

OUR Children's Voice

Retarded Children Can Be Helped

City Chapter Honors Joseph P. Kennedy, Jr. Foundation — Ann Greenberg Receives Chancellor's Medal



New York City Chapter Dinner Chairman, James P. Murphy; NYSARC State Association President and Vice Chair of dinner, Blanche Fierstein; New York City Chapter President, Charles King seen presenting John F. Kennedy, Jr. Award, honoring Joseph P. Kennedy, Jr. Foundation.

John F. Kennedy, Jr. accepts award on behalf of foundation

It was an evening of excitement and thrills as the New York City Chapter celebrated its 40th Anniversary on Saturday, May 20, 1989. Honoring the founder of the New York State Association for Retarded Children, Inc., the Chancellor of the City University of New York, Joseph S. Murphy, presented Mrs. Ann Greenberg with the City University of New York Chancellor's Medal. It was Mrs. Greenberg's small ad in the New York Post Home News Want-Ad Section in 1948 that started the largest parent-based organization of its kind to assist persons who are mentally retarded and developmentally disabled.

In addition to Mrs. Greenberg receiving the Chancellor's Medal, the City Chapter honored the Joseph P. Kennedy, Jr. Foundation. Since its inception, the Joseph P. Kennedy, Jr. Foundation has been a major force in changing the nation's attitudes and approaches to the programs and challenges posed by mental retardation. From the beginning, the Foundation viewed these problems comprehensively, yet focused on two firm objectives: to seek the

prevention of mental retardation by identifying its causes and to improve the means by which society dealt with its citizens who are already mentally retarded.

Established in 1946 by Ambassador and Mrs. Joseph P. Kennedy to honor their eldest son who was killed in World War II, the Foundation has used its money and increasing influence to support and develop innovative model programs that would be replicated elsewhere, to provide seed money to encourage innovation, and to capture the attention of the American public in order to promote public awareness.

To make sure excellent facilities existed, the Foundation established centers from coast to coast, most of them at distinguished, research-oriented universities. Indefatigably, the Foundation has funded institutes, schools, and centers for diagnosis, treatment, and education of children and adults who are mentally retarded, as well as supported scientific meetings, seminars, special courses, and conferences in its areas of special interest. Its renowned Special Olympics program to encourage socialization, recreation, and sports activities for individuals who are mentally retarded has been adopted by schools, communities, and institutions, not only throughout the United States but also in some 70 nations of the world.

On hand to accept the award was John F. Kennedy, Jr. ■



Recipient of the City University of New York Chancellor's Medal and founder of the NYSARC, Inc., Ann Greenberg receiving congratulations from John F. Kennedy, Jr.

Final 1989-90 New York State Budget Adopted

Legislature restores funding for key Local Assistance programs — adds \$42,000,000 to restore development levels for community residential and day program facilities for persons living at home.

At five o'clock on the morning of April 19, 1989 the Legislature completed its enactment of the final New York State budget for fiscal year 1989-90. Without a doubt, this was one of the most difficult State budgets in recent memory. A two billion dollar deficit faced by the State caused the Governor to recommend massive cutbacks in a wide variety of State-funded programs including areas critical to NYSARC. These cutbacks created a budget impasse which delayed budget passage beyond the April 1st deadline for the fifth straight year.

The Legislature finally decided to enact nearly one billion dollars in new fees and taxes on items like cigarettes, liquor and motor vehicles in order to make restorations in a broad range of areas.

The Executive Director of NYSARC, Marc N. Brandt, commented that "while important issues, including employee recruitment and retention and further enhancements to developmental center staffing were not addressed, the final budget for programs serving persons who are mentally retarded and developmentally disabled will be adequate during the 89-90 State fiscal year."

Funding for key Local Assistance programs and community development was restored while developmental center staffing levels were held steady.

The following is an overview of what the final adopted State budget contained concerning programs and services for persons who are mentally retarded and developmentally disabled:

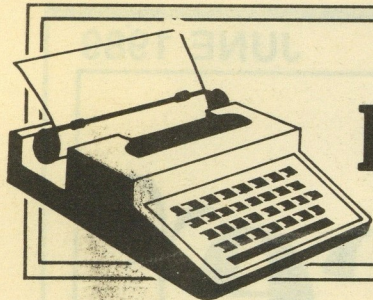
I. State Budget Highlights

The Legislature restored funding to key areas in which the Governor recommended cutbacks and made some additional enhancements.

A) Key Restorations

- Addition of \$2,800,000 to implement a restoration of SEP exempt income from \$600 per client recommended by the Governor, to the existing level of \$1,000 per client.

(Continued on Page 4)



EDITORIALS

A Cautious Victory

This certainly was the year for the Voluntary sector to assert itself politically. Our success at getting the Legislature to make key budget restorations was doubly important. First, it got us through the 1989 State fiscal year without substantial harm while maintaining the pace of community development. Second, we proved that we are not defenseless when it comes to mobilizing on a large scale in the face of impending emergencies. No doubt that will lessen the possibility that if lean times continue, voluntary organizations can conveniently be used to bear a disproportionate responsibility for solving the State's fiscal problems regardless of the human costs.

But as significant as our 1989 achievements in the State budget are, they must be viewed realistically and cautiously.

First, realism. Our 1989 budget "victory" can be measured in terms of survival, not in terms of a milestone towards the resolution of big, nagging and unresolved issues. We still have an employee recruitment and retention problem that is not getting any better; waiting lists for community-based services are getting longer; and staffing standards in many D.C.s are abysmal. True some of these issues would have grossly deteriorated if we had not been successful at getting the Legislature to make important restorations. Our "victory", therefore, was that they remained only as bad as they are and did not get alot worse. Had the Legislature not, for example, independently taken the unprecedented action of appropriating \$44 million for community development, waiting lines of persons living at home in need of community residential care would have ceased to be an issue since there would no longer be any such care to wait for.

Next, caution. It is very possible that the State's fiscal situation is still not good. There are grumblings that the budget deal that was put together was a patch-work arrangement based on many shaky assumptions about the states ability to generate revenue and continue to simultaneously cut taxes. Whether or not this is just propaganda generated by the Governor as part of his campaign to counterbalance what he sees as the Legislature's voracious appetite to irresponsibly spend more money is a moot point. In fact, the Division of the Budget will behave as if this financial scenario is reality. They will do everything they can to control spending in this fiscal year and especially to minimize the establishment of new programs that will cost more money to operate in future fiscal years.

This is not a good omen, especially for the \$44 million which the Legislature

appropriated in order to restore development. The 700 additional residential placements and the 1,000 or so additional day placements expected to be built from this sum have an "operational tail" that will cost the State nearly \$50 million annually. No doubt DOB will do everything it can to minimize the size of this "operational tail" by cutting or substantially delaying expenditure of restored monies to build new programs. And, no doubt there will be a continuing need for the voluntary sector to assert itself politically to minimize the effects of DOB's activities. It is one thing to have gotten \$44 million appropriated; it may be quite another to get it spent.

And finally another budget issue may have emerged that will need to be very carefully monitored. It appears that the Commissioner felt that our gain was his pain; that \$12 million was cut out of the State side of the budget by the Legislature in order to make \$11 million in restorations to the Voluntary side of the budget. Reports have it that the Commissioner's tone of late has been one of extreme vindictiveness, that he is going to use his administrative authority over appropriated dollars in such a way as to get even with voluntary providers.

Needless to say, we hope that the Commissioner cools off. Certainly, the Commissioner knows that we do not advocate for cutbacks in State-operated programs; he also knows, and has in the past, admirably displayed a willingness to work hard to maximize the fiscal health of both State and Voluntary-operated programs. If the 1989 budget marks the beginning of an era of stringent budgets, neither we nor the Commissioner can afford to let such momentary lapses in composure deteriorate into a bitter and permanent feud.

The 1989 budget marks a truly great victory for the Voluntary sector. We showed that we have the political ability to make a substantial impact on governmental policy making; an impact that cannot be ignored or scoffed at. But this year's budget victory may have more significance for our ability to survive than thrive: an ability that may become increasingly critical in the years ahead. ■

How Far Can Government Trust Parents? The Guardianship Crisis

Nothing is more basic to the values of our Association than Guardianship. Guardianship assures parents that they will continue to have the responsibility for making the major decisions in their child's life even after such child turns 18; and

that despite the passage of time, the legal, as well as emotional bond between parent and child will be preserved. Perhaps even more importantly the appointment of standby guardians means that such decisions will continue to be made by trusted individuals even after the death of a parent.

The peace of mind afforded parents is invaluable. Not surprisingly guardianship on a corporate and individual basis has expanded dramatically. NYSARC alone oversees 500 separate court decrees; up over 100% within the last decade.

Twenty years ago Guardianship became a reality through the enactment of Article 17-A of the Surrogate's Court Procedure Act. Our Association was instrumental in the creation of this legislation. For us the meaning of Guardianship was clear: it recognized that the right of a parent to continue to care for a child with mental retardation is self evident; intrusive legal procedures necessary to confirm this right upon the adulthood of such child should, therefore, be minimized. The founders of our Association strongly believed that government should act to facilitate, not to impede the most basic of human relationships. Thus, parents could go to court and swiftly obtain legal Guardianship upon a simple showing and order by a Judge.

Yet, 20 years later, Guardianship is coming under unprecedented scrutiny in the Congress, in State Legislatures and in the media. To be sure this attention has been triggered primarily by abuses perpetrated by guardians of elderly individuals. But the resulting scrutiny has not differentiated between the many kinds of guardianships that exist. The popular notion, true or false, that anyone can easily obtain legal authority over the life of another is very powerful in the public mind; it quickly suggests imminent danger to civil liberties, personal freedom and the material well-being of helpless individuals. As one expert stated

"proposed wards are generally afforded few legal rights than criminal defendants."

In the New York State Legislature alone, 37 bills are under consideration dealing with every aspect of every type of guardianship. These bills do everything from extending the authority of the courts over guardians to placing automatic termination and renewal dates on otherwise permanent arrangements.

Clearly then, the underlying premise of Article 17-A is riding against the tide of popular sentiment. Where we maintain that the lack of complex procedure and red tape in this statute is a simple recognition of the inherent need of parents to continue to care for children with severe disabilities, others maintain that therein lie the seeds of abuse and neglect of some of our most helpless citizens. Certainly, one reflection of this is OMRDD's position on medical consent: that the lack of explicit authority should, in fact, be a prohibition against the authority of guardians to consent to treatment. Similarly, legislation introduced at the request of the Quality of Care Commission, though reasonable in most respects, provides additional controls over the appointment of 17-A Guardians.

Clearly, the institution of Guardianship is at a crossroads. There is a move afoot to make it a more complex and cumbersome arrangement in order to protect what society feels are the civil liberties of helpless individuals. Undoubtedly, our Association's notion of Guardianship as a simple and unfettered mechanism for maintaining parental decision making will be increasingly tested. In this regard it should be noted that on June 6th the Assembly Mental Health Committee will hold hearings on proposed revisions to Article 17-A. This forum should give us a first-hand view of concerns about this important institution; concerns that we will have to consider very carefully if we are to preserve the values that Guardianship has come to epitomize. ■

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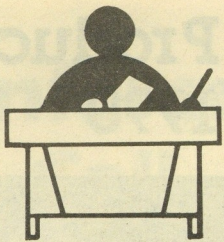
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From The Executive Director's Desk



by Marc N. Brandt
Executive Director

Local Assistance Reform

Question: What do the 1983 Executive Budget, the 1984 Executive Budget and the 1989 Executive budget have in common?

Answer: In each one the Governor sought major cutbacks in Local Assistance programs. The proposed cutbacks were rejected by the Legislature but only after enormous lobbying campaigns by terrified providers.

Question: What do Chapter 612 of the Laws of 1981, the Commission on Local Mental Hygiene Financing, Rehabilitation Facility Redesign Projects, the 1988 Ad Hoc Task Force and various other unnamed initiatives have in common?

Answer: They are all failed attempts at Local Assistance reform. While providers unanimously agreed that massive problems in the system had to be rectified, there was no agreement on how to do it.

Let's face it: net deficit funding is irrational, Local Assistance programs lack the most rudimentary level of fiscal accountability, there are no program standards for sheltered workshops, and SEP, for lack of a better alternative, has been preserved as a sacred cow. I doubt that anyone who knows anything about this area would disagree with these observations. Similarly, I think that many of us would not state them with these observations. Similarly, I think that many of us would not state them publicly. But I think that it is high time to do just that and once and for all bring the backbone of our day services system into this decade of the 20th century.

Personally, I am sick of waiting for the Governor's budget proposal each year to see if these programs will once again be the target of budget cuts. I know that each year this is a distinct possibility. It's a distinct possibility because everyone who makes State budget decisions knows what we know about these programs and realizes that in an era that increasingly demands high levels of fiscal accountability, Local Assistance programs do not measure up.

Don't misunderstand me. Local Assistance programs are essential to persons with developmental disabilities; they are underfunded; and they certainly lack the year-to-year resource stability that we need to responsibly plan and deliver services. But if I were a public official and needed to suggest an area to cut, in this day and age, I'd do exactly what the Governor tried to do this year and in years before it. And given New York's current fiscal situation, I'd plan on going after these programs again next year.

Yes, SEP may be a sacred cow, but it's also a sitting duck.

What's frustrating, and let me repeat myself, is that I don't think that any of us disagree with these statements. In fact, if a secret poll were taken, there would probably be a greater unanimity of opinion by our Executive Directors around what I've said than on any other issue.

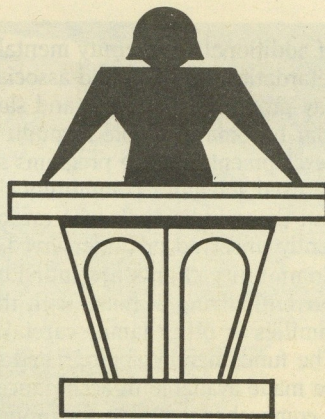
The trouble is that there is as much disagreement about how to reform Local Assistance as there is agreement that it needs to be reformed. This will not get us anywhere.

Certainly one of the most logical solutions is to go to a cost based or quasi cost-based rate or fee system like we have for Community Residences, ICFs and Day Treatment. These systems are not perfect, but they have credibility. Remember, just a few months ago when the Governor was recommending cutbacks in Local Assistance; at the same time his budget called for a 5.7% inflationary increase for rate and fee programs. 5.7% is quite good, it's especially good in the midst of the worst budget deficit in the State's history.

The Governor did not make this recommendation because he is generous or because he wanted to distract our attention from the bad points of his budget request. Rather, the sophisticated rules and regulations which drive the rate and fee programs have the force and effect of law. Arbitrarily manipulating them is beyond the whim of OMRDD and DOB. Rates and fees do not necessarily change because the State's fiscal condition has deteriorated or because some high public official is in a bad mood.

But Local Assistance funding directly depends on exactly these conditions. Unlike the rate and fee systems, Local Assistance contracts are not predictable from year-to-year nor are they in anyway intended to fund even adequate program levels. Year in and year out they are at the mercy of State's fiscal condition and the individual bureaucrats who have both the best and worst of intentions.

Yet, merely mentioning the prospect of converting Local Assistance to some form of cost-based funding evokes cries of protest from providers. Some complain that cost-based funding is overly complex and difficult to learn. That is true but once mastered it has proven a boon to those of us who have learned to use it. Others complain that moving to cost-based funding would eliminate the "flexibility" which is after all the great thing about the existing Local Assistance system. Maybe, but



The President Speaks

Legend has it that Sisyphus was given as punishment, the task of eternally pushing a huge boulder to the top of a mountain. Each time as he neared the top, the boulder would jump out of his hands and roll to the bottom. We all know the feeling! But from our common memory and outlook comes our collective strength and when we couldn't budge the boulder we moved the mountain.

Recently I listened to an OMRDD official complain about the financial ramifications of mandated support services in treatment plans. He attributed what he described as an overkill of obligatory services to parent pressure

which is based on our memory of the way things used to be. He wanted parents to have faith in his staff to prescribe services without making it an expensive specific requirement. There is a point at which doubting stops and trust begins. We haven't reached it. Several centuries ago, a religious teacher taught that "in remembrance is the secret of redemption." The challenge is to continue to keep that lesson in mind.

Enjoy the summer.

Sincerely,

Blanche Fierstein

Blanche Fierstein

remember that "flexibility" works both ways; and it is becoming more of a factor enabling the State to restrict Local Assistance funding than a factor enabling us, the providers, to maximize that funding.

I don't know that cost-based funding is the answer. Maybe something else makes better sense. Unfortunately, there is likely to be no one solution that will make everyone happy. That has been the major impediment to Local Assistance reform over the last decade: a decade during which we were continually but unsuccessfully threatened with major cutbacks in these programs.

Someday, perhaps someday soon, our luck will run out. In the meantime, we are most certainly doomed to have to scurry back to the Legislature again and again to beg and plead for restorations to a system of funding that is archaic, inadequate

and which we don't have the collective will to change. This is, at the very least, a highly questionable way to use our energy.

But maybe we have started to appreciate the futility of all of this. More of us than ever before talk about being willing to accept change. At NYSARC's request S.5037 by Spano and A.6917 by Connelly were introduced this legislative session. This legislation requires the development of a proposal to reform Local Assistance. Maybe this will turn out to be just another in a series of failed attempts. Hopefully, the recent display of willingness by all major statewide provider groups to quickly agree to an amended version of this bill indicates otherwise. I hope so because I also believe that time is running out before we finally fail to turn back yet another attempt by government to devastate the important programs that we call Local Assistance. ■

- Addition of \$2,100,000 in order to restore reductions recommended by the Governor for various voluntary-operated programs including summer camp, recreation and clinic services.
- Addition of \$317,000 to maintain Unified Services funding for the five counties (Westchester, Warren, Washington, Rockland and Rensselaer) funded through this reimbursement stream.
- Addition of \$42,000,000 in MCFFA bonded funds (see "Other Legislative Actions" below) to restore development levels for community residential and day program facilities for persons living at home.
- Addition of \$2,400,000 for non-bondable costs attributable to the restoration of development for persons living at home.

B) Legislative Enhancements

- Addition of \$500,000 to the supported work program to serve persons who are severely disabled.
- Addition of \$500,000 for Family Support Services.

C) Other Legislative Actions

- Passage of legislation authorizing voluntary providers to utilize low-interest, tax exempt financing provided through the Medical Care Facilities Financing Agency (MCFFA) for the development of community-based programs.
- Approval of 1.26:1 staffing ratio recommended by the Governor for upstate developmental centers.
- Approval of \$7,519,000 recommended by the Governor to provide relief staff to backfill for employees absent because of low-incidence leave. This represents a \$3,500,000 increase over funding expended last year for this purpose.
- Addition of \$700,000 to restore the Youth Opportunities Program.
- Addition of \$2,000,000 to restore the Career Opportunities Professional Recruitment Education Program (COPREP) to the State Education Department's budget. COPREP provides grants to colleges and universities to establish on-site training programs for Occupational Therapy Assistants and Physical Therapy Assistants.

II. Additional Information Regarding Selected Issues

The following are excerpts from language contained in the FY 89-90 budget pertaining to areas of interest to NYSARC.

A) Restoration of Community Development

Budget language restoring development for persons living at home states:

"The funds hereby appropriated shall be used for the acquisition of property, construction and rehabilitation

of additional community mental retardation facilities and associated day programs. The beds and slots that become available through the development of these programs shall be used solely for community clients and those individuals who are currently unserved or underserved. Community clients are individuals currently living at home with their families or other family caretakers. The funds hereby appropriated shall be made available in accordance with a comprehensive plan for proposed projects approved by the director of the budget..."

B) Study of Rate Setting Methodologies

Pertinent budget language states:

"The commissioner shall complete a system wide evaluation of all current rate setting methodologies to identify alternative methodologies which promote enhanced cost effectiveness and efficiency of the various residential and day service models. The assessment should include, but not be limited to, a historic evaluation of rate trends by type of program and categories of expenditures within; provider-specific rate history profiles, including rate appeals and the justification, therefore, an update on the implementation of the developmental disabilities profile (DDP) and its anticipated impact on staffing standards and reimbursement within the rate setting system; an analysis of standard staffing levels employed by the voluntaries by title, number of staff and across the various service modalities. The commissioner shall submit a report to the director of the budget no later than September 1, 1989." ■

Quote of the Quarter

"I firmly believe that without aggressive public and private support, disabled people will not be able to achieve their highest priority, namely, the independence necessary to achieve control over their own lives and integration into the mainstream of American life." "Handicapped individuals are not a small, uniform minority with narrow interests. The disabled community includes every race, culture, age, sex and economic class. Membership is open to all and most of us who live our full life span will join this community sooner or later."

George Bush
United States President

Legacy of Love Product Selected for 1990



1990 Legacy Of Love Product

With its most successful Legacy Of Love annual promotion behind it, the NYSARC Public Information Committee has now selected the 1990 Legacy Of Love product.

Fifteen products were submitted at the Public Information Committee's Resource Group meeting held during April in Syracuse. A selection process of picking the top five submissions and winnowing that down to the top two before a final vote, resulted in the designation of the Oneida Chapter's product. That item includes a Valentine's Day theme consisting of a preserved real rose at the base of a hurricane lamp surrounded by white Victorian lace and leaves. At the top of the lamp there is a tempered votive cup and candle decorated with red ribbon. The item is

attractively boxed in a gold-tone box with a see-through window.

About twenty-five chapters participated in the selection during which the Committee's Chair, Bob Katz, especially thanked the Cayuga Chapter for providing the Legacy Of Love product during the past three years contributing to the success of the Legacy Of Love.

Oneida's Legacy Of Love product will be on display at the convention and samples will be sent to chapters during September with information about ordering as well as the promotional activities of the 1990 Legacy Of Love. Oneida is gearing up to fill orders and initial reaction across the state to the product has been very favorable. ■

James M. Hayes Appointed NYSARC Guardianship Chairman

The President of NYSARC, Inc., Mrs. Blanche Fierstein, has announced the appointment of James M. Hayes, Esq. to serve as Chairman of the Association's Guardianship Committee. Mr. Hayes replaces Paul H. Dhalle who resigned due to his busy schedule and other pressing matters.

Mr. Hayes is no stranger to our Association or to our Guardianship program having served in the 1970's on our State Association's Legal and Legislative Committee. He has been a member of the State ARC Guardianship Committee for the past several years.

He was born and raised in Long Island and graduated from Lehigh University and Harvard Law School. He has been a resi-

dent of Binghamton, New York for the past 21 years. He is an attorney and partner in the law firm of Hinman, Howard and Kattell.

Mr. Hayes and his wife, Maryann, have three children, including Paul, age 21, who is mentally retarded and will be entering the Broome-Tioga Chapter's Day Treatment Program this month. Both Jim and Maryann have been active with the Broome-Tioga Chapter for nearly 20 years.

On introducing Mr. Hayes to the Board of Governors at their spring meeting, President Fierstein stated that "I think you will agree that our Association's Guardianship program is indeed in good hands with Jim Hayes as Chairman." ■

NYSARC Minimum Insurance Standards — A Proven Record of Success

Adequate and affordable property and casualty insurance coverage is an essential component to the operations of any organization. Without it, the financial security of an organization is severely compromised.

In October of 1984, the NYSARC Board of Governors established minimum insurance standards for all Chapters and endorsed a unique group coverage plan through the Continental Insurance Company in which Chapters could participate. This action reflected tremendous foresight by the Board in understanding the importance of Chapters having adequate insurance coverage to protect the Association from major losses.

Both the guidelines and NYSARC group coverage plan through Continental have proved to be highly successful in achieving the following goals: (1) ensuring that Chapters have the insurance coverage necessary to adequately protect them from loss; (2) allowing Chapters to purchase such coverage at a reasonable cost through group rates; and (3) enabling Chapters which participate in the group coverage program to receive insurance dividend payments. These dividends have amounted to over \$1 million since 1984.

Under the leadership of David Wilke, Chairperson of the NYSARC Insurance and Pension Committee, and with the support of David Lettman, then NYSARC President, the Committee initiated, in early 1984, an extensive review of the insurance liability industry and the coverage needed by Chapters to protect the financial integrity of their program operations to minimize their risk of loss. The Committee also surveyed Chapters on the insurance coverage they held at that time.

The purpose of the Committee's review was: (1) to determine the adequacy of liability protection for each Chapter and the extent, if any, of their risk of exposure and; (2) to develop minimum insurance standards to better assure that all Chapters had the necessary coverage to protect their program operations as well as that of the entire corporation. The Committee also hoped to identify an insurance plan which would best meet the needs of ARC Chapters, would offer a coverage plan unique to the features of ARC programs and, would allow for special group coverage purchase rates.

Mounting insurance premiums reached crisis proportions in the early 1980's and became the subject of great concern throughout the nation. In response, the industry came under the scrutiny of both the federal and state governments. Many chapters lost coverage and a number of insurance companies discontinued business in New York.

After careful study of the NYSARC insurance guidelines which were in existence in early 1984 and the insurance policies held by Chapters, the Committee concluded that the policies and standards which were then in force were inadequate. Specifically, the Committee found that the standards/policies did not provide coverage in a number of extremely high risk areas such as professional liability, automotive etc. and/or did not provide sufficient

coverage in the event of total or significant property loss. To correct these gaps in coverage, the Insurance and Pension Committee developed minimum insurance standards for all Chapters to use. The new standards were reviewed by the Board of Governors and adopted in October of 1984. With this action, all Chapters were required to bring their insurance policies into compliance with the minimum standards.

The Committee also examined policies available in the market to determine one which NYSARC might specifically endorse for its Chapters as a group policy plan. The challenge was to find a company which could understand and appreciate NYSARC's corporate structure, the programs of ARC Chapters and would then offer a plan which reflected these characteristics.

A number of insurance carriers submitted proposals in an effort to receive the endorsement of NYSARC. However, only one, Continental Insurance, met the test of the Committee and the Board of Governors. Continental, founded in 1853, is headquartered in New York City. Its regional office is located in Glens Falls and serves all of New York and Vermont. It has annual revenues of \$5 billion and assets of \$13 billion; insurance is its only business.

When the Board of Governors adopted the minimum insurance standards, it also gave its endorsement to Continental which offered a comprehensive coverage package unique to the insurance industry for not-for-profit developmental disability organizations. Included in the package was a dividend plan whereby Chapters could receive dividend payments based upon their individual and group claim experience. From 1984 through 1988, the Chapters participating in NYSARC's group liability plan through Continental have received over \$1 million in dividend payments and have benefited from generally stable premium rates.

Other group insurance plans during this period of time did not enjoy similar success. Some plans in New York State had premium rate increases which jumped from 9% to 85% in 1985 alone, causing financial disaster for those who sought and needed coverage. There are a number of key factors which have been paramount to the success of the NYSARC group plan with Continental.

First is depth of understanding Continental has about the corporate structure of NYSARC, the programs of the Chapters and the persons they serve. Integral to the high level of regard Continental holds for NYSARC is the strong parental involvement, which is unique among not-for-profit organizations both in New York and throughout the country.

Second is the involvement, genuine interest and ability of local Chapters in reducing their risk of exposure. This is most clearly reflected by the safety committees established by each Chapter to reduce the likelihood of incidents which would lead to submitting an insurance claim. The NYSARC Safety Group Management Committee has played an essential role in the efforts of reducing Chapters' risk of exposure by developing model

safety guidelines. The Committee continues to perform this important function by reviewing and modifying the guidelines and providing assistance to Chapters when needed. The Committee also has a member serve as liaison to the NYSARC Prevention Committee to coordinate efforts between the two groups.

Third is the "penetration" of potential purchases in the plan. All but four of NYSARC's sixty-two Chapters participate in the Continental group liability plan. The NYSARC group plan is large enough to influence Continental to provide coverages that would be unavailable to an independent risk.

Fourth is the strong management ability of the Irwin Siegel Agency which is the Administering General Agent for the Continental Plan. The Siegel Agency essentially serves as the intermediary or liaison between the Chapters, their independent insurance agents (through which they may purchase the Continental group plan coverage) and Continental.

The fifth reason for the tremendous success of the program is the fact that the plan and the minimum insurance standards adopted by the Board of Governors is tailor made to the operations of NYSARC Chapters. Some of the features that are unique in this include:

— **Functional Replacement Costs.** This feature recognizes that many buildings which Chapter programs occupy, were not originally built for such purposes. In the event of damage or destruction of a Chapter's building property, functional replacement costs provide the Chapter with money to build a new facility to

accommodate the Chapter's present need, rather than simply replacing the old facility.

— **Blanket Business Interruption Coverage.** This provides Chapters with money to replace loss in revenue from expenses incurred from a claim.

— **Emergency Vacating Expenses.** This provides expenses of up to \$10,000 for the cost of having to vacate a Chapter premise due to a claim.

— **Payment of up to \$1,000 for expenses which may be incurred in proving the validity of a claim made to Continental.**

— **Coverage for violations of clients' bill of rights.** Continental insures Chapters for damages on claims made regarding violations of the rights of persons served by Chapters.

This spring, NYSARC through a recommendation of the Insurance and Pension Committee, retained an outside independent insurance consultant to evaluate the adequacy of the minimum insurance standards. The consultant chosen was The Wyatt Company, one of the largest insurance consultant groups in the nation. On April 28, 1989 NYSARC received the consultant's report which gave the standards and the Continental Plan extremely high ratings.

NYSARC believes the findings of the Wyatt Company to be a tribute to the diligent efforts of the Insurance and Pension Committee; the foresight of the Board of Governors; the cooperation of the Irwin Siegel Agency, of the Continental Insurance Company and especially of all ARC Chapters.

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GUEST COMMENTARY

(From time to time, OCV will feature a guest commentary. The contents of these guest articles will be reflective of the author and does not necessarily represent the views or opinions of the NYSARC, Inc.)

The Parents' Role in Self-Advocacy Betty Pendler: Parent/Advocate

"I have had the pleasure of attending several conferences on self-advocacy and listened to the young men and women talk about how they want to be able to make their own choices and not be controlled by parents or staff. It was then that I realized that many parents are so afraid to 'let go' that they make this exciting new movement all the more difficult to achieve. The sad thing is that many of us parents are not even aware of it, as many of us truly believe that we are doing that which is best for our sons or daughters.

I thought I was a pretty enlightened parent until I listened to some of the young people in this workshop, and I realized that I was not giving my daughter Lisa enough credit for knowing what she wants in her own limited way, and that I still wanted to subtly take over, and am almost afraid of seeing her become her own self-advocate. I firmly believe that we parents must begin to get some kind of training on how to let go, and be honest with our feelings. Parents have ambivalent feelings as our sons and daughters leave the security of the public school. I think we are always hiding our early unconscious feelings of the early guilt, early rejection, and are almost afraid that they *will* succeed. If we want this self advocacy movement to go ahead, we parents need help in learning how to be honest with ourselves. It is true that we have a daily accumulation of frustration, disappointment and anger as we think of the limited ability of our offspring. I think though we have to look at the subject of over protection and not letting go, and seeing how much of it is truly justified. It is true that because of what we call our battle with ourselves and society, we parents were, indeed, forced to over protect our children in the early years, because we had so much rejection and were forced to be outsiders. In many cases, without realizing it, we have become dependent on the dependency, which is doing a real disservice to our son or daughter. We call our protection and our concern 'love', but if we parents stop to think about it, it is a form of subtle selfishness, because more often than not, what we are doing is more to alleviate *our own* anxiety, rather than take risks and let our son or daughter grow. My struggle in letting go came when Lisa was moving into a residence. I thought that I was prepared — she was ready — I was ready — and it was she herself who said she was dying to get rid of her mother. I think our tendency not to let go is so subtle we are not aware of it. To prove this I have to share one personal experience; I have to backtrack and explain to you that when Lisa lived at home with me, I almost resented to

have to take her shopping on Saturdays at age 21, 22, 23, etc. I had had three girlfriends, all of whom married late in life, as I did, and all of whom had daughters, but not retarded; their daughters were doing their own shopping at that age. So although I hoped I never let Lisa know how much I resented those Saturday shopping days — resent it I did. Be that as it may, after she moved into her group home, the first year she was going to summer camp and needed a lot of clothes. When the manager told me they were going to take her shopping my heart skipped a beat and I said to him, "Why I *love* to take Lisa shopping, and go to lunch," forgetting completely all those Saturdays that I felt such strong resentment! This points out how inconsistent we parents can be and how subtle is our need to be needed.

If we truly want our sons and daughters to be self-advocates, we have to watch out for this — recognize it — and admit it. Working with parents on this issue does help, as in my case the following year when Lisa went to camp and needed shopping, I wasn't even around. So let us parents acknowledge that we have unconscious needs for various psychological reasons, some of us need to control our sons and daughters without realizing it; to make up for our own feelings of inadequacy that many professionals have instilled in us. We parents have to recognize that our unconscious needs have a profound affect on our sons and daughters, and we recognized that our fears are exaggerated. Often times we persist in holding on to our fears even in the face of demonstrated ability on the part of our sons and daughters to cope with adult living. We are so busy doing everything *for* our children, we never stop to think of what we are doing to *them*. The truth is that the more they can do for themselves, the more free time we can have for ourselves. The sooner we parents deal with separation, the happier both parties will be.

It is hoped that parents will be able to learn not to be afraid of this new and exciting development of self-advocacy, and encourage and welcome it. It is true that what parents and professionals do for people with disabilities is important, but what people with disabilities do for themselves is crucial. So good luck to this movement." ■

Reported from: SELF-ADVOCACY
ASSOCIATION OF NEW YORK STATE.

Anthony Terranova, Executive Director of
Cayuga County ARC, congratulates 1988-89
volunteers.

(Continued from Page 5)

NYSARC takes pride in knowing that the minimum insurance standards are an insurance model within the nation for the field of developmental disabilities. This was recognized in a September 1987 letter to David B. Lettman, then NYSARC President, from Carl B. Castoldi, Resident Vice President of Continental Insurance. Mr. Castoldi's letter stated, "I have been monitoring the progress and success of NYSARC's (insurance) program since its inception in 1984. That we have seen the Association earn substantial dividends in both 1985 and 1986 is tremendous, but equally important is the fact that our mutual success to date has allowed us to broaden our base in your industry.

...Continental is actively pursuing Developmentally Disabled facilities throughout the state and beyond, using the same package of coverages we developed in conjunction with NYSARC and Irwin Siegel Agency, Inc. While these facilities are not members of your Association I think you should be proud that they are able to secure state-of-the-art insurance coverage, in part due to your foresight and efforts."

The NYSARC minimum insurance standards are not only tremendously benefiting the Association, but a model for other organizations serving the developmentally disabled in the State and the nation. For this, we can all be very proud. ■

1st Annual Self-Advocacy Conference: The Time is Now for Speaking Out and Taking Action!!

The Self-Advocacy Association of New York State, Inc. announces its 1st Annual Self-Advocacy Conference.

The conference is scheduled for:

Saturday — June 24, 1989
at

Hunter College
68th Street and Lexington Avenue
New York, New York

This is a conference for self-advocates and people interested in the self-advocacy movement. This conference will be run by self-advocates — persons that have a developmental disability but want to be seen as people first and people that can speak out and take action on issues that affect their lives.

The purpose of this conference is to give self-advocates in New York City the opportunity to meet with other self-advocates to share ideas, discuss issues, work on resolving problems and to have fun. Some people will already belong to a self-advocacy group — some will come to learn about self-advocacy for the first time.

If you are interested in registering for the conference or would like more information about self-advocacy and how to start a group, please contact the Self-Advocacy Association of New York State, Inc. office at (212) 627-2104 and ask for either Bernard Carabello or Amy Bittinger.

NOTE: Pre-registration is required and limited to 225 persons. ■

Cayuga Honors 1988-89 Volunteers

Cayuga County Chapter honored their 1988-89 Volunteers Thursday, April 20th, at a Recognition Tea, which was held in the Community Room at Comprehensive Training Center on North Street.

Mr. Anthony Terranova, Director of Cayuga Chapter ARC, thanked all the ladies and gentlemen who helped with the 1989 Legacy of Love Campaign and the several other volunteers who give their time on a weekly basis with the Senior's Group Program.

Thirty-five of the sixty-two volunteers were present to receive their Certificates of Appreciation. As the certificates were

awarded, Mr. Terranova extended a big "Thank You" and a hug to each volunteer personally recognizing the graciousness in which they offered their time.

Special mention was given to Helen Hoadley, the Parent Team Coordinator, and to Carol Kenny, the Director of RSVP, who organized the Senior Volunteers.

Cayuga Chapter is privileged to have so many kind and caring people in our county. The Chapter appreciates the graciousness of each volunteer and have found our relationship to be very heartwarming. ■





Columbia ARC – "Ellen Crawford, Columbia Chapter, making a point."



George Hirsch, Treasurer, Presenting NYSARC Budget

Highlights of Spring Board of Governors' Meeting

On Friday and Saturday, May 5-6, 1989, the Board of Governors met in Rochester, New York. In addition to the Board members, NYSARC committee chairs and numerous executive directors were on hand. The governing body reviewed many issues, all of which affect the lives and well-being of persons who are mentally retarded and developmentally disabled.

A summary highlighting the major actions of the Board of Governors' Meeting are as follows:

1. Welcomed Judy Catalano (Dutchess Chapter), Judy Condino (Jefferson Chapter), Thomas Williams (Niagara Chapter), I. William Stone, and Gail Fishkind (New York City Chapter) to the Board of Governors.
2. Adopted the State Association's budget for fiscal year June 1, 1989 – May 31, 1990.
3. Requested the Budget and Finance Committee to review future years' administrative charge formula.
4. Received reports from the President, Treasurer and Executive Director.
5. Received a report from the Scholarship and Awards Committee announcing the winners of the Association's scholarships.
6. Received a report from the Ad Hoc Committee to Review the Issue of Re-affiliation with National ARC-US.

7. Listened to a presentation from Mr. Thomas Wallace, Resident Vice President, Continental Insurance Company regarding NYSARC Insurance Program.

8. Heard a presentation from James Hayes, Esq., Chairman of the NYSARC, Inc. Guardianship Committee on the Guardianship Program.

9. Received an update and discussed the issues concerning the Ombudsman positions in developmental centers.

10. Discussed the recent published book, *An Exposure of the Heart*. ■

Thanks From Frances

Frances Reville, past Board of Governor member and past President of our Welfare League Chapter, wishes to thank the many friends within our Association who sent good wishes to her while she was recovering from an accident. Frances is well and once again keeping a busy schedule. On behalf of Frances, thank you all. ■

A Message to Safety Supervisors

Why are Safety Meetings so Important?

Why is it so important that supervisors meet regularly with small groups of employees to discuss the various aspects of job safety and health? Because it is only through face-to-face contact that effective communication on the subject can take place. The open, informal atmosphere of a small group meeting encourages the kind of questions and discussion that "personalize" the issue of safety by focusing on its day-to-day applications. What other purposes do regular safety meetings serve?

They encourage safety awareness. Other means of getting the safety message across are often too easily ignored. But when a small group of workers gets together to discuss the hazards they have encountered and the steps they can take to eliminate them, it increases each worker's safety consciousness.

They get employees actively involved. In a sense, safety meetings put employees "on the spot"; that is, they demand feedback. They get employees thinking about safety and encourage them to come up with ideas and suggestions for preventing accidents and minimizing the hazards with which they are most familiar.

They motivate employees to follow proper safety practices. Small group meetings are the best place to demonstrate the uses of protective equipment, proper lifting techniques, and other specific safety procedures.

They can nip safety hazards in the bud. A department safety meeting is the time to pinpoint minor hazards before they result in real problems. It also presents a good opportunity to discuss hazards that are inherent in the environment and that experienced employees are likely to take for granted.

They introduce workers to new safety rules, equipment, and preventive practices. In addition to introducing new things, a safety meeting is a good time to reinforce the importance of long-standing safety procedures and to remind employees of the reasons behind them.

They provide vital information on accident causes and types. Regular meetings are the best way of keeping employees up-to-date on the hazards in their environment and what the Chapter is doing about them. They also make it easier for the Chapter to maintain accurate accident statistics, an important tool in tracing the progress of prevention efforts.

Types of Meetings

Departmental or work group safety meetings can take a number of different forms. One example is the "tailboard conference" used by public utility crews

before they tackle a job. The crew gathers around its truck to discuss the work, laying out the tools and materials they'll need to decide who will handle each task. Another example is a departmentwide meeting that is held shortly after an accident has occurred. Its purpose is to make other employees aware of the hazard, to discuss why the accident happened, and to head off similar incidents in the future. Some agencies use small group meetings to supplement safety campaigns or to reinforce agency policies. Such meetings usually focus on a specific safety problem — for example, fire prevention, proper lifting and carrying techniques, infectious disease control, etc.

While safety meetings obviously require some planning and forethought, there is a danger in adhering to a set "formula." Employees quickly become blasé about attending meetings that are carbon copies of each other. This is why you, their supervisor, must go one step further and see to it that: (1) their interest is aroused and held; (2) they are not overloaded with information and ideas;

(3) they are comfortable enough — both physically and emotionally — to prevent restlessness and encourage participation; and (4) they leave the room with an improved attitude and more useful information than they had when they came in.

Perhaps the most successful type of safety meeting — and one that lends itself to a small group format — is the weekly instructional meeting designed to provide employees with the pertinent facts about a specific hazard or safety procedure. Such meetings typically last only 5 or 10 minutes — long enough to get the information across but short enough to avoid boredom and restlessness. The meetings outlined by the NYSARC Safety Group Management Committee and available from the State Office can be presented as is or integrated into a longer meeting format. They make use of statistics, visual aids, and other devices to catch and hold employees' attention. But their impact on employee attitudes and work practices depends on your ability to plan and communicate.

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Planning for the Future: Establishing Burial Provisions

Up until recently in the last several years, there has been very little attention devoted to the financial planning needs of persons who are disabled or their families.

There appears to be a heightened awareness and clear recognition for the need to plan ever so carefully for the future well-being of individuals who are mentally retarded and developmentally disabled, especially when parents or family members are no longer available to ensure their young or adult children's welfare and security.

One area which may require some special or long-term financial considerations is that of making burial provisions for persons who are unable to plan for this stage in their life cycle.

Quite frequently, questions have been raised by families and service providers concerning the establishment and handling of burial fund accounts for individuals who are mentally retarded and developmentally disabled, residing in various residential facilities operated or certified by the Office of Mental Retardation and Developmental Disabilities.

In an attempt to address these inquiries, the following information is provided to our readers with the invaluable assistance of James Moragne and Wayne Borek, Principal Resource & Reimbursement Agents for OMRDD. This article contains information only on Medicaid and SSI programs.

Burial Spaces

The Social Security Administration has defined burial spaces as being conventional gravesites, crypts, mausoleums, urns, or other repositories which are customarily and traditionally used for the remains of deceased persons.

In determining the resources of an individual, the value of any burial space which is intended for the use of the individual, his or her spouse or any immediate family member is excluded. If the space is

not intended for the use of any of the above individuals, its value will be applied against the applicable program resource limit.

Although the law provides the Secretary of Health and Human Services the authority to set limits on the size and value of the burial spaces that are excluded, presently there are not such limits.

Immediate family includes an individual's minor (younger than 18) and adult children, step-children, and adopted children, brothers, sisters, parents, adoptive parents, and the spouses of those persons. Dependency and living in the same household are not factors to be considered.

Burial Funds

Burial Funds are funds set aside to meet the expenses connected with the individual's burial, cremation, or other funeral arrangements. This includes revocable burial contracts and burial trusts, cash, savings bonds, or any separately identifiable assets.

The law provides that funds set aside for the burial expenses of any individual are excluded up to a limit of \$1,500 for each person. This limit will be reduced by the following:

1. The face value of any life insurance policies, except term insurance (a policy that covers a person only for a specific period and has no cash value), with a total face of \$1,500 or less.

For example, if a client has a life insurance policy with a face value of \$1,000, this \$1,000 is considered as part of the burial fund exclusion. The client is only allowed to put \$500 into a separately identifiable account in order to meet the maximum ceiling of \$1,500 for an excludable burial fund. Life insurance that cannot gain cash surrender value is not considered an available asset. In addition, if the client is not the owner

of the policy, it does not count towards the burial fund.

If the face value of the life insurance policy is in excess of \$1,500, the cash value of the policy must be counted toward the applicable resource level. If the individual is resource eligible, he or she is allowed to set aside an additional amount of up to \$1,500 as a burial fund.

2. Any amount held in an irrevocable trust or other irrevocable arrangement.

Both the Social Security Administration and the New York State Department of Social Services will apply the exclusion in all cases. The Social Security Act was changed to repeal a provision of the SSI program that applied the burial fund exclusion to only individuals who would be over the resource limit without it.

As noted above, burial fund accounts *must be separately identifiable* from other resources owned by the client which are not set aside for burial. If such funds are mixed with other resources not intended for burial, the exclusion will not apply to any portion of the funds. The intended use of funds is determined by the statement of the applicant/recipient. The case record should contain a statement from the applicant/recipient or his or her representative to document that the funds are set aside for burial of the applicant/recipient or his or her immediate family.

Interest earned on excluded burial funds, or appreciation in value of pre-paid burial arrangements, is excluded from consideration as a resource in determining Medical Assistance eligibility or SSI entitlement if they are left to accumulate and become part of the separately identifiable burial fund. The time this burial fund begins is when the benefit or entitlement begins. Therefore, if the entitlement for the two programs begin at different times, the burial fund and its starting amount are set at different times. For example, a person may be eligible for Medicaid long before he or she is eligible for SSI. SSI will allow up to \$1,500 as of the date the SSI starts.

If the interest income or appreciation in value, however, is not left to accumulate, these are considered as available income or resources. Interest earned on burial funds or on portions of burial funds which are excluded is considered unearned income in the month it is posted and a countable resource thereafter.

If excluded funds, accumulated interest or appreciated value are used for purposes other than the burial arrangements of the individual, future SSI benefits will be reduced by an amount equal to that used for other purposes. The Department of Social Services will consider any amount used for other purposes as income in the month that the burial funds were used inappropriately and a countable resource thereafter. Both the Social Security Administration and DDS allow for the use of excluded funds, interest or appreciated value to be used for purchasing burial related items for the individual, i.e. headstone and burial plots.

Gifts

When an individual other than the client retains ownership of a fund established for an OMRDD client's burial, this fund is not considered a countable resource in determining the client's eligibility for Medical Assistance. For SSI purposes, such funds also are not considered a countable resource as long as the client does not have access to or control of the funds either individually or through a representative payee.

When a burial fund or funds specified for establishing a burial fund is presented to an SSI-related Medicaid client as a gift, the first \$1,500 is considered an exempt burial fund with the remainder, if any, applied directly to the available resource standard. A written statement from the individual presenting the client with a gift of a burial fund is needed to document granting a maximum of \$1,500 of the gift as an exempt resource.

When a burial fund or cash equivalent is presented to an SSI recipient, the amount received counts as income in the month received. The recipient would lose an exempt burial fund and the beneficiary would again be eligible for SSI in the following month. Retrospective Monthly Accounting (RMA) rules adjusting income for two months do not take effect when the recipients eligibility begins a new cycle due to a full month's ineligibility as just described.

Establishment of a Burial Fund

If the individual is filing for SSI or medical assistance, funds which exceed the resource limit can be put into a burial fund in order to make the applicant eligible for benefits. The burial fund may be excluded retroactively back to the first day of the month in which the applicant/recipient intended funds to be set aside.

If a client is in receipt of Title XIX Medicaid and exceeds the allowable resource level for MA, the excess is treated as part of the NAMI. (i.e. as income)

If the client is in the community and his resources exceed the MA level, the client has the option of utilizing the burial fund provisions in order to reduce his assets to the MA resource level prior to the start of the next month. If the assets remain in excess of the resource level, the client loses his MA eligibility.

If an SSI recipient either in the community or in a Title XIX facility exceeds the SSI resource level on the first of the month, the client becomes ineligible for SSI for that month. An acceptable method to reduce the assets in order to make the client eligible for future SSI benefits might be the creation of a burial fund under PL 97-258 using part of the client's assets. First consideration must be given to the client's personal needs and maintenance (e.g. room and board, etc.) before use of assets for a burial fund is considered.

For additional information about how the SSI and Medicaid programs treat burial funds, you can contact your local Revenue and Reimbursement Office. ■

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Eight Chosen for Association Scholarships

— It was announced on Friday, May 5, 1989 at the Spring Board of Governors' Meeting that eight (8) individuals were selected as recipients of NYSARC's scholarship program and those chosen will be awarded a total of \$16,000 over a four-year period.

Kay R. Nogaj, Chairperson of the NYSARC Scholarship and Awards Committee, indicated that the eight (8) individuals receiving the scholarships were selected from a total of 41 candidates statewide.

The following persons have been recognized by the New York State Association for Retarded Children, Inc. for their outstanding achievements in their work in the field of mental retardation and/or for their distinguished academic records and recommendations of support submitted by their sponsoring chapters and college faculty.

Recipients of the 1989 Joseph T. Weingold Scholarship

Criteria

1. Recipient must be a full-time student enrolled in his/her sophomore year in a special education program who after graduating is planning to teach individuals who are mentally retarded.

Award

Two recipients each will receive \$2,000

1989 Recipients

Danielle Germain

Danielle is currently enrolled at the State University College at Buffalo majoring in Exceptional Education. Her goal is to become a Special Education Teacher at the primary school level. Danielle's experience with the mentally retarded include officiating at the Special Olympics and volunteering at People, Inc.

Kittie Hoch

Kittie is currently enrolled at SUNY Geneseo majoring in Special Education. Her goal is to become a Special Education Teacher at the elementary school level. Kittie's experience with the mentally retarded include volunteer work with a preschool special education class; volunteer for Special Olympics; and worked with a BOCES program.

Recipients of the 1989 James F. Reville Scholarships

Criteria

1. Recipients must be a high school graduate enrolled full-time in any year of their college training, in a field related to mental retardation.
2. Recipients have been actively involved in serving individuals who are mentally retarded in some capacity.
3. A letter of recommendation from his or her local chapter be included with the application.

Award

Two recipients will each receive \$2,000.

1989 Recipients

Pamela Neveu

Pamela is currently attending the State University at Buffalo pursuing a degree in Physical Therapy. Upon graduation, Pamela would like to work with mentally and physically disabled children.

Pamela's experiences with individuals who are mentally retarded include: volunteer at the Summer and Winter Special Olympics; worked as a teacher's aide with Oneida County BOCES; worked at All-Care Health Services as an aide to elderly physically disabled adults; a sister who is mentally retarded.

Gretchen Winert

Gretchen is currently attending Brigham Young University majoring in Psychology. Gretchen plans to use her degree to counsel individuals with mental retardation and emotional problems.

Gretchen has been involved as a volunteer for Special Olympics and is a member of Youth-ARC. She is very involved in ARC activities as 12 of her 24 siblings have mental and/or physical disabilities.

Recipients of the 1989 Jonathan Weingold Scholarships

Criteria

1. Recipient must be actively employed full-time by the Association.
2. A letter of recommendation from the chapter board must be included with the application

Award

One recipient is selected from each of the four geographical regions of NYSARC. Each recipient will receive \$2,000.

1989 Recipients

Northeast Region

Gail O'Connor

Gail has been employed at the Essex County ARC for almost two years as a Special Education Teacher. Gail is currently enrolled at Castleton State College pursuing a Masters Degree in Special Education.

Southeast Region

Katherine Walsh

Katherine has been employed by the Ulster County ARC for the past six years as a Recreation Worker.

Katherine is pursuing a Bachelor of Science degree through Empire State College in Recreation with an emphasis on therapeutic recreation. Her goal is to become a Recreation Therapist.

Central Region

Pamela Dority

Pamela has been employed by the St. Lawrence County ARC for the past ten years. Her current responsibility is that of Department Head Supervisor for the chapter's Container Redemption Program.

Pamela is currently enrolled in Empire State College pursuing a Bachelor of Arts Degree in Social Service, enabling her to work as a Rehabilitation Counselor.

Western Region

Mary Jane Sledz

Mary Jane has been employed by the Genesee County ARC for two and one-half years. Her current position is that of Interim Director of Adult Services/Residential Services Coordinator.

Mary Jane is currently attending SUNY at Buffalo pursuing her Masters Degree in Educational Administration, Organization and Policy.



CHAUTAUQUA

Allied Industries Obtains Key Military Supply Contract

Allied Industries, a division of The Resource Center, has been awarded a contract to produce 38,400 electrical grounding rods for the U.S. Defense General Supply Center located in Richmond, Virginia. This product will be utilized by the U.S. Military Services to provide an electrical ground for military mobile shops and temporary power stations. The total sales value of the first contract for this item is estimated at over \$477,000.

According to The Resource Center's Director of Manufacturing, Thomas McConnon, the military contract will provide work for approximately eight skilled workers with disabilities from the Chautauqua County area who are presently employed by Allied Industries. Commenting

on the contract Mr. McConnon said, "Since 1978 Allied Industries has annually manufactured one million wooden tent pegs and 50,000 nylon insect bars for the U.S. Department of Defense. Clearly the successful high standards of performance and quality workmanship maintained by our manufacturing operation provided the basis to produce this contract."

Allied Industries has been in the process of developing the primarily copper ground rod for the past year. After passing the "first article" inspection conducted by the Federal Government, volume production began in late December of 1988 with the first disbursement of the contract shipped in early May 1989. ■



Virginia Beacom, Quality Control Supervisor, demonstrates for Joyce Fonti, Workshop employee, the use of a testing meter used to test the electrical resistance of each ground rod produced.

SCHOHARIE

BOCES Building Project Aids Students, County ARC Clients

A cooperative effort of two area BOCES and the Schoharie County Adult Rehabilitation Center is designed to increase productivity of ARC clients and aid their development.

A Building Trades class at the Schoharie BOCES Center constructed two "side-lyers" for the ARC, for use in Physical Therapy. The "side-lyer" enables physical therapists to posture their clients for several hours a day and still work with them on other skills, ranging from coordination to conversation.

The BOCES Center in Albany is currently working on some equipment to increase productivity of workers at Toe Path Industries. The equipment being developed at BOCES includes a platform table for loading bolts and screws directly into packages, a vise to assist in taping the ends of crossbows and a lever to put plastic tips into cable TV unit housings uniformly.

Toe Path Industries employs more than 100 ARC clients, the majority of them at the Day Treatment Program. A few work in off-site night programs, including a janitorial service. ■

PUTNAM

PARC's Legacy of Love Essay Contest Winners Announced

Julie Kahn has been named the First Prize Winner of PARC's Second Annual Legacy of Love Essay Contest. Ms. Kahn's winning essay was "If I Were Him/Her." Second and third prizes were awarded to Natalie Vicini and Mitch Jacobs respectively.

This year's Legacy of Love Awareness Week celebration contained a contest for high school seniors to enhance the awareness of young people regarding handicapped persons.

The 300-500 word essay entitled "If I Were Him/Her" and the content judged was understanding, awareness, way to care, compassion, responsibility, and the ways in which education helps.

Winners were given the opportunity to meet and network with teachers and department heads in the field of special education so that they could learn first hand what it's like to work with handicapped people. They also have been given first option to work in the PARC Summer Jobs Programs.

Honorable mention in the contest was given to Dan Bullen and Thomas Lombardi. All students were from Mahopac High School. ■

NEW YORK CITY

NYC/AHRC Develops Extensive Respite Program

The New York City Chapter has recently expanded its already comprehensive respite program to include its third free-standing and fourth hotel respite sites. These new sites enable AHRC to offer a wide variety of year-round, city-wide programs that provide parents, siblings and other full-time caretakers with much-needed "time out."

In 1987, NYC/AHRC became the first MR provider to operate a free-standing respite site in New York City, opening two additional locations during the following two years. The project is jointly operated by the Department of Residential Services and AHRC's Developmental Evaluation Services Department. AHRC's Clinic screens clients and oversees the admissions, while the Residential Services Department provides on-site direct care and recreation. A fourth site is scheduled to open within the next year.

NYC/AHRC first developed the hotel respite program when it was determined that hotels provided a perfect weekend

respite setting: they conventionally serve a transient population, have fire and security systems on site, adjoining rooms and restaurants; provide maid and room service; many are wheelchair accessible; and often have pools, exercise rooms and other recreation facilities on site.

AHRC has conceived and administers such innovative programs as Harriman Lodge (the first "summer resort" for mentally retarded adults). AHRC also sponsors evening and Saturday respite programs, overnight camps, a summer vacation house on the shore, and a recreation program which includes photography, bowling clubs, long and short-term trips.

NYC/AHRC is also expanding its respite programs and services to encompass more severely disabled people of all ages, as well as specialized disability groups, including persons with Prader-Willi Syndrome, for whom special provision has been made at our Queens respite house. ■

ONEIDA

Oneida County Association for Retarded Citizens Progress Industries Awarded 1990 Legacy of Love Contract

The Oneida County Association for Retarded Citizens' sheltered workshop program, **Progress Industries**, has been awarded the contract to produce the 1990 **Legacy of Love** Valentine Rose Arrangement, for the New York State Association for Retarded Children's (NYSARC) Fourth Annual Mental Retardation Awareness Week.

The 1990 **Legacy of Love** product will feature a *real red rose*, that has been preserved to capture its beauty for all time, in a hurricane vase, and is surrounded by white Victorian lace and rose leaves. Inserted in the top of the vase is a tem-

pered votive cup and candle, enhanced with a bright red ribbon and bow. The vase is attractively packaged in a gold foil display box imprinted with the **Legacy of Love** emblem.

Currently Progress Industries is in the process of setting up a sales and shipping network to supply NYSARC chapters across the state, with this attractive product.

The Oneida Chapter is looking forward to making this the greatest year ever for the **NYSARC Legacy of Love** campaign, and it is already involved in research and development of new products for future campaigns. ■

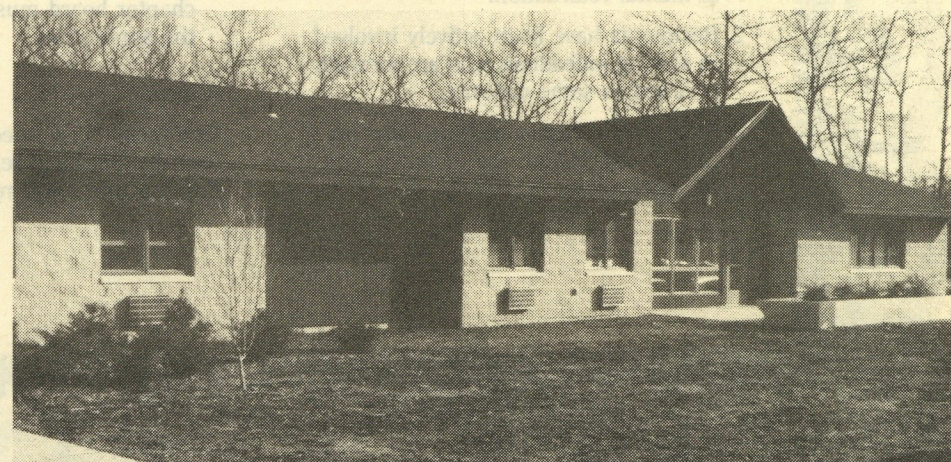
SUFFOLK

Second Shoreham ICF Opens

Suffolk AHRC's second intermediate care facility, Shoreham ICF II, recently opened its doors to the first of 48 new residents.

Shoreham ICF II, located adjacently west of the original ICF on Defense Hill Road, was built and designed to the residential

needs of it's very special multi-handicapped residents. Shoreham ICF II offers everyone the opportunity to achieve his highest level of functional development in areas such as self-care, communication, mobility and independent living. ■



Suffolk Chapter's second intermediate care facility in Shoreham opened earlier this year to 48 clients. (Photo by D. Dunbar)

WAYNE

The D.A.T.P. Greenhouse is Part of the Wayne County ARC Programs

In the D.A.T.P. greenhouse classes at Newark, the participants take home the plants they successfully propagate.

The Key Greenhouse plant store which

is open to the public, offers foliage house-plants and is also growing hardy mums for the local hospital. ■



Laurie McPartland, Seniors Program Instructor, admires a cape primrose in the D.A.T.P. greenhouse.

DELAWARE

ARC Bike-A-Thon Raises Record \$41,589

The Delaware County ARC Bike-A-Thon, the ARC's only annual fund raiser, generated a record \$41,589 in pledges and business sponsorship. Two hundred and eighty-six (286) riders in three areas of the county brought in \$25,479; business sponsorships totalled \$61,110.

This compares to \$20,822 in the 1988 Bike-A-Thon where 263 riders turned out; business sponsorship in 1988 was \$13,579 for a 1988 total of \$34,401. This year's results represent an increase of 17%.

Fifteen (15) ARC clients also rode stationery bicycles at the Community Living Skills Center on Wagner Avenue. These riders rode for a total of 202 miles and brought in \$1,275.96 in pledges!

In all areas there was tremendous participation by volunteers as checkers and patrollers, including the Safety Chairman Sheriff Paul Peterson, whose staff patrolled all three areas. This greatly enhanced safety, which is the most important concern during the Bike-A-Thon. In addition, drivers were most courteous and respected the bikers.

The money raised in the Bike-A-Thon is used to fund programs and services for people who are mentally retarded and reside in Delaware County. All these funds stay right here in Delaware County. In addition, the funds raised allow the ARC to secure matching funds from other sources. ■

CHENANGO

Employee Training on Safety in the Workplace

Employees of the Chenango County Chapter ARC facilities located on Midland Drive, Sheldon Street & East Main Street, Norwich, recently completed viewing the final segment of a series of video training programs centering on safety in the workplace. The series which was presented in four separate sessions, delivered important messages and lessons on: Correct Lifting Procedures, The Importance of Eye, Hand and Skin Protection, Hand Tool Safety, Wearing Appropriate Safety Gear, Some Common But Dangerous Housekeeping Hazards, Electrical Safety, Horseplay, Fire Prevention and Hazard Awareness.

The Safety Series was recently offered as just part of the on-going video training program that is currently being offered to its entire workforce including handicapped workers. It's hopeful that the Safety Series

presentation will result in heightened safety awareness where most industrial accidents occur.

In an effort to address and meet the needs and expectations of the modern day workforce, Chenango County ARC has developed the on-going video training program that will hopefully serve as a highly effective medium for raising employee standards, and boosting employee morale as well as supplying valuable information on a wide variety of issues and topics to employees and the handicapped population. In addition to the Safety Series, other presentations already delivered or scheduled for offering during the current year include several videos on the topic of AIDS Education and dealing with Hazardous Substances, Stress, Drugs and Alcohol among others. ■

ROME

Jimmy Lyon's to Celebrate 100th Birthday

"Jimmy" Lyons who resides at the Walsh Intermediate Care Facility (ICF), will be celebrating his 100th birthday on July 16, 1989.

A celebration is being planned at his new community residence on Cypress Street in Rome to commemorate this festive

occasion. Greetings from President and Mrs. Bush will be received as well as acknowledgments from the Rome Chapter, the Rome DDSO, local community leaders and hopefully Willard Scott on The NBC - TV Today program. ■

LIVINGSTON-WYOMING

Expansion Project Nears Completion

By mid-June, the expansion project at Hilltop Industries, the Livingston-Wyoming ARC's sheltered workshop, should be completed. The facility is located at 5 State Street in the Village of Mt. Morris. The construction, which started in September of 1988, will add 15,000 square feet of workshop, office, storage and vehicle maintenance space upon completion. In addition to the extra space, extensive repairs were made to the storm sewers, the electrical service was upgraded, the entire parking

lot will be resurfaced, and the area around the facility will be landscaped.

The project is being financed by a combination of monies from OMRDD, a mortgage from Norstar Bank, and a loan from the Small Cities Community Development Block Grant through the Village of Mt. Morris.

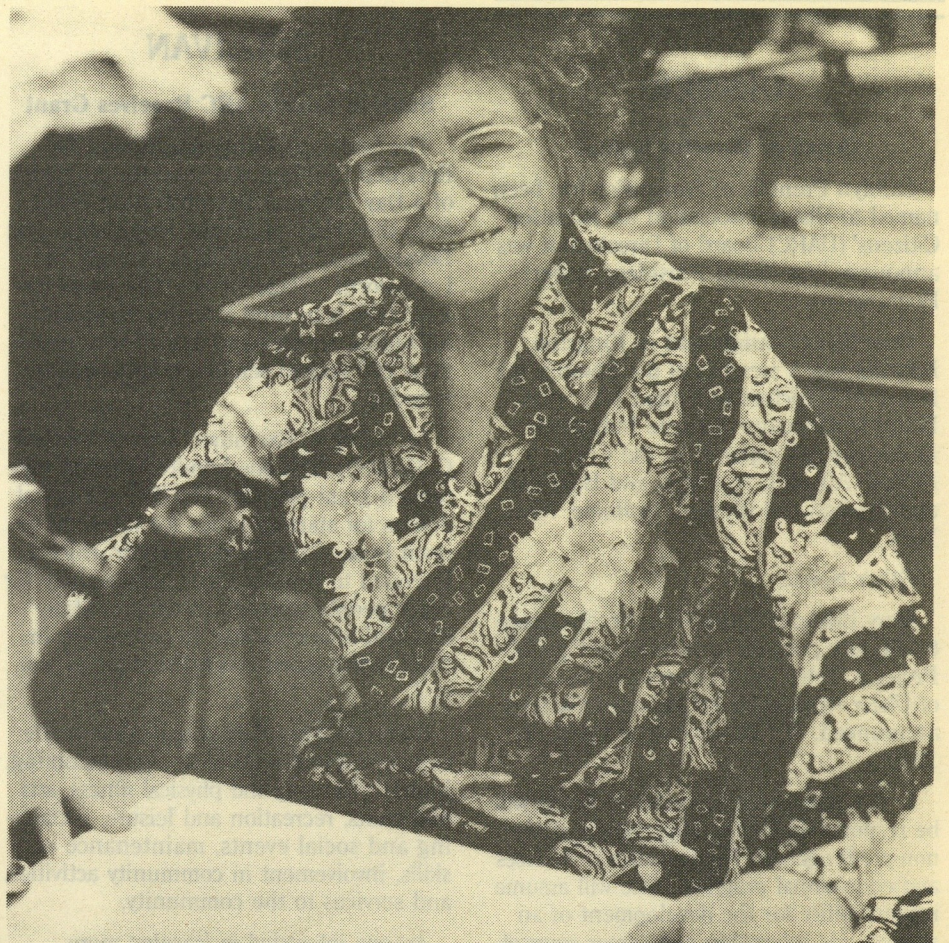
An open house is planned for later this summer. ■

COLUMBIA

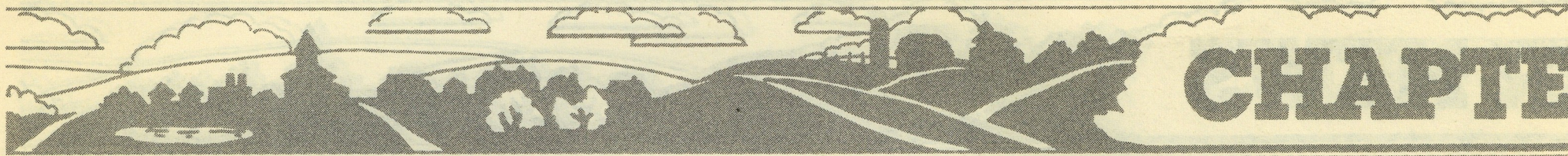
Pride in Fabric Bags Production

For more than a decade, COARC employees like BERTHA HACKETT have justifiably taken enormous pride in their production of nationally-marketed quality fabric bags. The hundred thousand or so trademark COARC Bags that Bertha and her colleagues turn out annually bear the logos of prestigious universities, corporations and

non-profit organizations all over the country. Now in its annual Spring membership drive, the Columbia County Chapter is offering, for the first time, three of the dozens of different COARC Bag models to donors as premiums in order to increase the size and number of donations. ■



"I like sewing," Bertha Says. "I've been making bags since 1981 and I'm glad they're being used to get new members." (Photo - Paula Bossert, Valatie)



ALLEGANY

Allegany Chapter Expands

The Allegany County ARC will be constructing a new 17,000 sq. ft. facility in Wellsville, New York. This facility will house the Day Training Program in 12,000 sq. ft. and the PWI Program in the remaining 5,000 sq. ft.

The project will be funded by a HUD grant, grants from OMRDD and UDC (Urban Development Corporation) low interest loan. The project is estimated at over one million dollars. Construction is scheduled to begin in May 1989.

The facility was necessitated by the fact that the landlord, Alfred University, is also expanding and growing and needed the space. To date, the agency's sheltered work-center (PWI) has been moved to Wellsville. PWI serves 100 employees (clients) and occupies two facilities. These facilities were donated to the agency by Walter and Beulah Babbitt and Edward and Edna Antoon in 1984 and 1986 respectively.

Other News...

The Allegany County Association for Retarded Citizens has named Richard Witowski, Executive Director and Kathleen Terwilliger, Director of Business and Finance.

Prior to joining the ARC staff in Wellsville, Mr. Witowski served as the Deputy Director with the Monroe County Department of Public Health for ten years.

Before coming to the ARC staff, Ms. Terwilliger worked as an accountant in the private sector. ■

DUTCHESS

Catherine Seeberger Honored

Dutchess County ARC was pleased to honor Mrs. Catherine Seeberger on April 1st, by presenting her with the Bessie H. Payne Award. Mrs. Seeberger has dedicated her life time work to the mentally retarded/developmentally disabled children of Poughkeepsie.

Prior to her retirement in 1973, Mrs. Seeberger was a Special Education Teacher at BOCES.

Today, Mrs. Seeberger serves as a parent-advocate for ten handicapped individuals who have no family connections. She is the Co-Founder of Dutchess County ARC. She opened and served as administrator for the first respite care facility in the county. Mrs. Seeberger's continual dedication has been an inspiration to ARC clients and all who work with her. ■



Mrs. Catherine Seeberger

SULLIVAN

Sullivan County ARC Receives Grant

The Sullivan County Association for Retarded Children was recently in receipt of a Day Training Demonstration Grant from the Office of Mental Retardation and Developmental Disabilities through the Letchworth Village DDSO. The grant for \$325,000 is to fund a facility to provide individual services and activities to more than 100 retired senior workers who are retarded.

According to Executive Director, Stephen C. Helfgott, "The one hundred percent state funded grant provides \$50,000 additional dollars for start-up funds for the soon to open Rose Valley Senior Center which is intended to provide retirement activity for older people who are developmentally disabled and who wish to slow down in their senior years, much the same as you or I."

Some of the activities and services are counseling and referral day programming, health, well-being and physical fitness, arts and crafts, recreation and leisure, socializing and social events, maintenance of skills, involvement in community activities, and services to the community.

Anyone interested in learning more about this center may do so by calling (914) 434-3415. ■

STEUBEN

Steuben ARC Celebrating 25th Anniversary

Steuben ARC is celebrating their 25th Anniversary this year, making 25 years of dedicated service to developmentally disabled individuals. The Silver Anniversary will be celebrated at Steuben ARC's Annual Dinner Meeting on Saturday, May 13, 1989 at the Days Inn Restaurant in Bath, New York. Assemblyman Donald R. Davidsen (127th District) will be the guest speaker.

Blanche Fierstein, President of the New York State ARC, will be Honored Guest for the evening's activities. Among her many responsibilities, Fierstein presides over the 108-member Board of Governors which is responsible for all policies of the Association. This annual celebration, will include induction of in-coming Board of Directors members and special awards presentations. In-coming Board Members serving a one-year term are as follows: President, Joseph Monaco, Bath; Vice President, Agnes Tobia, Corning; Secretary, Emily VanScoter, Hammondsport; Treasurer, Arthur Stilwell, Corning. Directors elected to serve a two-year term are Michael Austin of Bath, Amy Christensen of Bath, Sandra K. Curtis, Hammondsport, William Dinehart of Bath, and Arthur Hansen of Canisteo. ■

WARREN/WASHINGTON

Job Discovery '89 A Success

On April 25, 1989 the chapter participated in Job Discovery 89, a job fair held at Adirondack Community College, Glens Falls. Representatives from 45 area businesses, employment and training agencies set up booths to give out information and discuss job openings with prospective employees.

Rick Borden, Personnel/Training Coordinator, said that out of the 2,000 job seekers, 40 completed employment applications and helped themselves to the brochures and membership applications that were readily available.

The job fair was organized by representatives from area businesses, various state and county employment and training agencies, and the Adirondack Regional Chamber of Commerce. Organizers considered the fair a great success with many favorable comments from employers and applicants alike.

Other News...

In tribute to the late Sidney VanDusen, the chapter board has voted to acknowledge Mr. VanDusen's numerous contributions by naming its Respite Center the Sidney VanDusen Respite Center when a permanent site is located. ■

MADISON

Madison County ARC to Build Recycling Facility

A cooperative effort which has brought together individuals from the County government, as well as representatives of Madison County ARC, has been successful in securing \$600,000 from the Office of Housing and Urban Development's Community Development Block Grant Small Cities program.

These monies will be used to build an 11,506 sq. ft. materials recovery facility. This facility will be built on or near the present Madison County landfill. It will also have the capacity to recycle up to 95 tons of combustibles per day, but will also

recycle ferrous and non-ferrous metal, glass and plastics. Madison County ARC's role will be to manage and run the processing end of the facility, while the County will be responsible for marketing. One example of innovative marketing which is being researched is the shredding of paper for use as animal bedding in place of straw.

The recycling facility will employ 13 people in the first year and up to 30 in five years when it is operating at full potential. The work force will be integrated employing persons with disabilities as well as non-disabled individuals. ■



The last stage of the agreement between ARC and the County is celebrated.

Left to right: Raymond Lewandowski, Executive Director, Madison County ARC; John L. Ayer, Chairman, Solid Waste Committee, Madison County Board of Supervisors; Lois Jones, President, Board of Directors, Madison County ARC; and Bob Kuiper, Chairman, Madison County Board of Supervisors.

ULSTER

Board of Director Named

Carolyn Prentice of Saugerties has been named to Ulster Association for Retarded Citizens' (UARC) Board of Directors, it was announced by Board President Robert Boening.

Prior to her assignment in Kingston, Prentice was a member of the Kiwanis, the Board of Directors of United Way, the Board of Directors of Rome Industrial Development Corporation, the Griffis Military Affairs Committee, and Business and Professional Women, in Rome, New York.

Other News...

Mary Brady, of Kingston has been named to the new position of Director of Special Projects, Peter Pierri, Executive Director of Ulster Association for Retarded Citizens announced. Ms. Brady joined UARC in 1980.

In the newly created position, Brady will be responsible for the supervision of the non-profit agency's Family Support Services and educational programs. She will assume responsibility for the development of an agency-wide internship and career counseling program, as well as the development of an agency volunteer program. ■

NASSAU



Many of the chapters have horticultural programs where people and flowers grow. At the Nassau Chapter's greenhouse there was special activity during the summer as the horticultural program put on its Famous Geranium Sale.

ONTARIO

Family Support Services Expanded

The Ontario ARC recently has expanded several areas associated with its Family Support Services Program.

We are currently in the process of offering educational programs on Guardianship and Wills and Trusts to area groups including BOCES PTA and our Chapter members. We are also planning programs to explain under what circumstances ARC could be named guardian. Staff persons are available to answer questions and assist in the application process.

In mid-April, Ontario ARC began a new Special Olympics Program. This will be a year-round program, concentrating in the areas of volleyball, basketball, soccer, bowling and cross country skiing.

Finally, Ontario ARC was just awarded an Overnight Respite Grant through

OMRDD Family Support Services. This grant will allow us to provide up to 72 hours of respite services for 20 families. We have had a considerable number of requests related to this program; and up until now, we have not been able to provide this service. This is a new opportunity for the families of the developmentally disabled of Ontario County, and we look forward to beginning this program.

In addition to the Family Support Services, Ontario ARC has also begun implementation of its Human Growth and Development Program. This program is being made available to clients at Abbey Industries, and provides information concerning self-awareness, personal hygiene, physical and emotional differences, appropriate behaviors and various types of relationships. ■

SCHENECTADY

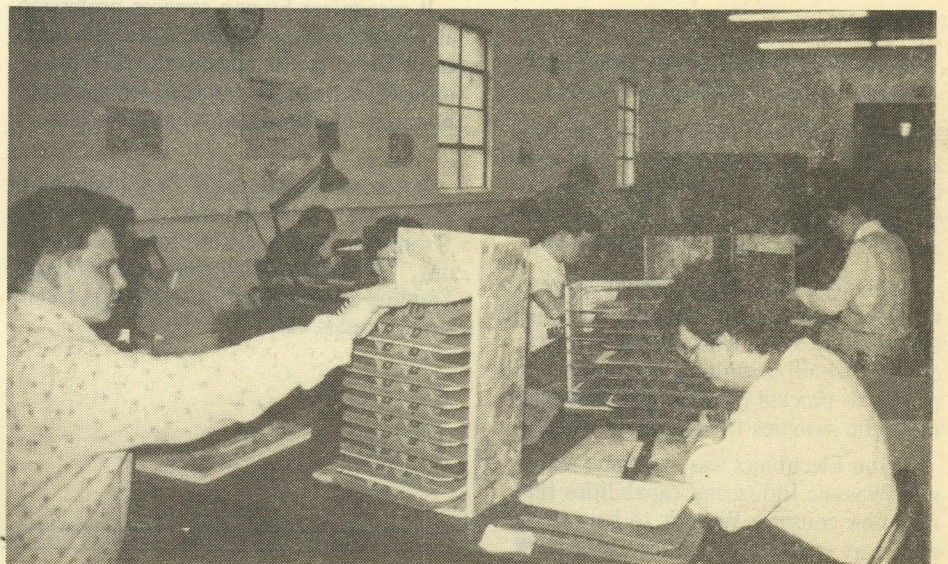
Pine Ridge Industries — Not a Traditional Sheltered Workshop

Pine Ridge Industries, the sheltered workshop operated by Schenectady County Chapter, NYSARC, has for many years served clients whose behavior problems are not typically manageable in a workshop setting. Some of the behaviors include chronic work refusal, running away and frequent non-compliance leading to severe verbal and sometimes physical aggression. In early 1988, a move to a new workshop facility and increased productivity expectations for clients seemed to intensify the needs of this group. It became apparent that the traditional workshop setting was insufficient to provide the necessary structure, supervision, and behavioral intervention that would allow a safe working environment for everyone.

In November of 1988, a staff-enriched work area was established to serve an identified target group of 12 vocationally-capable clients who demonstrate severe behavioral and self-direction needs. The area also includes eight well-adjusted sheltered employees who can benefit from the enriched staffing but who serve as role models of positive work behavior. A quiet room was constructed and the area was staffed with a behaviorist, an assistant and two production supervisors. Individualized behavior plans call for frequent positive reinforcement of desired work behaviors; "rewards" include extra breaks, lunch with staff, and the opportunity to work in another area of the workshop for one day.

At this point, the program is demonstrating significant impact on client productivity and behavior. An overall average productivity increase of ten percentage points has been observed for all 20 clients in the area. The number of major outbursts has decreased and are well-contained by the staff in the area using the quiet room. There has been no need to discharge any of the targeted clients to a more restrictive setting.

The project continues to develop and be refined as various techniques and methods are evaluated for effectiveness. It is apparent, from the initial results of a statewide survey of ARC vocational programs, that there is a growing need to address the question of how to serve aggressive clients in a sheltered work setting. ■



SENECA

Seneca ARC President 1988 Volunteer of the Year

Natalie Loucks, President of the Seneca ARC Board of Directors, has been named Seneca County's top volunteer for 1988 by the Seneca County United Way. Ms. Loucks was selected from nine nominees.

Ms. Loucks has been a board member since ARC was founded in 1976. Her interest in programs for the mentally retarded came naturally as she witnessed first hand the struggle her parents encountered in trying to get appropriate education for her brother who is mentally retarded.

In addition to her ARC duties, Natalie has been involved in many community activities such as the Salvation Army and Brownies.

The Association extends a heartfelt congratulations to Natalie. ■



Seneca County 1988 Volunteer of the Year Natalie Loucks, Seneca ARC President

"Role model" and "targeted" clients work side-by-side stapling cardboard cutlery display decks at the clinically supported work area in Pine Ridge Industries.

CHAPTER NEWS

CHEMUNG

Chemung Launches New Micrographic Department

Chemung Chapter launched its new Micrographics Department in March and within five days was hosting tours by prospective customers. By month's end, worker/trainees had exceeded their start-up goals. The chapter has secured a number of long-term contacts for this much needed service.

Summer Events

The Elmira Pioneer Red Sox and players from our softball teams take to historic Dunn Field July 13th for our third annual Baseball Clinic with the Pioneers. This popular event takes our players onto the field where team members take them through the basics of fielding, throwing and pitching.

We'll close off the summer at ringside... this one indoors at the Chemung County Fairgrounds. The attraction: Horses competing from all over the eastern United States and Canada. Known as Elmira Charity II, the show annually benefits our Association.

On the Move

Jamie Hulse has moved from Recreation Supervisor in Day Services to Community Residence Supervisor of Chemung's newest community residence for senior citizens. ■

COMMUNITY LEAGUE — WASSAIC

Annual Luncheon Held at New York's International Vista Hotel

On May 7, 1989 Community League — Wassaic Chapter held its Annual Luncheon in the beautiful banquet room of the International Vista Hotel at New York's World Trade Center where dining is extra special. Included in our guest list were representatives from the Office of Mental Retardation, members of City and State Chapter, members and Administration of Wassaic and family and friends of the residents of Wassaic for whom this money raising affair is done and they had a great time.

Other News...

Bicron Electronics Finds that Good Help is Easy to Find at Wassaic

On September 6, 1986, Wassaic received a call from Bicron Electronics Company of Cannan, CT. Bicron had 20,000 solenoids (electro-magnetic switches) that had been assembled with a defective component.

Utilizing some creative thinking by our workshop and Wassaic Adaptive Equipment Department Staff, Wassaic had fixtures devised which permitted our workshop people to process bicron's 20,000 electro-magnetic switches in very short order.

Bicron Electronics was so impressed with Wassaic Industries' capabilities that they now consider Wassaic to be a permanent part of their productive capacity. ■

ONONDAGA

Recreation Program Expansion

In the past, the Onondaga ARC's recreation program focused primarily on activities such as swimming, ceramics and bowling during the fall and summer months. In 1989, however, the program has expanded to include activities such as walking, fishing, and softball.

All of the activities stress involvement in events in the community and enjoyment of the outdoors. Participants in the new activities hope to improve their different recreational skills. ■

PUTNAM

PARC's Dr. Lindenbaum to Have Papers Published

The Assistant Executive Director of the Putnam Association for Retarded Citizens, Louis Lindenbaum, Ed.D., has recently been informed that a paper recently presented by him entitled, "The Current Challenge for Mental Health Professionals" will be included in a textbook soon to be published.

Lexington Books is currently copyediting select papers presented at a National Conference sponsored by the National Association for the Dually Diagnosed.

Dr. Lindenbaum is a Licensed Psychologist in New York and Connecticut and a former Board member of the National Association for the Dually Diagnosed. He maintains a private practice in Ridgefield, Connecticut. He was instrumental in the development of the PARC Clinic Treatment Program in 1980, which is presently one of the very few clinics in New York State providing mental health services to the developmentally disabled and their families.

Dr. Lindenbaum was selected for inclusion in the national reference directory, *Who's Who Among Human Services Professionals*, for 1986-87.

It recognizes human services professionals throughout the United States who have contributed to the advancement of their profession through practice, scholarship, research, teaching and administration.

Other presentations by Dr. Lindenbaum at National conferences have included, "Transition Shock: Institution to Community," "Psychiatric Admission" and "Clinical Training and Supervision of Mental Health Professionals." ■

ESSEX

A Personal Thank You from the First Lady

Gary Dolan, a resident of Witherbee Community Residence, Essex County ARC, Port Henry, NY, received a personal Thank You card from First Lady Barbara Bush. On February 7, 1989 Gary sent the First Lady a **Legacy of Love** rose wreath in honor of the Third Annual New York State Mental Retardation Awareness Week. In response, the First Lady sent a personal Thank You card and a photograph of President George Bush and herself.

Essex County ARC participated in the **Legacy of Love** campaign for the first time this year and sold more than 600 rose wreaths while presenting others to local businesses, town supervisors and friends of the ARC who have been supportive and helpful through the years. More than a fundraising drive, the sale and presentation of wreaths enabled the staff of the ARC to make a great many contacts with their neighbors to talk about the mission of the ARC and about the prevention of Mental Retardation. ■



Gary Dolan with Personal Thank You Note from First Lady Barbara Bush

SENECA

WIXT-TV Personality Visits Spectrum Industries

Seneca Chapter was visited by WIXT-TV personality Mike Price, who had the close-knit workers at Spectrum Industries in stitches with his puns and jokes when he stopped by to film a story for Syracuse's Channel 9 television news recently. Mike told viewers how the Spectrum workers turned out the colorful hats and scarves for the St. Patrick's Day parades in Syracuse and Utica.

Sylvia McDonald, coordinator of the knitwear project, said her talented crew is looking for more work. If you belong to an organization, team, school or are staging a special event and would like some distinctive hats, scarves or headbands, give Sylvia a call at (315) 539-8600. ■

ERIE

Annual Poinsettia Sale Continues to Grow

Once again, Erie ARC's annual poinsettia sale soared past its previous year's goal resulting in a new record. Nearly 20,000 plants were sold during the 1988 holiday season to area businesses, churches, schools, community groups and individuals.

Proceeds from the sale benefited the Heritage-Oak Foundation, a not-for-profit corporation whose purpose is to provide philanthropic support for Erie ARC's programs and services.

Other News...

FSS Provides "Loving Touch"

Mothers and infants in Erie ARC's Family Support Services' Intensive Parent Training Program responded with enthusiasm to "Loving Touch" infant massage sessions taught by Magdalena Lehman, Team Leader for Early Intervention in Erie ARC's Heritage Education Program.

The Intensive Parenting Program is offered to parents of mentally retarded children ages birth to three years. The training seeks to provide a comprehensive system of hands-on service delivery around all aspects of parenting ranging from very basic child care issues such as feeding and bathing to the understanding of behavioral and developmental concepts. These services provide the support, specific instruction, and parenting skills training that will help parents give their children quality care. Since many parents in the program do not have a history of positive parenting experiences, "Loving Touch" may prove to be a wonderfully effective activity which promotes positive and nurturing parent/child interaction. ■

NASSAU

Nassau's Thirty-Sixth Annual Rose Ball

The Nassau County Chapter held its thirty-sixth annual Rose Ball at the New York Hilton on June 17th.

The event, which helped to initiate that chapter's fortieth year, featured the presentation of the AHRC Humanitarian Award to Danny Kapilow, a former president of Local 966 of the International Brotherhood of Teamsters and well known labor leader and supporter of the Nassau Chapter.

A telephone book sized journal of about six hundred pages was distributed at the ball containing contribution ads and listings from several thousand supporters who together raised around \$300,000 for the Nassau Chapter. ■

"Eat Your Way to Better Health"

Janet M. Kenny, R.D.
Seneca County Chapter, NYSARC, Inc.

Do you feel you're constantly bombarded with information about diet and health?

The U.S. Surgeon General recently summarized our dietary practices. "Americans are eating their way to early graves, bite by bite, meal by meal, consuming too much fat and seasoning it with too much salt." Furthermore of the 2.1 million Americans who died last year, the Surgeon General's study said that nearly 1.5 million succumbed to diseases associated with diet.

As dietitian consultant for Seneca ARC Day Treatment Programs, I advocated optimum nutrition for both staff and clients.

Previously our main nutrition concerns focused on nutrient deficiencies that produced diseases such as rickets (vitamin D deficiency), scurvy (vitamin C deficiency) and pellagra (niacin deficiency). Today the problem for most of us has shifted to over consumption of certain dietary components — particularly fat.

We tend to eat foods high in fat at the expense of high complex carbohydrate foods such as vegetables, fruits, and whole grain products. Complex carbohydrates promote better health by providing vitamins, minerals and fiber to your diet.

Just how do we reduce our fat intake while increasing our consumption of complex carbohydrates? Remember three simple words when selecting your foods:

- LEAN — Look for low-fat varieties in meat, dairy products, cheese or salad dressing.
- COLOR — Choose fruits and vegetables with deep colors — yellow, green or red.
- GRAINS — Reach for breads, cereals and pasta made from whole grain flours.

Don't try to change everything in your diet overnight. Small changes mean better nutrition. For example: a peanut butter and jelly sandwich on white bread contains just 263 calories if you use only one tablespoon of peanut butter and one tablespoon of jelly. However, a peanut butter and banana sandwich on whole wheat bread packs more nutrition within the same

number of calories. The banana supplies fiber and minerals such as potassium while jelly supplies mostly sugar.

To select a nutritionally complete meal, one high in complex carbohydrates, include some of the following foods:

Grains

Whole wheat or other whole grain bread
Bran muffins or oat bran muffins
Low fat whole grain crackers
Whole grain English muffins

Vegetables

Carrot, celery, zucchini or cucumber sticks
Raw broccoli or cauliflower pieces
Green pepper sticks
Cherry tomatoes
Spinach salad
Tossed salad

Protein

Chicken, broiled or baked
Tuna fish salad (use water-packed tuna and a small amount of mayonnaise), add pineapple for variety
Lean roast beef slices
Low-fat cottage cheese
Low-fat cheese slices
Turkey slices
Leftover meatloaf (use extra lean meat)
Low-fat yogurt

Finishing Touches

Fresh fruit such as apples, pears, bananas, peaches, plums, oranges
Dried fruit such as apricots, raisins, apples, figs, dates
Fresh fruit salad
Banana bran muffin
Low-fat yogurt
Baked apple

Today why not take an inventory of your eating habits and start making small changes to reduce your risk of chronic diseases and promote a healthy lifestyle.

For additional information on nutrition, contact your local Cooperative Extension, American Heart Association, Diabetes Association or hospital dietary department. For a free copy of Consumer Information Catalog which includes available nutrition education materials, drop a postcard to: Consumer Information Catalog, Consumer Information Center, P.O. Box 100, Pueblo, Colorado 81002. ■

Section 202 Guide Available

A 500 page workbook entitled, *Developing Housing for Persons with Disabilities* is now available from the U.S. Department of Housing and Urban Development (HUD). The purpose of the workbook is to explain the requirements and procedures of HUD's 202 program. It is intended for use by non-profit organizations, consultants, architects, lawyers and other housing professionals who wish to use Section 202 direct financing and HUD rental assistance to develop shared or independent housing for persons with developmental disabilities.

The workbook outlines the entire Section 202 application process. It includes the proposed regulations that were published by HUD to govern the revised Section 202 program for persons with developmental disabilities.

Developing Housing for Persons with Disabilities: A Guide to HUD's Section 202 Program is available for \$60 from: Housing and Community Development Resource Center, 7035 Bee Caves Road, Suite 202, Austin, Texas 78746. ■

Advertisement

IRS Keeping an Eye on Fund Raisers

Fund Raisers, take notice! The IRS is watching your activities more closely than ever. Most charitable organizations sponsor many types of fund-raising events ranging from golf tournaments to gala balls. In the past, most individuals who purchased tickets to these events deducted the entire amount as a charitable contribution. According to the tax law the amount deductible is only that portion which exceeds the fair market value of the benefit derived by the purchaser.

IRS revenue ruling 67 — 246 states that it is now the charitable organization's responsibility to educate the public regarding the deductible portion of any ticket purchased for a fund-raising event. This ruling requires that organizations state clearly in any invitation to a fund-raising event the dollar amount of the fair market value of the benefit received and the portion of deductible contribution included in the ticket price. This creates a new challenge to all fund-raising departments for creativity in designing events where a higher percentage of the total requested purchase price is tax-deductible contribution.

The first question generally asked is "How can I determine the cost of an event before the invitations are even printed?" It is important to distinguish between the cost of the event and the fair market value of the benefit derived from the event. Only the fair market value of the event is important in determining the amount of tax deduction. The cost of the event is the cost paid by the charitable organization. This may approximate the fair market value in some cases, but is generally not a good guide. For example, in the case where an organization has received donations of all the materials, supplies and space from corporate sponsors, there is no cost to the organization. However, the fair market value of this event could be substantial.

The fair market value of the event can be generally defined as the amount that the general public would pay if the event were not for a charitable purpose. For instance, if your organization is hosting a golf tournament to raise funds, the ticket purchaser may be entitled to play eighteen holes of golf with use of a golf cart and attend an evening buffet. Let's assume that the owners of the golf course have donated the use of the course, the golf carts and the prizes. A local restaurant has agreed to cater the event for free. The only costs involved in the event are the printing of invitations and tickets which is estimated at \$550. The organization expects one hundred (100) people to attend the event. Therefore, the cost to the organization will be \$550 and the cost per person would be \$5.50 (\$550 divided by 100 people). This cost of \$5.50 has nothing to do with the fair market value of the event since most of the costs were donated. Let's assume that this golf course has a weekly Sunday afternoon event which consists of eighteen holes of golf and a buffet which is open to the general public for \$25 per person. This amount would represent the fair market value of the charitable golf tournament. Therefore, the purchase price would have to exceed \$25 for the purchaser to deduct any portion of the ticket purchase price.

This ruling also applies to parent organizations and their events on behalf of charitable organizations. Fund raisers should retain copies of documentation showing how the fair market value for any event was determined. Providers and advocates should be aware of these changes to insure compliance.

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Cayuga Youth Benefit by Job Coach Program

The Summer of '88 will certainly be well remembered. Without a doubt not many will forget living through that sweltering unending heat. It is inevitable that not one of us will be able to side step the effects of this country's unprecedented drought which seemed to be our destiny this summer. Some experienced it more than others, nevertheless, it was a common thread that pulled folks together, young and old alike.

The magnitude of these events were not alone. Another far reaching event happened right in our community. Twenty seven vocationally handicapped Cayuga County teens had the opportunity to work in a summer job. This all came about with the intervention of the Job Coach Program. This program made it possible for a coach to work with the youth right at their worksite.

The Job Coach Program previously established in the county eighteen months ago is primarily used as a means to assist the vocationally handicapped adult worker in his or her new work experience. The coach being the personal teacher or supervisor was able to help the worker achieve competitive standards in his job. Although this is an ongoing program offered to the adult worker, it is important to acknowledge another service the Job Coach program can offer.

As it happens, Job Coaching is being used in additional job related methods. Another important need is to help the young adult develop pre-employment skills and a good work ethic. Job Coaching has been used successfully with the Summer Youth Employment Training Program for the second consecutive summer to help

those students who are vocationally disabled, work at selected job sites when they normally would not have been able to take a summer job on their own.

Each student is placed at a work site in their geographic area of the county and at their own personal skill level. The job coach matched with the student, encounters the job with them from the very beginning. They meet on orientation day and generally stay together to the final day of the summer job. Because each student has different needs or more extreme requirements, it may be essential for some coaches to stay at the site on a full-time basis throughout the summer.

Other students with higher levels of performance and understanding might have their coaches fade away from them as the weeks pass with partial contact on a weekly basis. For each of them, the coach is there to help develop or refine work skills needed for future employment and "plant the seeds" along the way of good work behaviors and good work attitudes that will eventually be as important and truthfully more important, when that first "real job" comes up.

While all of this sounds a bit metaphysical, it is with pleasure to let you know that some genuine "simon pure" results have come from coaching these youths. The most remarkable has been a change in one youth's family attitude; a change brought about by a successful work experience during the first summer youth job which carried over to this young man's school year. For him, his second summer work experience was met with a change in sentiments from his family, resulting in positive reactions and support for his

summer job, and a greater determination on his part to do a good job. It is a story to be told, but I'm afraid it would lose a lot in its abbreviation. Trust me, the amount of communication and cooperation that took place was worthy of the comments "Oh my gosh, I can't believe it".

The young man was one of many that was travel trained and instructed in time recognition. Skills that were needed to get to the actual work place. Many times the coach's role extended from the home to the work site to insure overall success. For some it wasn't usual to plan for a savings account. And it seems like history that each summer one or two were schooled by their coach for a Driver's Permit. Quiet opportunities did come up for them. Sometimes waiting for that next bus didn't seem as long when the time was spent studying the manual over a soda with the coach.

At the job site, actual work skills were slowly built up. Many a coach guided the youth that washed walls and lockers or pushed a broom to insure true understanding of correct cleaning methods. Coaches who worked with students with left or right side paralysis helped them devise ways to accomplish tasks such as stuffing envelopes, collating paper and loading typing paper into the machine for a one-handed typing technique. One young woman with cerebral palsy was able to have her computer keyboard adapter brought to her worksite so she could do office work.

The summer jobs didn't lack for variety. Three young women had the opportunity to work with the elderly, one in a nursing home helping with activities and meal times, another rode an escort van to help the older folks come aboard or depart the

van, and the third young lady helped at a Nutrition Site in one of the distant parts of the county.

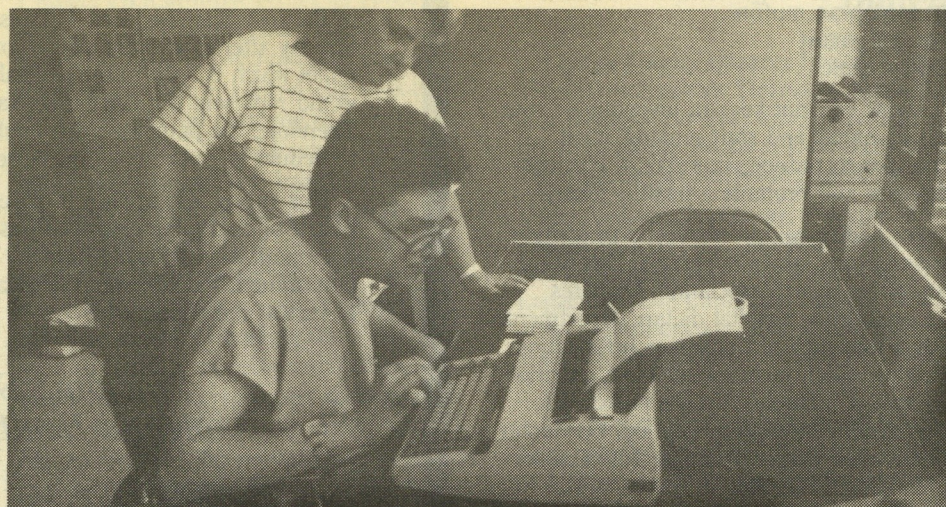
Most of the coaches agreed that the tangible work skills were the easiest to teach. Tackling work behaviors and work ethic were another story. It wasn't easy to know if the student understood that it was a privilege to have a job, and that we must work hard to earn our wage. Being a young adult, learning proper behavior at the work place was sometimes difficult to master, but not as difficult as it was for them to approach the site supervisor for tasks and assignments. Shyness was a factor. Not knowing what to say or how to ask was another. Several workers would never have that ability ever. The insight needed to understand a job or the mental processing to organize a job was beyond their capability. As long as the task was routine they were fine: routines had to be developed for each job, and in this realm they were successful.

Looking back over the summer it was good to see how many accomplishments were made. When twenty-seven young folks start a process of becoming responsible workers it can mean nothing less than a success story. The opportunity they had to experience a work environment and to start setting goals was an excellent way to get ready for what's ahead in their future.

It is especially nice to know a Job Coach program is available to help these young people develop individually and to allow their progress to keep pace with their ability. What better environment for them to grow, learning work skills gradually as a coach guides them along the way. ■



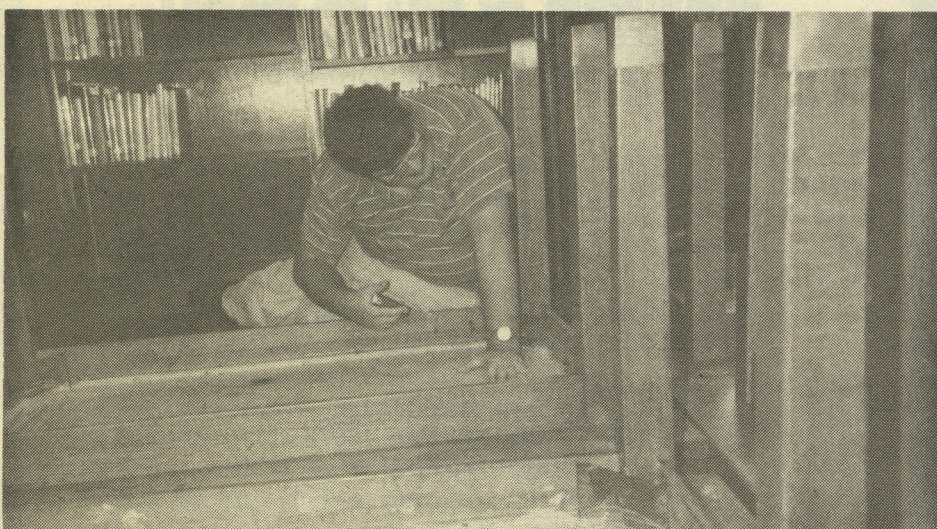
Mackenzie — Childs, Kevin Gallaro and Jenny Poz.



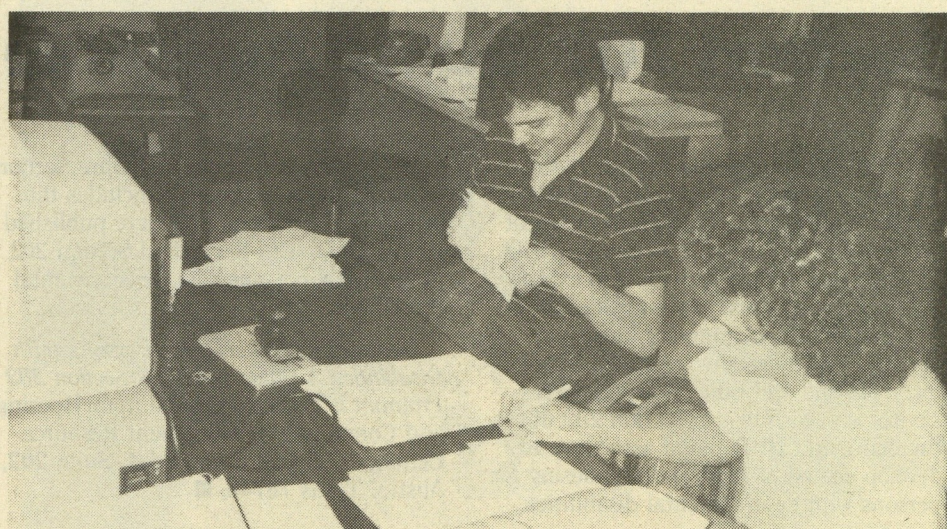
Auburn YMCA — Welu — Rich Wawro types letters and performs general clerical work while Job Coach Elaine Colella oversees his work.



SCAT Van, Tracy Horton as van escort helping a rider get off at her stop.



East Middle School — Auburn, Tim Simmons cleans debris from bottom of Library tables as part of the Summer Youth Job Coaching Program provided by Cayuga ARC.



Cayuga Summer Youth 1988 Job Coaching. Tom Jackson with Coach, Ann Davis perform clerical work; stuffing envelopes, collating papers, using a computer, copier, etc.

Conference Call

Grant Establishes Regional Center at University of Rochester for Developmental Disabilities and Aging

National trends show that the life expectancy of persons with developmental disabilities, such as mental retardation, epilepsy, and autism, is increasing. However, will there be enough trained personnel — habilitation specialists, health care and service providers, administrators, planners, etc. — to deal with the special problems and challenges of these people as they age?

To address this issue, two units of the University of Rochester Medical Center — the University Affiliated Program for Developmental Disabilities and the Center on Aging — have established the Training Program for Developmental Disabilities in Western New York, which will link the educational resources in gerontology and in developmental disabilities at all institutions of higher learning in the Rochester, Utica and Buffalo areas and create training opportunities for the broad spectrum of personnel working or about to work with this population.

The new program is funded by a three-year \$277,500 grant from the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services and is one of seven university-based training programs in the country.

In Monroe County alone, there are approximately 400 known developmentally disabled individuals between the ages of 40 and 50, and another 400 individuals over age 55. Since the program's activities will cover a region that stretches from Oneida County in the east to Niagara County in the west, the number of aging persons with developmental disabilities is in the thousands. "But those are just the known individuals. There might be up to four times that number of unidentified individuals, and all of these people are living longer lives," says the project's principal investigator, Philip W. Davidson, Ph.D., Associate Professor of Pediatrics. "As this group ages, they'll need highly specialized services in both quantity and quality."

Dr. Davidson is working on this project with Paul E. Coleman, Ph.D., Professor of Neurobiology and Anatomy.

"We see this new program as a way to enhance the quality of care of and the access to services by the aging developmentally disabled population," says the grant's project director, Jenny Overeinder, ACSW, a senior social worker at Strong Memorial Hospital. "We'll work with professionals already in the field and with undergraduate and graduate students about to enter it, enhancing both their professional skills and their awareness of the issues facing this population."

The program will include in-service programs, lectures, seminars, clinical rotations, regional workshops and an international conference. During the third year of the program, a fellowship in aging and developmental disabilities and an advanced seminar will be instituted.

For more information, please contact Jenny C. Overeinder, ACSW, at (716) 275-2986. ■

Regional Pediatric Aids Conference: A Success

By Pamela Murphy-Cleary
Director of Children's
and Community Services

The Resource Center combined efforts with the Western New York Prevention Task Force, J.N. Adam DDSO, Erie I SETRC, and the State Education Department to sponsor a regional conference on pediatric AIDS.

Dr. Peray Ogra, Director of Pediatric Infectious Diseases at Buffalo Children's Hospital, gave the opening remarks. Dr. Gary Diamond, Assistant Professor of Pediatrics at Albert Einstein College of Medicine in the Bronx, NY, spoke on "Pediatric HIV Infection and Developmental Disabilities." Dr. Diamond is working with Dr. Herbert Cohen at Einstein, doing some of the most recent research in the area of pediatric AIDS. These researchers have identified an AIDS embryopathy, although this has not been seen in other populations. Dr. Diamond outlined the specific impact the virus has on the developing child and demonstrated the correlation between the severity of the symptomatology and the loss of developmental milestones.

Dr. Diamond was followed by his associate at Einstein College, Ms. Jeanette Grosz. Ms. Grosz is a senior social worker for the AIDS Developmental Unit at Einstein. She discussed the complex issues associated with program development for children with AIDS and stressed the need for providing support to the families of these children.

Dr. Piotr Kozlowski, a research scientist from the Institute for Basic Research on Staten Island, NY, addressed the topic, "Central Nervous System Involvement in Pediatric AIDS." Dr. Kozlowski outlined specifically how the HIV attacks the central nervous system, and the medical implications of this disease.

Gary McCunn, coordinator of the Regional AIDS Training Center from the State Education Department, addressed the legal aspects of AIDS infected children in the public schools. He also discussed the educator's role in the prevention of the disease and in community awareness and sensitivity.

The presenters allowed a great deal of time for discussion and did a fine job fielding some very difficult questions as well. Conference attendance was about 100 persons, more than originally anticipated, and indicates the great interest in the topic. The conference evaluation forms were overwhelmingly positive, regarding the presenters and topics.

Closing remarks were made by Patsy Dodge, which ended a day that was fascinating and yet disturbing at the same time. ■

IN MEMORIAM Sidney VanDusen

On March 12, 1989, Sidney VanDusen passed away. Mr. VanDusen was one of the Board of Governors of our Warren/Washington Chapter and a past President and Vice President of the Chapter.

He was extremely active at the Chapter level and involved in numerous community affairs.

Our entire Association extends our condolences to the VanDusen Family. ■



Casey Preston learns the skill of make-up under the guidance of Lori Gifford, Instructor.

"Life Skills Training"

In September of 1987 a program called "Life Skills Training" was launched as a cooperative venture of the Fulton County ARC and Gloversville and Johnstown School Districts.

Twelve students, aged 16 to 21, all of whom are multiply handicapped or mentally retarded are enrolled in the program this semester. Components of the program include Academics, Daily Living Skills, and Vocational Readiness.

The Academic portion takes place at Gloversville High School where the students are mainstreamed on an individual basis. The students as a group are involved in mainstreaming experiences in adaptive physical education, art, music, and home economics.

At the Gloversville High School site the students are taught skills such as the value of coins by a certified special education teacher and a teacher's aide. The skills are then applied to practical problems in an apartment daily living program or in a vocational setting.

The Daily Living Skills component, staffed by an instructor and two aides employed by Fulton ARC, takes place in a three-room apartment leased and especially furnished for this program. The apartment is located in downtown Gloversville, centrally located for easy accessibility to community resources.

Participants in the Daily Living portion of the program learn to cook, clean, plan

meals, prepare shopping lists, compare prices, pay and count their change, store the items, prepare the meals and eat together — all the time learning to interact appropriately with their peers and in the world.

A major focus of the daily living training is in the use of the community resources, such as the post office, library, banks, stores, and public transit.

The third component of the program, Vocational Readiness, is also staffed by Fulton County ARC's instructors and aides.

Students receive vocational readiness training depending upon their individual needs.

The experiences may be vocational tasks in the classroom, on-the-job training at the sheltered workshop, or touring local factories and businesses.

Vocational training may also be hands-on experience. This semester students gained volunteer experience at an Office for Aging meal site and a local day nursery.

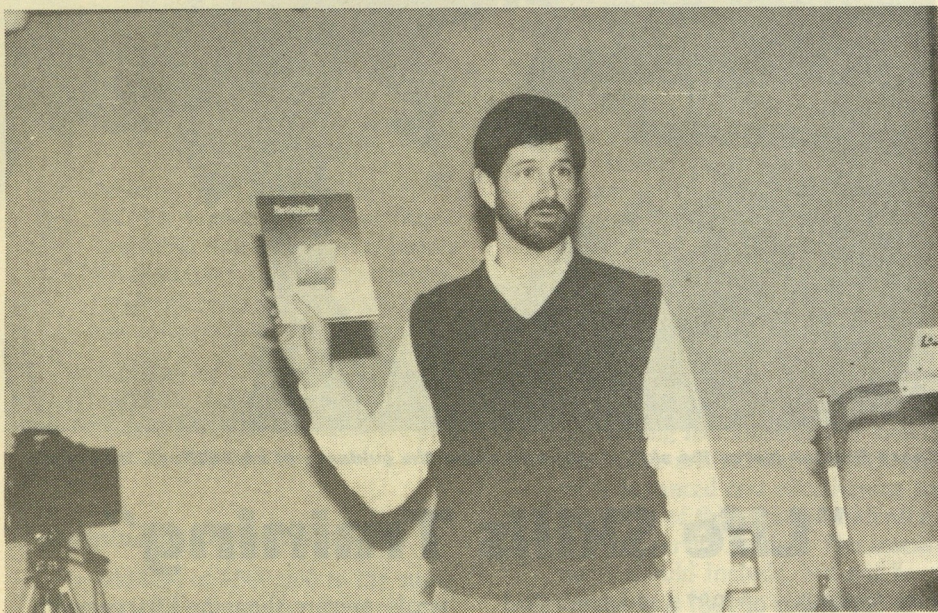
Following graduation from high school, students are referred to appropriate vocational programs. For some students, this may be the traditional sheltered workshop. Others may be placed directly into competitive employment as part of Fulton County ARC's special "aging out" Supported Work Program.



Ray Fox considers the answer to a question posed by Gloversville High School Instructor, David Smith, while Instructor Teresa Barbuto looks on.

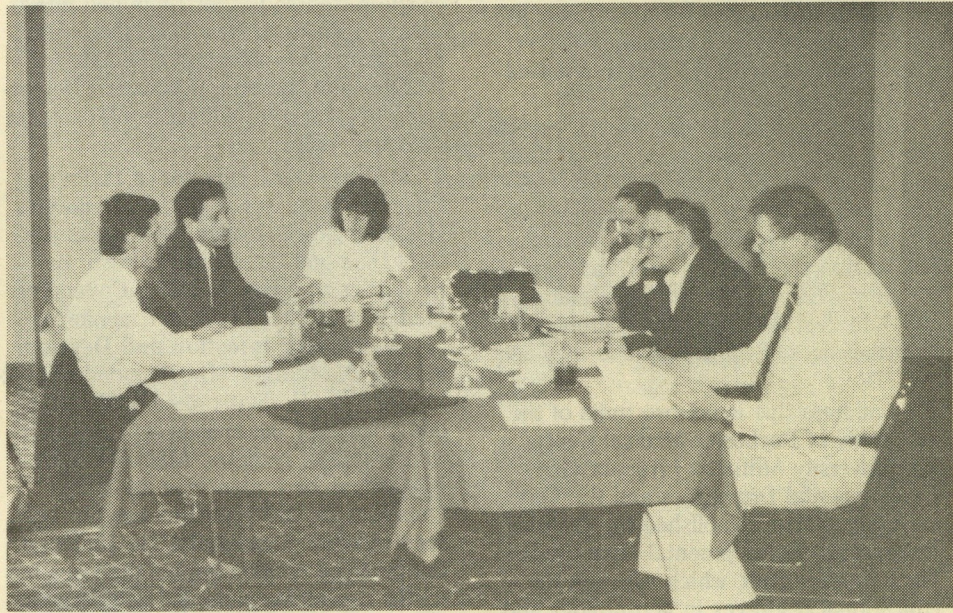
NYSARC COMMITTEES

... AT WORK
... IN ACTION



Chapter Resource Committee

Les Parker, Executive Director, Essex County Chapter, demonstrates desk-top publishing software to Chapter Resource Group Meeting in Syracuse.



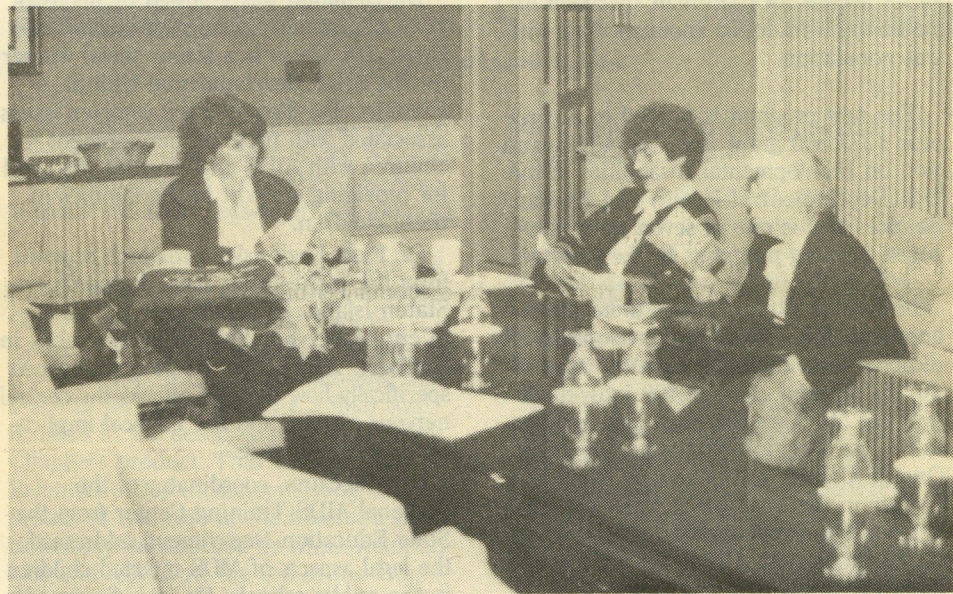
Adult Services Committee

Adult Services Committee meet on May 5, 1989 in Rochester, New York. (L to R): Joseph Poliquin, John Kemmer, Bonnie Bowes, Lyle Lehman, John Keller, and James Mroczek.



Family Support and Outreach Services Committee

(L to R) Henrietta Messier, Ellie Pattison and Jodi Rosenhein-Atkins at a recent Family Support and Outreach Services Committee Meeting on May 5, 1989.



Nominating Committee

Nominating Committee Members (L to R) Ellen Owens, Patricia Campanella and Audrey Strickland discuss 1989 slate of officers at a May 5, 1989 meeting.



Guardianship Committee

Members of the NYSARC Guardianship committee gather at their March 1st meeting to wish Paul Dhalle a fond farewell as he steps down from serving as Chairperson for the past four years.

Left to Right: Ellen Owens, Erie County Chapter; Gene Flagello, Community League Wassail D.C. Chapter; Paul Dhalle; Peter Pierri, Executive Director, Ulster County Chapter; James Hayes, Broome-Tioga County Chapter and new Chairperson of the Committee; Deborah Weiss, Monroe County Chapter and Erica Berman, NYSARC Staff.



Scholarship and Awards Committee

Scholarship and Awards Committee Members (L to R) Cheryl Englert, Betty Butz and Kay Nogaj review 1989 Scholarship Applications at May 5, 1989 Committee Meeting.

UARC Participates in "Fragile X" Pilot Program

Ulster Association for Retarded Citizens staff is undergoing special training as part of a statewide pilot program that will help identify males who may be retarded as a result of a genetic disorder only recently recognized as the most common hereditary form of mental retardation, said Peter Pierri, the agency's Executive Director. Marcene Basch-Johnson, Director of UARC's ARC Center School, said that the State Office of Mental Retardation and Developmental Disabilities (OMRDD) asked UARC officials to participate in Phase II of a screening project initially undertaken by OMRDD's Institute for Basic Research at state-operated programs.

The state now is expanding the screening into private agencies that serve people who are developmentally disabled, said Basch-Johnson, UARC's coordinator for the project.

UARC, which serves approximately 700 people from birth through adulthood who are developmentally disabled, was asked by the state to participate for Ulster County, Pierri said.

Pierri said that training is scheduled to begin within the next few weeks to help nurses and staff identify several distinguishing physical features unique to males who are retarded as a result of the "Fragile X" genetic disorder.

The distinguishing characteristics include among others notably large ears and short inter-eye distance. Once a client is identified based on the physical criteria, a consent for blood testing would be sought from the client's family or guardian, Pierri said. The blood test would determine the presence of the Fragile X chromosome.

In the last five years, the Fragile X Syndrome has been recognized as the most common hereditary form of retardation. It is second in occurrence after Down's Syndrome as a leading cause of mental retardation.

It is called Fragile X Syndrome because of the appearance of the X chromosome under the light microscope. Fragile X has a prevalence rate of about 1/1,350 males. Approximately twice as many females are carriers. About one-third of the females are affected and manifest some of the clinical features, such as mild retardation, according to OMRDD data.

The latest available prevalence data suggest that five to ten percent of mental retardation among males is due to Fragile X. Additionally, Fragile X has been found in 10 to 15 percent of autistic persons. Thus, Fragile X is a very common and significant cause of mental retardation, according to OMRDD officials. Since researchers have only recently come to understand the syndrome, most cases have not been identified yet, Basch-Johnson said.

The pilot screening project is considered a primary method toward prevention of mental retardation, OMRDD officials. The families of affected persons can be tested and females identified as carriers of the Fragile X chromosome can be counseled about the risk of bearing a child with Fragile X Syndrome, Basch-Johnson said. UARC serves more than 300 adult men who are developmentally disabled, but the exact number of men who could be effected is still being evaluated, Pierri said.

OMRDD officials said that families of persons with Fragile X Syndrome deserve to have accurate testing done to identify the affected individuals and those females who are at risk of giving birth to a child with Fragile X. Identification of those affected couples with testing and counseling can lead to the primary and secondary prevention of Fragile X Syndrome, hence relieving families of a tremendous emo-

tional burden, according to OMRDD. The Institute for Basic Research and UARC will collaborate to identify males with the Fragile X Syndrome, provide outreach to and testing for their families and provide referral for genetic counseling to interested female carriers.

For further information, contact UARC at (914) 331-4300. ■

UPCOMING CONFERENCES

1. NYS Bar Association

Theme:

"Representing People with Disabilities"

Date:

June 2, 1989

Place:

New York Penta Hotel

For more information contact:

Pete Danziger, Esq.
Program Chairperson
O'Connell and Aronowitz
100 State Street
Albany, New York
(518) 462-5601

or

NYS Bar Association
(800) 582-2452

2. Young Adult Institute

Theme:

"Working Effectively with Families: A Comprehensive Training Program for Parents of Infants and Young Children with Developmental Disabilities"

Date:

June 15-16, 1989

Place:

Young Adult Institute
460 West 34th Street
New York, New York

For more information contact:

Jordana Zeger
(212) 563-7474

3. Unit Cerebral Palsy Association of Nassau County, Inc.

Theme:

4th Annual Long Island Sibling Day Conference

Date:

September 23, 1989
9 a.m. to 3:30 p.m.

For more information contact:

Robert Pasfield, C.S.W.
Project Coordinator
UCP of Nassau County, Inc.
380 Washington Avenue
Roosevelt, New York 11575
(516) 378-2000 - Ext. 285 ■

New York State Association for Retarded Children, Inc.

SAFETY GROUP MANAGEMENT COMMITTEE

Commends those chapter employees whose individual actions have prevented loss of life or saved the life of another. These actions often undertaken despite personal danger manifests the strength of character, self sacrifice and respect for human life shared by all NYSARC Staff.

RICKY HOLLENQUEST

On May 19, 1989, Mr. Hollenquest saved the life of a client by applying the Heimlich Maneuver. The client, who had been choking, lost consciousness as Mr. Hollenquest arrived at the scene. Ricky is employed by the New York City Chapter.

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ASSOCIATION CALENDAR OF EVENTS



October 25-29, 1989

Kutshers Country Club

Monticello, New York

JUNE

- 13 Family Support Services
Committee Meeting
Delmar, New York
- 23 Resolution Committee
Meeting
Delmar, New York
- 29 Community Residential
Services Committee
Meeting
Onondaga ARC
Syracuse, New York

JULY

- 13 Public Information
Committee Meeting
Delmar, New York
- 14 Youth Committee Meeting
Delmar, New York
- 22 Ad Hoc Committee on
the DD Offender Meeting
Delmar, New York

AUGUST

SEPTEMBER

- 1 Resolutions Committee
Meeting
Delmar, New York
- 14 Public Information
Committee Meeting
Albany, New York
Chapter Public
Information
Resource Meeting
Albany, New York
- 15 Supplementary Recreation
and Special Olympics
Committee
Meeting
Delmar, New York
- 20-21 NYSARC Conference on
Prevention
Sheraton Inn and
Conference Center
Utica, New York

OCTOBER

- 25-29 Board of Governor's
Meeting and 40th
Annual Convention
Kutshers Country Club
Monticello, New York
- 25 Scholarships and Awards
Committee Meeting
Monticello, New York

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