and assessment procedures were being administered on a one to one basis with profoundly retarded and multiply disabled individuals. NFDH project protocol has dental hygienists designing comprehensive oral hygiene programs with the staff at participating centers. Teachers, counselors, and houseparents assume responsibility for supervising their students — clients as daily oral health education is implemented. All oral hygiene supplies are provided by NFDH. Primary prevention, effected by intensive instruction in self-help oral hygiene skills, is intended to reduce the future incidence of dental disease among the developmentally disabled. As a secondary preventive measure, hygienists complete an annual health assessment for each participant. Teeth, tissues and prosthetics are inspected and obvious or suspected findings of pathosis are recorded. Parents — guardians and social workers are notified of the results, and examinations by a dentist are recommended. The hygienists carefully monitor referrals and a tracking system is used to chart an individual's progress. This system has been designed also to identify problems which impede access to therapeutic care.

## CAMPAIGN OF CONCERN ESTABLISHED

NFDH has established this "campaign of concern" preventive dentistry — systematization of care projects in special education schools, sheltered workshops, and congregate residential facilities in eight states: Colorado, Massachusetts, Pennsylvania, Louisiana, Minnesota, Michigan, Wisconsin, and New Jersey. The process of development of the pilot

programs was similar in each state and consisted of establishing a coordinating unit comprised of dentists, health planners, and representatives of advocacy organizations for the handicapped; formulation of a grant proposal for a preventive dentistry project; submission of the application to local philanthropic organizations and government agencies; implementation of the program upon receipt of financial support; and exposure of the demonstration project to appropriate state legislators to gain support and assistance for long-term funding.

NFDH, through grants from the Robert Woods Johnson Foundation, provided technical assistance to the eight states helping plan for the establishment of preventive dental care programs.

NFDH will be expanding its services to three new sites, one of which already has been chosen. Two factors are taken into consideration by NFDH in selecting a new state or site. The first factor involves the degree of interest expressed in establishing preventive dental care programs. The second factor involves the availability of funding. Added support will be needed for NFDH to consider New York as one of the two remaining sites for expansion.

The Association of Medical Schools in New York State has contacted NFDH about staffing a program in this state. The Bureau of Health Services in the OMRDD has been involved in an assessment project since July 1980. Other State agencies such as the Department of Health, Bureau of Dental Health, and the Dental Unit of the Office of Health Systems Management have expressed interest in dental care for the disabled.

## Many handicapped children learn by chance

The Association for Severely Handicapped recently reported in its newsletter some disturbing news provided by teachers in questionnaire responses.

The teachers voluntarily participated in a research study that involved hours of their time spent reading, attending training sessions, and reporting to the researchers. — The group of 69 teachers from all parts of the country were identified by colleagues of the researchers and were responsible for the education of 724 students. The discouraging news:

— Two of the teachers admitted that they did not provide any instruction to their pupils, and twelve others that instruction was not provided every day. Less than half the teachers thought that regularly conducted instruction, during which pupils were allowed to respond individually, was "very applicable" in their setting. All of these teachers had assistance provided by aides, volunteers, student teachers, and/or others for an average of 47.5 hours per week.

— About half of the participants did not have aims for their instructional programs. Less than half had procedures for deciding when it was time to move to the next curricular step.

— Only 46 percent evaluate student progress in almost all of their instructional programs and 13 percent evaluate in less than half the programs.

Instruction is the basis for education. It is incredible to find even one teacher who admits to not teaching. How can severely handicapped persons learn if teachers don't teach, if they don't teach on a regular basis, and if they don't allow their students to respond individually? Instruction without aims, without planned progression, and without evaluation can only be described as haphazard. If the pupils learn, they are lucky; if any learning occurs it is not by design.



## Employer of Year

# ARC honors Batavia firm

Batavia's 114-year-old shoe manufacturing firm, P.W. Minor & Son Inc., has been named "Employer of the Year" by New York State's Association for Retarded Children.

The honor was presented at the state association's annual convention at Albany to P. W. Minor President Missy Minor Shaw. Genesee County Association for Retarded Citizens officials nominated the firm for the statewide award. They said the city company won over many businesses.

The recognition is "a tribute to P.W. Minor and the Genesee County ARC," Thomas Glair, new ARC director, stated. He said usually the state's top honor goes to huge companies that employ thousands of workers.

The shoe factory, which employs about 250, has "worked with the handicapped, generally, for years," Mrs. Shaw said. The association with ARC began about three years ago, she said. As many as six ARC referrals have been employed at the Industrial Park firm at one time. Three are currently employed.

"We decided as an employer in the community we should take responsibility to employ handicapped people," Mrs. Shaw commented. She said employees have come to work at P.W. Minor through ARC placement services and others have applied for jobs on their own or through family and friends.

Former ARC program participants employed at the shoe factory have tended to work out well, Mrs. Shaw said. She explained ARC has a well-organized training facility for clients who seek outside employment. "They know basic employment skills, such as reporting to work on time, working conscientiously and how to react to supervision."

Any problems with ARC — referred employees are of the same type as all workers experience, Mrs. Shaw said.

Former ARC participants and other handicapped people come with the "usual range of people problems," Mr. Glair commented.

Dyder Smith, foreman in the stock fitting department, supervises most of the ARC referrals. Employees in her

department cut and assemble soles of shoes.

"I'm proud of every one of them" Ms. Smith said of employees under her charge. "They've all been so successful."

The foreman, who was honored earlier this year by the county ARC for her work, said one former ARC-referred employee went on to study at Genesee Community College. She said several others have gone on to find different or better jobs.

Mrs. Shaw said she hopes the success of P.W. Minor helps encourage other area companies to hire handicapped people, "especially in light of budget cuts that I'm afraid we are going to have to live with."

"If every employer contributed just three to four percent of their employment to the handicapped of any kind it would help everyone," she said.

## Employers receive awards

By unanimous vote, P. W. MINOR & SON, INC. (See related article) nominated by Genesee County Chapter, has been named our 1981 Employer of the Year. As is our custom a plaque was presented at our State Convention, and an Award Certificate was provided for the following nominees:

P. W. Minor & Son, Inc.  
Episcopal Church Home  
Marionat Bridal Veils  
Tri-State Industrial Laundries, Inc.  
Brewster Plastics, Inc.  
Sullivan County Steam Laundry  
Schneller's Restaurant  
Creative World

Nominated by:

Genesee County Chapter  
Monroe County Chapter  
New York City Chapter  
Oneida County Chapter  
Putnam County Chapter  
Sullivan County Chapter  
Ulster County Chapter  
Westchester County Chapter

## N.Y. Special Olympics founder retires

After eleven years of distinguished service to the mentally handicapped in the state of New York, Dorothy Buehring Phillips, the founder and president of New York State Special Olympics, Inc., is retiring. Mrs. Phillips has been the driving force behind the development of this program of sports training and athletic competition for mentally handicapped children and adults.

Mrs. Phillips' work with Special Olympics began in 1969 when 80 mentally handicapped athletes with their coaches traveled to their first Special Olympics competition at Boston College. Today nearly 40,000 athletes ages 8-80 participate in New York Special Olympics with the assistance of 14,000 volunteers.

Mrs. Phillips, who recently retired as an Associate in the education of the handicapped for the State Education Dept., has invested thousands of volunteer hours as President of New York Special Olympics and is also involved in field testing the Sports Skills Instructional Program developed by Special Olympics,

Inc. under the guidance of Mrs. Eunice Kennedy Shriver through a federal grant.

Over the years Mrs. Phillips was actively involved with the Ulster County Chapter Association for Retarded Children and has been president of the Ulster County Girl Scouts Council. Her directorships and board memberships include the Albany Girls Club, the Volunteer Council of the O.D. Heck Developmental Center and the Capital District Chapter of the State University College at Genesee Alumni Club. Her many years of public service have earned her many awards including the Outstanding Business Woman of the Year by the Albany Business and Professional Women's Club, the Jefferson Award presented by WTEN-TV 10 Albany and the Distinguished Citizen Award presented by the State University Board of Trustees.

A testimonial dinner in her honor was held in September at the Empire State Plaza in Albany.

Mrs. Phillips resides in Albany with her husband, William.



Master of Ceremonies John McLoughlin saying a few words at Convention Banquet, flanked by Albany's Mayor Erastus Corning II and President Ellie Pattison.

## Respite services planned for families

Respite services for families of disabled children are being set up by the Ulster Association for Retarded Children. This new service is being launched with a \$22,545 grant received from the New York State Office of Mental Retardation and Developmental Disabilities, and will be headed by Barbara Morgan as respite coordinator.

Lack of respite care in this area has long been a major problem for these families who often cannot attend family functions and social affairs or take vacations because of the extreme demands required by their special children.

Ms. Morgan will recruit and train a network of people to provide care for disabled children either in their own or in the family's home. She plans to contact service organizations and church groups to promote participation in the program.

With respite care, UARC hopes that families will be better able to cope with the extreme care required to maintain handicapped children in their home, avoiding unnecessary and costly institutionalization of the child.

Ms. Morgan was formerly educational coordinator at the Astor Day Treatment Center, Poughkeepsie, and community outreach coordinator at Bard College where she established a recreation program for the handicapped, and trained and supervised students to act as advocates for deinstitutionalized adults. Most recently, she was educational consultant for community services at Wassaic Developmental Center, Poughkeepsie.

Ms. Morgan is a graduate of City College of New York and S.U.N.Y., New Paltz, where she earned a M.S. in Special Education. She is currently a doctoral candidate in Applied Neuroscience in Holistic Medicine at Union Graduate School.

## CEC Conference to be held in March

The Council of Exceptional Children (CEC) Chapter at the State University of N.Y. at Genesee announces its Sixth Annual Special Education Conference. The theme of this year is Behavioral Disorders including Autistic, Emotionally Handicap, etc. The conference will be held at the campus on March 5 and 6, 1982. The conferences in the past have attracted many professionals and students in the area.

## Open Letter to Sonya

The lament of an angry taxpayer complaining about the cost of financing special education is addressed in an open letter to the editor by Judy Shalvey, member of NYS ARC Education Committee, in which she states:

RE: "Financing Special Education"

Your letter states that you are a "mother, taxpayer and former teacher" questioning the cost of special education — more specifically, questioning the worth of certain human beings. As a mother of three children, taxpayer and former teacher, I shall respond to your questions.

Fortunately there are federal and state laws (The Education for All Handicapped Children Act of 1975, Sect. 504., The Commissioners Rules and Regulations, etc.) which guarantees a "free appropriate education" To All Children who are handicapped. There was a time when these laws did not exist. It was not too long ago that disabled children and their families were at the mercy of people such as you. These are the very children who received so little or nothing at all. Their bent bodies travelled cross-county 50 miles daily to receive a substandard education, usually in a church basement.

My 13 year old son happens to be one of your innocent victims. The medical profession deemed his life worthy of saving at birth. However, you have chosen the omnipotent role of judging whether or not his life is worth living in dignity equal to other children. To clarify: "equal to" does not mean the "same as." Surely, as a former teacher you must be aware that each child learns at his own rate and therefore, requires a commensurate education. Surely, as a mother, you should have acquired the compassion and understanding essential to motherhood.

You should have done your homework, Sonya Bradley. At the very least, you must have learned that the Constitution states: "all men are created equal". It does not state that they must have blue eyes, blonde hair, "perfect" bodies or "perfect" intellectual ability as prerequisites to their inalienable rights.

**A happy, healthy  
fulfilling 1982!**



# Receivership bill signed by Carey

Residential facilities for the mentally retarded that fail to comply with state regulations may be placed in the care of "receivership" of a voluntary agency or the state until violations are corrected or clients are transferred elsewhere, under a bill signed by Governor Carey.

The bill was proposed as a Governor's program bill prompted in part by the Commission's investigation and report on Greenwood Rehabilitation Center, Inc. entitled Profit vs. Care (March 1981). The report on this private school for the mentally retarded cited a long list of deficiencies in almost every area of the operation of the school. Lax monitoring had permitted the owners to violate regulations "with impunity."

Faced with limited facilities for the retarded, "there was not an effective alternative available to the state," Commission Chairman Sundram said. Closing schools that were persistent violators would have caused "tremendous disruption to the lives of innocent victims." Now the receivership bill "has given the state some options to pursue tough regulations of a relatively new industry," Chairman Sundram said. It has

moved the regulation of facilities for the mentally retarded and developmentally disabled out of the horse - and - buggy age."

The bill spells out two kinds of receivership; one in which the owners or operators agree to have the State take over the school and the other in which the State asks the courts to appoint a receiver "to protect the health, safety and welfare of the clients." The court - ordered appointment would be sought when the state revokes an operating certificate or refuses to issue one because of persistent or gross violations.

Under the legislation, a judge is instructed to give preference to voluntary or not-for-profit agencies over profit-making operators in selecting a receiver. The Office of Mental Retardation and Developmental Disabilities is to be the receiver of last resort.

The bill stipulates that the court terminate the receivership either when the facility obtains a new operating certificate, the clients have been provided alternate care or 18 months have elapsed.

The law will apply to profit - making, non-profit and voluntary schools and community residences.

## Changes in Food Stamp regulation

The USDA Food and Nutrition Service announced (Sept. 4 1FR) changes in the current Food Stamp Program in accordance with the 1981 Omnibus Reconciliation Act. The changes affect eligibility requirements and other parts of the program so as to reduce the expenditures of the program. Foremost is a change from the standard of "net income" to "gross income" as the criteria for eligibility. A household may not participate if its gross income exceeds 130 percent of the OMB-defined poverty level. The net income criteria will remain in effect only for households with an elderly or disabled member. Such households will also remain entitled to all the currently allowed deductions: medical, uncapped shelter, dependent care, earned income, and standard deductions. For all other households however, these deductions are rendered non-applicable by virtue of the gross income method of determination of eligibility.

Other program changes include for-

reach activities — except in the cases of nutrition education, public inquiry information, or information on program rights and responsibilities. Also, the definition of "household" was revised to define as a single household parents and children who live together. This would preclude separate claims — except in cases in which one of the parents is 60 years of age or older. Finally, the Consumer Price Index, used to revise benefit levels to reflect inflation costs, was revised to exclude homeownership costs from the index as applied to the Food Stamp Program. The interim rule will take effect immediately, although public comments will be accepted before a final rule is announced. For further information contact: Thomas J. O'Connor, Jr., Supervisor, Policy and Regulations Section, Program Standards Branch, Program Development Division, Family Nutrition Programs, Food and Nutrition Service, USDA, Washington, D.C. 20250 (202) 447-9075.

## Will Sheltered Workshops survive?

David Essrow, Chairman of State ARC Vocational Rehabilitation Committee, has issued a plea to all our Chapters who run a Sheltered Workshop program to be on their toes in the months immediately ahead. There are many projects in the works at all levels, local, county, state and federal, that are going to have a great impact on our agencies. Changing policies and legislation are going to affect the programs that our chapters will be able to run. Chapters that don't develop and maintain knowledgeable Board of Directors that can make timely and wise decisions will quickly find themselves struggling to survive this new wave of economic and programmatic change.

The Vocational Rehabilitation Committee will be monitoring any new legislation in Albany and Washington and keep our chapter representatives informed through our Bulletins.

Our Boards and Executive Directors are NOT the only ones in a position to make our agencies successful in the months ahead. You, the members and friends of

ARC can also be of help. You must continue to support funding and legislation for the handicapped through your local legislators. You can also help by finding contract work for our shops. Although many of our shops have a salesman out looking for jobs, you may have a contact that you could approach for work that could be done by our clients. We have many shops across our state that have the capability of doing all sorts of good work. If you have an idea or a prospective customer the Voch Rehab Committee can put you in contact with a shop that can do the work. You may also be in a position to obtain a new piece of equipment or machinery from time to time. Keep us in mind.

We remind you that the operation of a sheltered workshop is similar to that of any other business venture. In today's economic climate, only the well managed, efficient shops are going to survive. Don't wait until it's too late. Take an interest in your Chapter's Workshop program now and be sure that it will meet the test.

FROM LEFT TO RIGHT: TERRY WILSON, Client; SAN SCALETTA, Volunteer; MYRA JACKSON, Client; and FRANCES SEFLER, Client, are working on one of the many contracts issued by Fisher-Price Corporation. These contracts are provided by industry to help create a realistic assembly production line at Rehabilitation Workshops.



## Niagara Gazette salutes Chapter

Recognizing that people are Niagara's greatest resource, the Niagara Gazette saluted volunteers of Opportunities Unlimited, as an example of "Niagarans Helping Each Other!"

The work activity center for developmentally disabled adults provides counselling services, sheltered employment, vocational training and community work placement, and in addition operates seven community residences.

Volunteers consisting of a wide age range assist in Niagara Chapter

programs. College Students in Special Education and others volunteer in the workshop while other volunteers help in community residences by taking clients shopping, to the movies and by helping on special projects. Volunteers are also utilized in the Day Treatment Program for a more severely impaired population, where they are involved in teaching daily living skills.

The Niagara Gazette believes such volunteer service to the community should not go unnoticed.

## OMRDD Speaker's Bureau programs reach thousands

More than 25,000 New Yorkers have been reached with accurate information about developmental disabilities and OMRDD's programs through the Speaker's Bureau network.

This highly motivated cadre of professionals is becoming more and more adept at communications skill after two years of on-going, specialized training by OMRDD.

Speaker's Bureau Coordinators at home - base DDSOs assume the major responsibility for the "nuts and bolts" public education — promoting interest about the variety of OMRDD programs among community groups, soliciting speaking engagements, choosing appropriate speakers, maintaining the supply of informational materials and making sure all presentations are followed up adequately. The contribution of Speaker's Bureau members cannot be overemphasized, for each time a staff member is called on to answer questions about community residences or the issues by the news media, community groups, neighbors or local officials, a communications process takes place that can critically affect the public's perceptions for better or worse.

To keep the creative juices flowing, the second annual Public Education conference for BD-DDSO Speaker's Bureau Coordinators and their associates was held this summer in Albany. Sponsored by the OMRDD Public Education Bureau, an entirely new package of support materials was introduced at the conference featuring the theme "Right At Home, Right in the Neighborhood."

### NEW MATERIALS AVAILABLE

The new materials include the brochures Facts about Developmental Disabilities, Right at Home in the Neighborhood, which describes all the community living alternatives from supportive living to community - based Intermediate Care Facility residents, a 14-page booklet, "Community Living for the Mentally Retarded and Developmentally Disabled," summarizing current community programs and New York States'

philosophy of placing the mentally retarded and developmentally from state operated institutions into appropriate community residential and day programs.

Developed to work in tandem with the new print materials, a new side-tape program covering full range of community residential alternatives was also introduced and distributed to all BD-DDSO Speakers Bureau Coordinators.

### CONFERENCE HIGHLIGHTS

Among the highlights of the two-day conference were these stimulating presentations:

— A series of three skits with role-playing members of a Neighborhood Advisory Committee as a vehicle for gaining and keeping community acceptance. This clever technique was demonstrated by CRISP of New York City and Westchester.

— How to mount a media appreciation event, in this case a successful media recognition awards breakfast put on in Buffalo, with Meg Fein and Don Serota presenting.

— Three slide shows were viewed, each using a different slant to win community understanding. One show was on the subject of the Foster Grandparent Program in a developmental center.

— Dave Blatchley of Syracuse Developmental Center gave the group something new to think about — the use of the public access channel on cable television.

— Community meetings using persons who are retarded as speakers was discussed by Bill Dwyer of Westchester, and Betty Saverese of Brooklyn told the coordinators of her experiences with neighborhood youth groups.

Awards from the Office of Public Education for outstanding achievements were given to Bill Dwyer, Westchester, and Warren Palmiter of Rome.

More information about Speaker's Bureau activities or any of the new materials can be obtained through contacting Colette Crisafulli at OMRDD. Her number is (518) 474-4661.



## Director's Association works within NYS ARC framework

As part of its ongoing commitment to work collaboratively within the framework of the State Association, the Executive Directors Association held its most recent meeting at our State Convention. Our activities there as an Association were totally integrated within the framework of the Convention. Over the past 5 years, the Executive Directors Association has attempted to amplify its own activities in a manner that will strengthen and support the activities of the State Association as a whole.

At the State Convention, the Executive Directors Association reelected all incumbent regional chairpersons and reelected its' incumbent officers. The Regional Chairpersons are:

Western Region, Maryln Zahler (Niagara)

Finger Lakes Region, James Mroczek (Monroe)

Downstate Region, Michael Goldfarb (New York City)

Central Region, Raymond Lewandowski (Madison)

North County Region, Richard Laurin (St. Lawrence)

Northeast Region, Carol Anderson (Columbia)

Mid-Hudson Region, Marc Brandt (Sullivan)

The Officers are: Michael Goldfarb, Chairperson; Maryln Zahler, Vice Chairperson; and James Mroczek, Secretary - Treasurer. The principle goals of the Executive Directors Association have been and continue to be:

1. Technical assistance to the executive directors to allow them to better manage their chapters;
2. Implementation at the professional level of the goals, policies and practices of the State Association;
3. Strong advocacy on behalf of the retarded throughout the State.

In keeping with these goals, we have presented a variety of training seminars such as the sessions on residential services and day services provided at the recent workshops presented at the convention. Other topics upon which we have focused at recently held meetings include:

1. fiscal management;
2. stress management;
3. the development of day treatment programs;
4. residential audits;
5. legislation;
6. board - staff relations;
7. labor relations and unionization.

In addition to our formal programs, members of the EDA are encouraged to draw upon the strength of other executive directors in those areas in which they require technical assistance. Thus executive directors with special skills in fiscal management, program design and other areas have visited with executive directors requiring and requesting their assistance. The result has been a significant increase in the quality of management of the chapters.

In the area of legislation, the Executive Directors Association recently established a legislative committee which will work cooperatively with the Legal and Legislative Committee of the State Association. The Executive Directors Association will provide information to the State Association's committee regarding the impact of current or proposed legislation upon chapter operations and will also serve as a source of advocacy efforts on behalf of the State Association's legislative platform. A member of the Executive Directors Association will serve on the State's committee, while a member of the State Association's committee will be invited to serve on the EDA's committee. This will ensure coordinated and effective action at the local level will ensure coordinated and effective action at

the local level with regard to our State Association's legislative posture.

One of the most successful aspects of the recent operation of the Executive Directors Association has been the participation of one executive director on each of the State Association's standing committees. This practice, initiated by George Hirsch in his presidency and amplified by Ellie Pattison during her tenure, has substantially improved the working relationship between parents and professionals which the Executive Directors Association thoroughly supports.

The climate in which the State Association and its chapters functions has become more ominous. It is often difficult to accurately predict future directions. Consequently, it is my commitment and that of the Executive Directors Association to strengthen the ties which bind us to the State Association in a manner that will enhance our ability to survive and flourish in the future.

## Citizen Involvement Conference in June

If you're interested in learning more about effective involvement of citizens, fundraising, new program, and new ideas, if you're interested in meeting your peers in the fields of health, community organizing, education, corporate responsibility, arts and humanities, Voluntary Action Centers, if you're interested in your own personal and professional development, don't miss the National Conference on Citizen Involvement to be held at Yale University, June 6-10th. For additional information, contact Kris Rees, Conference Coordinator at Volunteer, 1111 North 19th Street, Suite 500, Arlington, Va. 22209. Telephone (703) 276-0542.

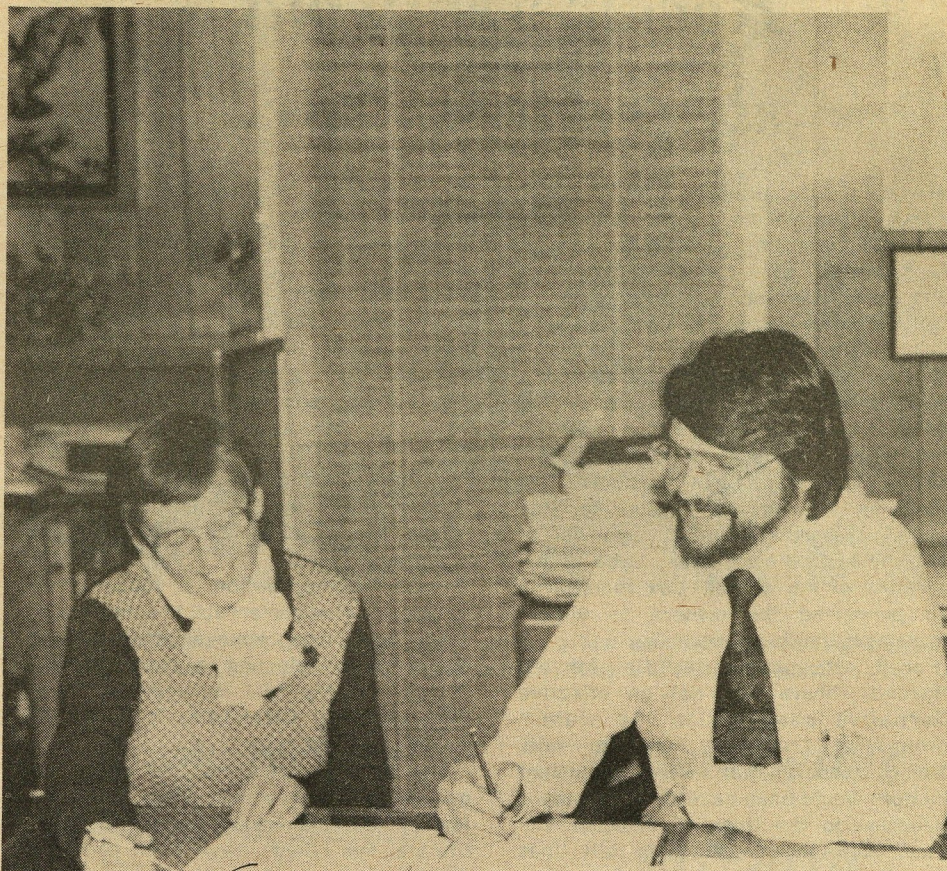
## Parent advocacy at Letchworth

The unique and exciting Advocacy Program, involving social workers and their training, sponsored by the WELFARE LEAGUE and being carried out at Letchworth Village Developmental Center (LVDC) has recently won the support of OMRDD. This highly successful program has been in operation since 1977. Until recently, it has been partially supported by Federal funds through the Developmental Disabilities Council.

The program was designed in response to the plan for the deinstitutionalization of mentally retarded persons at Letchworth Village, which was adopted by the State about 10 years ago to comply with Federal regulations. The purpose of the program is to assure that each resident being considered for placement in the community is adequately represented in order to protect his rights as a citizen and a human being — whether he has a relative to advocate for him, or not. The program also functions to secure services for those remaining in the institution.

In order to accomplish these goals, the WELFARE LEAGUE employs two MSW's who supervise up to 8 students of social work as they undertake to complete their required internship. These students, drawn from all the major schools of social work in the metropolitan area, learn to know each person slated for resettlement from LVDC on an individual basis. Under the direction of an MSW, the students talk to the resident, and by means of several visits attempt to determine whether he has been properly prepared for life "on the outside" — socially, physically, and psychologically, just as an interested relative would.

They learn his attitude with regard to leaving known surroundings and friends. They attempt to assess the adequacy of



Dorothy Hughes, President and Richard Swierat, Executive Director of Ulster County Chapter.

## Sex education conference planned by Ulster

The Ulster County Chapter, New York State Association for Retarded Children is currently planning a Spring Conference on the topic of "Sex Education for the Handicapped". The conference is anticipated to be held on April 16th and 17th. The Ulster County Chapter has made arrangements with Dr. Sol Gordon of Syracuse University to open the con-

ference with a key note address on Friday evening, April 16th. Other participants and speakers are being contacted at this time to roundout the schedule. More information will be available in the form of brochures mailed out to each of the Chapters as soon as final arrangements are made.

medical, residential, and physical facilities being provided for each resident in the program. they also attempt to determine whether his environment would be less restrictive — whether the quality of his life would be improved in the new setting. They visit the new home together with the resident on a pre-placement visit and follow up later, after placement, to ascertain the success of the transition. In every respect, under the close guidance of their MSW supervisor at WELFARE LEAGUE, these student social workers function as if they were a member of the resident's family.

The outline of the program was designed by Dorothy Gasman, in 1977, then president of the WELFARE LEAGUE, when faced with the enormous task of acting on behalf of the approximately 3000 residents at Letchworth Village at that time, who under the plans of the State and Federal governments, would have to be moved to reduce the population to 1500 by March 1982. The implementation of the design and the actual training of the neophyte social workers is the work of Carol Sussman, MSW, Project Director, who has conducted and developed the program since its inception. Presently she is assisted by one additional MSW.

The value of the program and its adaptability is attested to by the fact that it has survived a change in administration at the WELFARE LEAGUE (Bernice Volaski is now president) and a change in administration at Letchworth Village where it is receiving the same cooperation from Mr. Edward Jennings, the present director, as it enjoyed during Dr. Oleh Wolansky's administration.

One of the most important achievements of the Project to date, from the point of view of society in general, is the

development of an awareness in the schools of social work of the special qualities of retarded people — their humanity, their vulnerability and their sensitivity. Every student in the WELFARE LEAGUE program has emerged from it an ardent advocate for retarded people — in most cases never having known a retarded person before.

Sequestered in institutions as most of the more severely handicapped have been, retarded people have been non-persons in society, but deinstitutionalization is putting many back into their communities in hostels, family care homes, supervised apartments, etc. Others, who will never enter an institution, like the rest of us, will leave their parents' homes to live under suitable arrangements in their communities. These people, without relatives, will need advocates particularly sensitive to their needs and frailties. The WELFARE LEAGUE program is addressing this need in cooperation with the schools with which it is working.

The Project also serves as a resource for parents and relatives of residents of Letchworth Village. In that connection, it has produced several manuals which have won wide acceptance among professionals, as well as parents.

The Parent Manual describes the rights of relatives who represent their resident as well as the resident's rights.

The Placement Process Guide clarifies for relatives and advocates alike the process as prescribed by law and departmental guidelines.

The Unit Rep Guide standardizes the indoctrination of those members of the WELFARE LEAGUE who function as its representatives to each of the units of the Village.

Students have been drawn from Columbia, Adelphi, Fordham and New York Universities as well as from Dominican College.



## News and Views

## Education Committee

By Betty Pendler

Save the date. . . Friday, March 26, 1982 — Ramada Inn at Buffalo, State Wide Spring Workshop sponsored by the NYSARC Education Committee. We hope every chapter will send parents and professional staff to learn from our panel presentations about the status of the revised regulations, legal implications and the role of the Regional Associates.

We plan to have an exciting audience participation afternoon with workshops on (1) Evaluation and Assessment, What is Involved in Testing (2) How to Obtain Basic Rights in Education (3) Parents Role in the IEP and (4) Educational Advocacy — skills and techniques. Put the date down now.

Regents hearings of new regulations coming up. **THEY WANT TO HEAR FROM US. We need your input.** Please fill out questionnaire available from your local ARC Chapter.

Many chapters are doing great work in education - running their own workshops - writing articles in their newsletters - thanks from the Education Committee to all those chapters - we have already heard from Westchester, Rockland, Delaware, Herkimer, Livingston Wyoming, etc. Send us your advance announcement of your workshops - send for our over 50 reprints for you to distribute. Thanks to people like Sue Lyons in Fulton County who holds parent sessions, giving them all kinds of information, and thanks to all those capital district chapters who are working so well with our new project with the Commission on Quality Care.

#### New Titles for Handouts for your Workshop:

Physical and Occupational Therapy  
Adapted Physical Education, Perspective on Systematic Implementation  
Professional's Dilemma - Learning to Work with Parents

Towards a Realistic Image of Parents — A Teacher's Point of View  
Assertiveness Training for Parents of Disabled Children

In Praise of Teachers  
Section 504 — What it Means to Handicapped Children in School

Provision of Vocational and Technical Educational Services

Transportation for Pupils with Handicapping Conditions (A State Education Bulletin)

Physical Education and Handicapped Children

A newly revised publication list will be available shortly. NEWSLETTER EDITORS — send for our reprints — use them in your own papers — set up an Education Corner — you will always be able to fill up space!

**Education members speak up** — Marilyn Wessels addressed the 84th annual convention of the New York State Congress of Parents and Teachers in Syracuse. Betty Pendler, Shirley Reynolds and Mary Murphy were on a panel at the 1981 Convention of the Council for Exceptional Children and AAMD held in Buffalo on the subject of "Parents — Professionals — A winning Combination"; Georgia Sullivan led a workshop for Delaware County on the rules and regulations.

#### A PILOT PROGRAM

In addition to the success of our Eduletter, one of our most exciting achievements is the pilot project which has been entered in with the training staff of the Commission on Quality Care to plan, develop and implement a parent consumer education program, designed to inform parents and other concerned persons (staff of chapters, community, etc.) of the intent and content of 94-142, state law and regulations as well as to provide them with skills to effectively assert and exercise their rights. This project is currently being tried out with 12 chapters, who give con-

siderable individual input to the staff of the Commission on Quality Care through periodic face to face visits to develop outreach strategies for involving parents (the raison d'être of the Education Committee. The three major components to this pilot project are (1) development of a well - organized and readable parents resource manual (2) training workshops covering knowledge areas and advocacy skills and (3) extensive follow up programs after each workshop. The manual when completed will cover such subjects as understanding your child's educational needs, knowing the law, IEP, COH, and the advocacy part of the manual will include such subjects as aking your position clear, confronting the bureaucracies, stepping in to the real world with concrete case studies. We will continue to keep you posted of the exciting case studies.

We will continue to keep you posted of the exciting progress of this project.

#### The Education Committee goes to Albany Legislators

Because of the current climate, our committee has had to change focus and become more involved in monitoring implementation of regulations and legislation. In this regard we have established close ties with two important political contacts; both of whom have requested that parents send them directly their concerns on education — so write to:

Mr. James Campbell, Director  
New York State Assembly  
Task Force on Handicapped  
for Assemblyman Hevisi, Chairman  
Suite 1105 Twin Towers  
Washington Avenue  
Albany, New York 12210

and

Dr. Paul H. Schiffman,  
Executive Director of  
Assembly Standing Committee  
on Education (for Assemblyman  
Stavitsky), Room 836  
Legislative Office Bldg.  
Albany, New York 12248

**Readers: This is your column! Won't you share your experiences in education — be part of a parent network to help other parents attend COH meetings similar to the one that Westchester Chapter just initiated, following suit of New York City Chapter. We know that lots of you are doing great things — let us hear about it — we know some of you have concerns — let us hear about those too. The Eduletter continues to include items of interest to parents, teachers, administrators and other professionals. If you or anyone else you know would like to receive a free copy, please fill out coupon below.**

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

Name \_\_\_\_\_

Address \_\_\_\_\_

County \_\_\_\_\_

Tel. No. \_\_\_\_\_

Chapter Affiliation \_\_\_\_\_

Return to:

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



## New officers installed

With Senator William T. Conklin doing the installing in the background, the Association's Officers for 1981-82 smile for the camera. They are: (L. to R.) William Ingraham, Cortland County Central Regional Vice - President; Shirley Valachovic, Schenectady County N.E. Region Vice - President; Dr. Irving Caminsky, Rockland County Assistant Treasurer, Irene Platt NYC S.E. Regional Vice - President; David Lettman, Erie County Western Region Vice - President; Shirley Reynolds Secretary; George G. Hirsch, NYC Treasurer.

## Teenage education and motherhood training

Essex County A.R.C., with the assistance of a grant from the Bureau of Developmental Disabilities, has recently expanded the Teenage Education and Motherhood Training Program to provide prevention and support services to those in need in Essex County. Concentrating on education and training, T.E.A.M. serves a group of individuals, teen mothers, pregnant teens, and disabled mothers that has been identified as one in particularly high risk of producing developmentally disabled children. Intervention services are primarily directed at providing counseling and training to parents to prevent the harmful, debilitating effects children bear from being raised in neglectful, unstimulating homes.

Parenthood presents difficulties for most of us from time to time. However, an adolescent parent faces increased obstacles such as financial constraints, limited life experiences, health risks, and emotional stresses. Likewise, a disabled mother may lack information about her child's needs and may have difficulty interpreting available parenting materials.

The Essex county ARC TEAM Program reaches out to these potentially affected parents with its parenting education program. Through home visits and weekly education group sessions, TEAM provides parenting education, counseling, information and referral services, and a loan library of parenting materials. Additionally, TEAM can provide an in-home parent aide for those parents requiring direct, home-based assistance. Weekly education meetings for parents cover nutrition, child development, stress management, coping skills, community resources, discipline, parental care, human sexuality, and positive parenting skills.

TEAM provides weekly sessions in six locations in Essex County. Free transportation and child care are provided during the meetings. Currently, the TEAM staff which consists of Kristie MacDougal, Program Coordinator, and Alison Singleton, Counselor, are developing instructional materials for use with non-

reading parents. Audio tapes which deal with parenting issues are being created. TEAM staff are developing a series of instructional modules designed to be used as curriculum guides for parent training sessions.

Please contact TEAM if you have suggestions or information on positive parenting programs which could be used by a non-reading parent. Further information about TEAM can be obtained by writing or calling — Essex County ARC TEAM Program: P.O. Box 194, Port Henry, N.Y. 12974, 518-546-3354.

## Education Rights manual available

**Your Child's Right to an Education, A Guide for Parents of Children with Handicapping Conditions** has recently been revised. The terms and references used are in compliance with the new Part 200 of the Commissioner's Regulations. Although not finally effective until July 1, 1982, many school districts are using them voluntarily this year.

The guide provides basic information on types of handicapping conditions, the continuum of services that must be available and the school district's responsibilities for such children. There is an explanation of the Individual Education Program process and the role of the Committee on the Handicapped. Extensive information is given on the parent's right to participate in the planning and making of educational decisions about their child. The parent's right to challenge such decisions through procedural due process is also outlined. It concludes with a list of resources available.

Every parent of a child known to have or thought to have a handicapping condition should request a copy from the:

New York State Education  
Department  
Bureau of Program Development  
Resource Center  
Room 1069, Education Building  
Annex  
Albany, New York 12234



## Confidentiality and student records

### YOUR RIGHT TO KNOW

In the Fall issue of *Advocates for Children of New York, Inc.*, Staff Attorney, Frances Pantaleo, prepared the following report which explores the delicate balance which needs to be maintained in the complex issue of confidentiality involving access records, while safeguarding privacy rights of parent and child, in the pursuit of quality services and programs.

During the past school year, the City planning Commission requested the New York City Board of Education to provide it with the names and addresses of all students attending public schools. The Planning Commission hoped this information would help prove the City's claim that New Yorkers were undercounted in the 1980 census. To the surprise of some, the Board of Education refused to turn over these records, even though they could help the city obtain millions of dollars in federal aid during the next ten years.

### CONFLICT GROWS

The Board of Education's refusal to assist the City Planning Commission is but one aspect of a growing conflict over the proper use of information on private citizens maintained by government agencies. The Board refused to supply the requested data because it believed doing so would violate the privacy rights of students and their parents. Whereas some may believe privacy laws were never intended to prohibit disclosure of names and addresses, the Board's refusal is commendable in light of a history of governmental indifference to the right of privacy.

In the early 1970's, various laws were enacted to ensure that government information on private citizens was not released to other government or private agencies or individuals without the consent of the individual. At the same time that the principle of confidentiality was being recognized, other laws, such as the Freedom of Information Act, were passed to provide the citizenry with open access to the mechanics of government policy making.

### RIGHT TO CONFIDENTIALITY

The right to confidentiality of school records was firmly established in 1974 by the enactment of the Family Education Rights and Privacy Act (FERPA, or the Buckley Amendment). In addition, the Chancellor of the New York City Board of Education has issued a regulation governing the collection, maintenance and dissemination of student records. Together they establish a comprehensive series of parent and student rights including the right to:

- inspect and copy student grading, clinical, guidance, health and testing records;
- challenge school records believed to be inaccurate, misleading or derogatory and enter explanatory statements concerning these records;
- prevent others from seeing student records without parental consent, with certain specific exceptions.

Initial advocacy efforts to enforce the provisions of the federal law and Board of Education regulations focused on assisting individuals to obtain or challenge student records and on assuring that parents and students were notified of their rights. Our individual advocacy soon convinced us that the laws and regulations presumed that all student records were kept in neat files in the home school. The development of centralized information systems, including computerized data, was not anticipated. Perplexing problems arose. For example, how does a parent exercise the right to attach an explanatory statement to computerized information?

### COMPUTERIZED DATA

Many parents are afraid the hard-won right to confidentiality will be made meaningless by the computerization of student records. Familiar stories about computer "thefts" and the science-fiction aura that computers present for those unsophisticated in their technology contribute to these fears. Others, familiar with the disarray that often characterizes manual records, are justifiably concerned about the accurate maintenance of those records once they are placed on computer. Computerizing these records compounds the already difficult task of identifying and correcting for errors such as wrong grades, missing phone numbers, and inappropriate teacher comments.

Despite these fears, the era of computerized student data has truly arrived. The Board of Education now has a computerized pupil accounting system which stores each student's name, address, sex, date of birth, school, grade, class and nine-digit student identification number. In addition, various divisions of the Central Board collect computerized data concerning pupil transportation, special education, attendance, zoning and integration, testing scores and funded programs. Most community school districts utilize some form of computerized records. High schools may also contract to have student programs, transcripts and attendance data kept in a computerized system.

This vast array of computerized data developed haphazardly without any clear guidance from the Chancellor or the Central Board. In recognition of the need to establish safeguards against improper use of these records, the Chancellor established a Committee on Data Confidentiality, consisting of representatives from the Central Board of Education, community school districts, parents, students and advocacy groups, including *Advocates for Children*. Sub-committees were formed to develop standards for safeguarding computer records and to investigate every data request whether made by Board of Education personnel or outside organizations.

### COMMITTEE DEVELOPS PROCEDURES

The Committee convened in November 1980. One of its first tasks was to develop a procedure for parents to obtain copies of their child's computer records. Much of the year was spent assembling a complete list of centrally operated computer systems and investigating the methods used to protect these systems from unauthorized use. Security precautions include shredding no longer needed print-outs, coding print-out information and tapes, locking computer rooms and providing security guards to screen individuals requesting access. A set of interim criteria for the release of personally identified student data was also developed.

The establishment of formal procedures to monitor the release of computerized records has not met with uniform acclaim. Some officials at the Board of Education have privately grumbled that it takes too long for internal requests for information to be cleared and there are many ways for the dishonest to circumvent the system and obtain data more quickly, without proper clearance.

In addition, there is some apprehension that the screening process may be used to refuse requests for data by outside organizations, even if such requests must be granted under the Freedom of Information Act. This past year, several requests for statistics concerning ethnic enrollment and school profiles were reviewed by the Access to Data Sub-Committee, although no information on individual students was requested.

## Capital District Chapters

## Self help in educational advocacy workshops held

### CHAPTERS SHARE ADVOCACY EXPERIENCES

Two chapters shared their advocacy experiences with the group; Sue Lyons, Director of Children's Services in Fulton County described how she is expanding her resource file, and Joyn Kemmer, Executive Director of Warren Washington County Chapter described their successful experiences both helping to illustrate that if a chapter makes a commitment to help other parents to find their way through the educational system — it can be done!

To complete the afternoon session, Linda Kramer, an experienced advocate from Eleanor Roosevelt Developmental Services talked with the group about some of her advocacy tactics and techniques, such as how to assess available approaches to an advocacy situation, developing a sense of timing, using external support channels effectively and recognizing the importance of building a personal support network of other advocates.

A few worthy quotable quotes were:

"One parent helping another parent is like a lot of little fishes-getting together to defeat the big sharks which is not knowing the laws" (Dahlia DelDebbio):

Parents are a unique kind of professional, cutting across many disciplines and including areas sometimes too little used by experts" (Betty Pender):

"Let's not professionalize parents, but normalize professionals" (Henrietta Messier)

### ROLES OF ADVOCACY

Mildred Shapiro, who moderated the morning panel in her usual astute manner, came up with an incredible list of the many roles of an advocate: listener, strategist, helper, striver, agitator, sharer, giver, asserter, lawyer, interviewer, educator, diplomat, researcher, consoler, advisor, social worker, therapist, questioner, activist and information giver.

Many of the people in the audience came with specific advocacy experiences which were shared with one another at the end of the day. Using some of their newly learned advocacy skills, they helped one another explore alternate ways of handling advocacy problems that they had been struggling to solve on their own.

The workshop day ended with a summary of the next steps of the project, focusing on the chapter activities planned for the next three months prior to the second formal workshop on education law and due process.

We are very pleased with the enthusiasm and cooperation of each of the chapters in this pilot project, and congratulate the Commission staff for doing such a thorough and excellent job. We hope the success of this project will enable them to continue to work with us to eventually include all of our other chapters.

## IRS deduction

In a recent edition, the *Wall Street Journal* announced that the expense incurred in the use of disposable diapers for the care of the four year old brain-damaged child qualifies as a valid medical cost. A doctor testified that the diapers should be used to alleviate the effects of the aicardi syndrome on the incontinent child.

### OUTSIDE CONTRACTORS

Another problem which needs to be addressed is the use of outside contractors to analyze and program Board of Education data. Although the use of outside contractors increases the possibility of unauthorized release of data, these contractors are often better qualified to design and implement complex computer programs than are Board of Education staff. City policy now requires that all contractors provide assurances that data will be kept confidential.

In summary, providing public access to useful education data while safeguarding the privacy rights of parents and students is a difficult task, made even more complicated by the growing use of computerized data systems. Through monitoring Board of Education policies and through individual case work, *Advocates for Children* hopes to ensure that the correct balance is maintained between these conflicting rights.



# Help improve your child's education

Educational regulations, often referred to as Part 200 which define among other things, how and when children with special educational needs are placed in school programs, were revised significantly this past spring. In spite of a rather impressive outcry from individuals and statewide organizations pertaining to the handicapped, the Board of Regents agreed to accept the revisions with the exception of Part 200.6 which describe staffing and class size. Probably, in order to reduce their own doubts over their unfortunate move to adopt the regulations, they agreed to have another set of hearings around the state in the spring of 1982 in order to hear how well the new regulations are working or not working. While they will be hearing testimony on all of Part 200 they are specifically interested in receiving comment on Part 200.6 (class size).

The New York State Association for Retarded Children, individual chapters and members of those chapters have no way of evaluating Part 200.6 since we do not have access to teachers and because of the confidentiality issue, we do not have access to parents in any given school district. However, we can speak up about our concerns on what is or is not working.

You may recall the most important reason for revising the regulations was to remove the stigma that our children have to bear in being labelled in order to receive an education. Instead of labels, the State Education Department has now proposed four basic criteria for placing children and they are as follows: Academic achievement and learning rate — social development — physical development — and the management needs of the pupils in the classroom.

In theory this type of procedure sounds impressive; however, in reality in most cases it will not work. Monitoring on a statewide basis to insure that these criteria are really adhered to is impossible since there are simply not enough staff available from the department. Parental monitoring for the most part is impossible for one reason already stated, the lack of availability of information because of confidentiality rights. But even if that information were available, most parents do not have the skills to know how to use it.

We are also keenly aware of how Committees on the Handicapped have conducted the business of placing children under the old regulations (placing children according to label) and there has been justifiable criticism of how this is not working. The districts are not committed

to insuring that the COH can handle the overload of work which they already have.

We cannot stress too strongly, that **all parents must stand up and speak out**. We must go to all those hearings in the spring, singly and collectively and **demand** that they stop experimenting with our children's lives. What we have in the current class size and staffing ratio was arrived at arbitrarily; however, what is proposed now in Part 200.6 was arrived at in the same manner by those who have little contact with the real situation. We are **not** saying that what we currently have is necessarily good; in fact there are very definite areas that we have great concerns about, but to trade one set of figures for another, without adequate data to support the trade, we feel is inherently dangerous and wrong.

Furthermore, we must speak out loud and clear to our legislators. We must insist that they take some responsibility for what happens to the laws that they pass once they are sent across the street to the Education Department to be regulated.

The Board of Regents wants us to make alternative recommendations for class size and staffing ratio. We feel we cannot do that, because in that case, we would be doing nothing more than what we are criticizing the department for doing.

Therefore, we are demanding that they leave class size the way it is now, continuing to place children according to their label until such time as a study has been made that will prove to us that some data has been collected that will indicate that more thought has gone into the process and that our children will be protected from dumping. Nothing less is acceptable! If the Regents pass on Part 200.6 this spring without further study, it will be, in our opinion an irrational act which will set special education back many years.

In order for the Education Committee to put together factual testimony we need answers to particular questions. We urge you to take the time to answer the questions as best you can and return them promptly to the address indicated. In addition to the questions listed if you have any other comments that you would like to make, any area of concern, you feel should be brought to our attention, to be forwarded to the and the State Education Department, please take the time to let us know.

**Please fill out questionnaire below and return immediately to:**

Marilyn Wessels  
NYSARC 8 Education Committee  
160 Clayton Road  
Schenectady, N.Y. 12304

There are currently over two hundred districts and BOCES that are operating under the new Part 200 of the Commissioner's regulations.

- Is your district and/or BOCES operating under the new regulations?  
Yes                      No                      Don't Know
- If the answer to Question #1 is yes, were you informed of the new placement criteria upon which your child was placed?  
Yes                      No
- Where was your child going to school during the school year '79-'80?  
Local district, special education class  
BOCES  
Private school  
Other
- Where is your child going to school during the present school year?  
Local district, special education class  
BOCES  
Private school  
Other
- If there was a change please give reason(s) why.
- Does your Committee on the Handicapped do an annual review at year-end on your child? (This should not be confused with child's Individual Education Plan (I.E.P.))  
Yes                      No                      Don't Know
- Do you know who the Chairman of your C.O.H. is?  
Yes                      No
- Have you been provided a copy of the handbook, "Your Child's Right to an Education"?  
Yes                      No
- Has the parent member of the C.O.H. ever contacted you personally?  
Yes                      No
- Was the meeting time of the C.O.H. made convenient for you?  
Yes                      No
- Were you notified in writing of your right to have the physician in attendance?  
Yes                      No
- In New York State the Individual Education Plan (I.E.P.) is divided into two phases. Phase I is developed at a meeting of the C.O.H. The following eight pieces of information should be included in Phase I of your child's I.E.P. (This information is taken directly from the parent handbook). Please check yes or no as to whether all eight items are included. Yes                      No
  - A classification of handicapping condition, recommended program and placement including the extent to which the pupil will participate in the regular education program.
  - The present level of educational performance.
  - The individual needs of the pupil according to academic achievement and learning rate, social development, physical development and the management needs of the pupils in the classroom.
  - The class size in which the child should be placed.
  - The projected date for initiation of special education services, the amount of time per day the pupil will receive such services, and the projected date for the review of the need for such services.
  - A description of specialized equipment and adaptive device(s) needed for the pupil to benefit from education.
  - A listing of annual goals that are consistent with the pupil's needs and abilities.
  - A list of testing modifications used consistently in the instructional program.
- Did you participate in the development of Phase I with your Committee on the Handicapped?  
Yes                      No
- If the answer to Question #13 is no, why not?

Phase II of your child's I.E.P. is developed at a planning conference. It is during this conference that long and short term objectives and the method for determining progress toward those objectives are reached. The district must notify you of the planning conference at least five days in advance, stating the time, place and date for the conference. If you cannot attend the conference then the district must inform you of alternatives such as individual meetings or telephone discussions. The planning conference must be attended by your child's teacher and a representative of your school district, other than the child's teacher, who is qualified to provide or supervise the provision of special education. If your child is entering a special education program for the first time, the conference must also include a member of the evaluation team or a person who is able to explain the evaluation procedures used with your child. You or the district may choose to invite others to attend the conference.

- The following information must be included in Phase II. Please indicate by checking yes or no if it is included in your child's I.E.P. Yes                      No
  - A statement of short-term objectives consistent with the annual goals.
  - Appropriate objective criteria, evaluation procedures and schedules for determining, on at least an annual basis, whether the instructional objectives are being achieved.
- Were you invited to Phase II of your child's I.E.P. planning conference?  
Yes                      No
- Were you notified about the meeting at least five days previous to the meeting?  
Yes                      No
- Who attended the planning conference? (Do not state names, just titles)
- Was your child just placed in a special education class?  
Yes                      No
- Has your C.O.H. informed you of your rights to appeal recommendations regarding your child's placement, including continuation, modification or change of program?  
Yes                      No
- Has your C.O.H. informed you of your right to have an outside evaluation done in the event you do not agree with the district's evaluation(s)?
- Other comments:

Please feel free to copy this questionnaire and circulate it to other parents.

RETURN SURVEY TO:

Marilyn Wessels  
NYSARC Education Committee  
160 Clayton Road  
Schenectady, New York 12304



# Communications between Parents and Professionals

Betty Pender, Chair of NYS ARC Education Committee, tells us, that in the light of Public Law 94-142, it is essential parents and professionals learn to talk with one another rather than to one another. The preposition is very important because in the good old days, it was quite acceptable to have people in the helping professions talk 'at' and 'to' us. But now, with 94-142 and the need for parents to give more information to the teacher to make her job easier, there is a great need for new communication skills.

It is clear that these skills are required of parents and professionals equally. Heretofore parents felt that they had nothing to contribute in a parent-teacher conference, or they were intimidated or sad to say, they were over aggressive; often releasing their misplaced hostility on the wrong person — the teacher.

There have been an increasing number of articles in the professional literature about parent-professional partnerships. This is a heartening trend, because we both must realize that it can work. Teachers are beginning to realize that just as each student in a class has a different diagnosis, so there are all kinds of parents; the only thing that we parents have in common is that we have a child with a handicapping condition.

Given what most parents of children who are disabled go through because of societal attitudes before we meet the professionals — social adjustment problems, mothers at playgrounds pulling their children out of the sandbox, stares in the supermarket, rejection, etc., etc. — we are already full of anxiety, guilt, anger and hostility. A secure teacher or professional must understand that such feelings of guilt may, in some subtle ways, interfere with productive parent-professional relationships, unless the professionals have learned to take us where we are at.

Society has forced most of us to take on different life styles, and although it appears that many of us are mixed up, given what we have been through we, nevertheless are pretty terrific for having coped with the "system abuse," and professionals should recognize and value our ability to cope.

It is surprising to see how many teachers unjustifiably "fear" the parent conferences, and conversely, how parents are "afraid" to talk to the teacher. Hopefully this will change, as there is more attention paid to communication skills for both parents and teachers. Parents must realize teachers are as concerned with the success of our children as we are. Likewise, teachers must realize that mothers and fathers can contribute some worthwhile facts about their sons and daughters that will help them achieve the success they so earnestly work for.

The process is similar to an old fable about a husband and wife who were having constant battles. Their neighbors suggested they accompany them to the town Rabbi. The Rabbi heard the husband's story and said, "you are right." Then he heard the wife's story and said "you are right." Incredulously the neighbor interjected, "But Rabbi, you said he was right, and she was right. How can they both be right?" To which the wise Rabbi replied: "You are right too". So together, teacher and parent let us recognize that we each are right — and let us talk with one another.



During the summer about 750 children and adults attended the Nassau Association For The Help Of Retarded Children's Camp Loyaltown. Approximately 100 staff supervised a program which included arts and crafts, music, drama, sewing, cooking, woodworking, swimming and sports. The sessions are broken into three two-week periods with a minimum stay for the two-week session. Although most of the participants in the Loyaltown program come from Nassau County, admission is open to children from other areas of New York State provided that the campers are New York State residents and come from families who are members of the Association For Retarded Children.

## "Special friends" teach about handicaps

The elephant has a hearing aid, the cuddly bear an artificial leg and the ordinarily frisky monkey can't get out of his wheelchair. The animals are toys and their creator, Margaret Gibbons of Lowell, Mass. has designed them as a comfort to handicapped youngsters and a learning aid for "able-bodied children".

As a result of her interview with the toy designer, Associated Press Writer Martie Barnes described how the toy designer hopes to acquaint youngsters with the concept of handicaps.

It's a good way for getting able-bodied children acquainted with handicaps and the paraphernalia that goes along with them," she said.

"If a child can take a bear with a false leg and play with it, I see the potential of extending it to a real-life situation," she said in an interview at the Indian Brook Elementary School.

Ms. Gibbons is an occupational therapist who works with students in the Plymouth-Carver school system in Manomet and now also stuffs and finishes her eight animal creations with colleague Bonnie Stone, a Maiden toymaker. They are marketed under the name "Special Friends."

The idea evolved from Ms. Gibbons' experience with a paralyzed pet squirrel. Considering his disability, she made several contraptions to increase its mobility and in the process, she said,

thought others might be able to relate in the same way with toy animals.

"When I first started putting them out, a lot of adults were offended... because of their fear," she said. "A number of people put me down for doing it. They said how horrible it was, as if I was putting their children down."

She said that parents often don't want to accept that their children are different.

The turning point, for her and her business, she said, came in 1980 at the International Disabled Expo in Chicago.

"A paralyzed veteran came up to me and said 'it's about time there were gimp toys on the market.'" she said. "I knew right then I was doing the right thing."

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

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