

OUR Children's Voice

Retarded Children Can Be Helped

ASSOCIATION ANNUAL CONVENTION ACCLAIMED A SUCCESS

Largest attendance ever to hear Banquet Speaker, Gordon Ambach and Keynote Speaker, Clarence Sundram

Over 600 individuals registered and were in attendance at the recently held NYSARC, Inc. Thirty-Sixth Annual Convention. The Convention was held at the Grossinger's Hotel in Grossinger, New York from Thursday, October 24 to Sunday, October 27, 1985. Recognizing the thirty-six years of providing support and services to children and adults who are mentally retarded and/or developmentally disabled, the Convention theme for 1985 highlighted the achievements of the Association through its chapters' programs.

Helping to salute the efforts of the Association, those in attendance had over

New York State Association for Retarded Children, Inc.

Salutes Its Programs "Making It Happen" 1985 Convention

Thursday, Friday, Saturday and Sunday
October 24, 25, 26 & 27, 1985

Grossinger's Hotel
Grossinger, NY 12734



43 workshops to choose from. Included in the array of workshops were demonstrations of the Association's activities, programs and services. A film forum and numerous exhibits were also part of the convention activities.

The General Assembly gathered on Friday night, October 25, 1985 to hear the beautiful and touching words of Katie Cassidy. Her message set the tone for the convention and reinforced to all the purposes and objectives of our Association.

The Chairman of the NYS Commission on Quality of Care for the Mentally Disabled, Clarence J. Sundram, delivered the keynote

1986 NYSARC, Inc. Legislative Platform Adopted at the Annual Convention

At its thirty-sixth Annual Convention, the Delegate Assembly representing the membership of the NYSARC, Inc. sixty-four chapters approved the Association's 1986 Legislative Platform. Commenting on the adopted platform, the Chairman of the NYSARC, Inc. Legislative Committee, Mr. John Bryant said, "the platform does not include all of the areas that we would like to see covered but in the opinion of the Board of Governors as well as the delegate body of the Association, it represents the most important elements of legislation that we feel should be conducted by the Legislature this year."

The following is a brief overview of the adopted NYSARC, Inc. 1986 Legislative Platform.

continued on page 6

address. His message stressed the complexity of the developmental disabilities system and reinforced the role and responsibilities of parents within the system.

Election of Officers and Board of Governors to the State Association was carried out. The General Assembly began their Saturday morning session with a meaningful film presentation 'Mitchell Creates His Own Miracle.'

The most important business transacted at the General Assembly was the review and adoption of the Association's 1986 Legislative Platform. The Platform is reported in detail in this issue of O.C.V.

The Convention festivities were highlighted at the Annual Banquet. Commissioner Arthur Y. Webb of the NYS Office of Mental Retardation and Developmental Disabilities was present to offer greetings. The main banquet speaker was the Commissioner of Education and President of the University of the State of New York, Gordon M. Ambach. Commissioner Ambach addressed the Association concerning the direction of New York State in the areas of Special Education and Vocational Rehabilitation.

From the many comments that have been received in our State Office concerning the 1985 Convention, it appears to have been a huge success. The President of the Association, David B.

Lettman, commenting on the Convention said, 'While there were many changes in this year's Convention format, the traditions that have made our Convention the success that it always is remained intact. There are many people who should be thanked for their efforts, our staff, our various committees who participated in the planning and those volunteers who helped at the Convention.'

Next year's Convention will be held from October 23 to October 26, 1986 at the Concord Hotel in Kramers Lake, New York.

IN MEMORIAM

Robert J. Hodgson
Past NYSARC, Inc. President

It is with a sad note that we inform our Association of the passing of Robert J. Hodgson. Bob served as the President of the NYSARC, Inc. from 1969 to 1972. He dedicated his time and energies assisting persons who are mentally retarded and their families through his legal counsel.

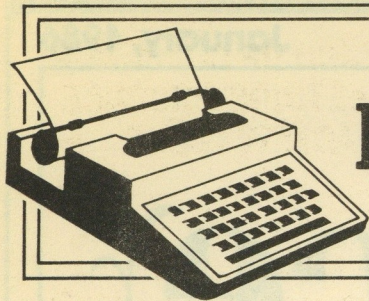
Among his other activities on behalf of the Association, he served as President of the N.Y. Retardate Trust, President of the Erie County Chapter, member of the NYSARC Legal Committee, was Western Regional Vice President from 1966 to 1969 and was appointed Senior Vice President of the Association from 1967 to 1969. Well known for his work in guardianship, Mr. Hodgson served as chairman and member of the Guardianship Committees for both the State and National Association's for Retarded Children for many years.

Among his many contributions in the legal field, he lectured and authored numerous articles on guardianship. Serving as a member of the Advisory Council to the Joint Legislative Committee on Mental and Physical Handicaps since 1965, Mr. Hodgson was instrumental in the development and passage of Article 17-A pertaining to guardianship of persons who are mentally retarded which has enabled thousands of families to provide for the future well-being of their children.

We send our sincere condolences to his wife Shirley and the immediate family. Bob is already missed.



Jonathan Weingold enjoys looking at photographs and gathering information at Chautauqua County ARC's exhibit booth.



EDITORIALS

Community Residences Admission Criteria vs. Quota System

Since the late 1960's, community-based residential programs operated by chapters of NYSARC, Inc. and other voluntary organizations have provided safe and comfortable homes for children and adults who are mentally retarded and/or developmentally disabled in New York State. In the late 1960's, realizing the need for the development of community residences, the State Association strongly advocated for legislation which would help provide such homes. In 1967, a law was passed (Chapter 576) which established what was then known as the 'Hostel Program.' One of the main purposes of that legislation was then and still remains to provide an alternative to institutionalization.

Initially, the growth of the community residential program was very slow and only a handful of homes were opened between 1967 and 1969. By 1972, the placement of persons from institutions into community programs, commonly termed deinstitutionalization, became a national and statewide movement. The development of new homes grew rapidly between 1969 and 1980. The NYSARC, Inc., through its sixty-four chapters, alone serves over 3,000 individuals on a daily basis within a full continuum of residential services. There are today, over 1,500 community residences certified by the New York State Office of Mental Retardation and Developmental Disabilities.

The initial intention of our Association in developing the legislation which ultimately became the Community Residence Law was to provide parents with an alternative to having to place their son or daughter in a state institution. While our Association acknowledges the need to provide community placement to those in need or desiring such placement from the developmental centers, it strongly opposes any quota system. Such a process has been in place since the deinstitutionalization movement started in the early 1970's. Such a system, while contrary to the initial intent of the law, discriminates against the very individuals that our Association is attempting to serve.

The problem arises when a community agency applies for start-up funding when they are opening a community residence. A contract is drawn which states that in order for the agency to receive the funding, a specified number of individuals has to be taken by the agency from the developmental center. In almost all instances, the requirement is fifty percent of the capacity of the home being developed. In other words, for every community placement into the home there must be an equal placement from the developmental center. This quota system is unfair, discriminatory and is beginning to cause poor groupings due to the different developmental and programmatic needs of two populations.

The quota system is also aggravating a growing waiting list of individuals residing in the community who need a com-

munity residence. It is as if we are going to deinstitutionalize our developmental centers only to cause institutionalization of community clients due to no available placements in a community residence. As reported in the last issue of OCV (Third Quarter 1985), OMRDD issued a report, their own report, indicating that there are 15,700 persons on waiting lists in the community.

Among the findings of the report was that practically every county in the state reported some individuals waiting for residential care. The greatest demand for residential care came from young adults transitioning from education programs to adult-oriented services.

The legislature in responding to this problem during the 1985 Legislative Session passed a bill in each of the houses. The Assembly passed A.2511-A. The Senate passed S.813 which was not amended. The Assembly bill that was amended and passed was sent to the Senate Rules Committee which took no action prior to recessing.

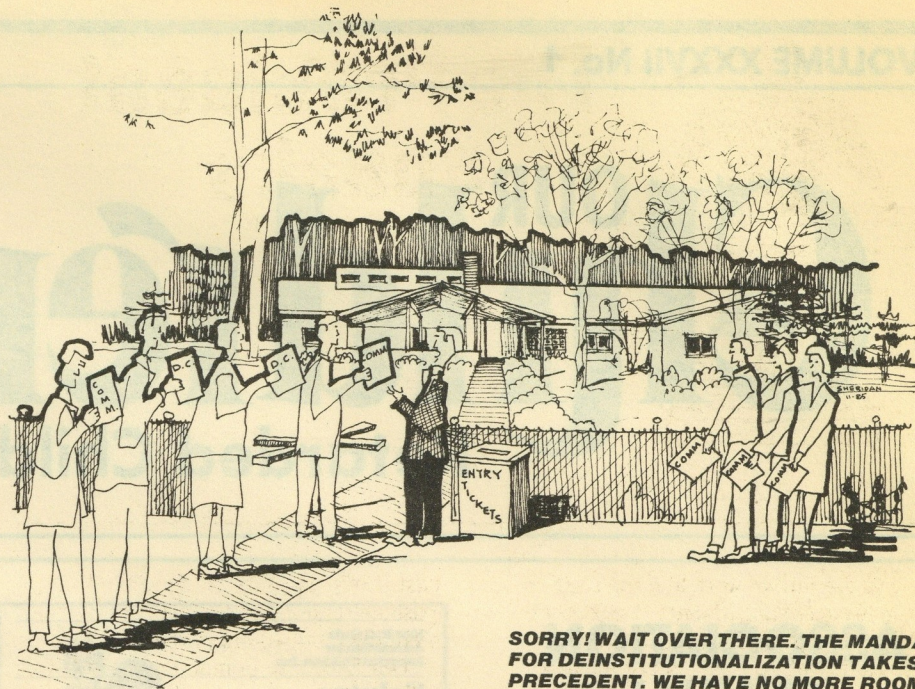
The Assembly bill that was passed has language that states that "for each placement developed in a community residential facility by the Office for individuals who have previously resided in a developmental center for a period of more than two years, at least one other placement must also be developed for individuals who have not so resided."

While the intention is not to have a 50-50 ratio in each house but to have a 50-50 ratio on a statewide basis, our Association finds this bill unacceptable. Placement into a community residence should be made based upon clinical decisions after considering such things as age, sex, medical condition and functioning level to name but a few. Placement should not be made based upon where someone resides.

Our Association has requested both the Senate and Assembly to further amend their bills to include language that would state "admissions criteria for community residential placements shall not discriminate on the basis of prior residency in developmental centers or in family homes."

While the Association recognizes the need of an appropriate placement of individuals residing in developmental centers, the thousands of individuals needing community residences and residing in the community need to be immediately addressed. The quota system is unconstitutional and must be replaced by an admission criteria which assist the parents, the aging-out problem and most of all the individuals living in the community who need the residential placement.

The Legislature has an excellent opportunity to help New York State's disabled family during the 1986 session. The thousands of disabled individuals in need of placement do not need a quota system, just a home in their community.



SORRY! WAIT OVER THERE. THE MANDATE FOR DEINSTITUTIONALIZATION TAKES PRECEDENT. WE HAVE NO MORE ROOM - MAYBE NEXT TIME!

HANDICAPPED CHILDREN - IS ANYONE LISTENING?

For the last several years, this Association has been working with numerous other organizations including the Association of Counties to get legislation that will begin to address the problems of preschool and summer school education.

Two years ago, after a great deal of discussion, this Association along with all of the major advocacy groups, the Association of Counties, the New York State Education Department and finally the New York State School Boards Association supported and worked toward the passage of S.1246 and A.6973.

S.1246 B passed the Senate with the Assembly Bill never getting out of the Education Committee. Furthermore, to complicate the situation even more, the Governor came out with a Program Bill which while it was similar to S.1246 regarding summer school, the preschool segment was much different and caused much concern for us as to some of the proposals.

We understand and sympathize with the position of the counties. We have always felt that education should, for all

children, fall under the responsibility of the State Education Department and the local schools. Children, who because of the seriousness of their handicapping condition, require a more intense twelve-month educational program should have access to it. Educationally, it makes sense and PL 94-142 mandates that it be available. It makes absolutely no sense for parents to have to go to court to obtain those necessary services for the months of July and August. For a concrete example of this problem readers are referred to the article in this OCV entitled "Children Target of Delaware Cost Cutting."

S.1246 and A.6973 does in no way correct all of the issues but with its passage, a major step toward resolution will be taken. It is time now for some serious talk amongst the Assembly, the Senate and the Governor's office to resolve this problem. On behalf of the disabled children in this state who are in need of these services, we are imploring the Governor and the Legislature to take the necessary action required.

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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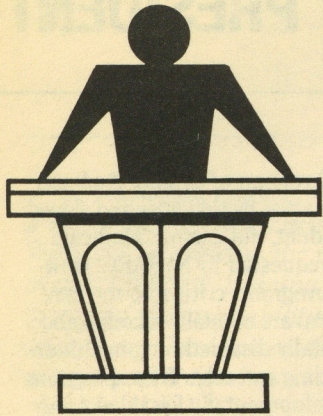
Sadieann Mazzotta

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

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The President Speaks

The following address was presented by NYSARC, Inc. President, David B. Lettman, to the Board of Governors at the 1985 Annual Convention:

"The amount of work and the result of the many accomplishments of our Association over this past year would take pages to report. As President of the Association I am constantly, almost daily, made aware of the feelings of our chapters and the concerns of many that our Association has and is becoming strongly centralized. Nothing could be further from the truth and, in fact, over this past year there has even been a definite effort to give our chapters more of a say and responsibility than ever before.

Examples upon examples more than demonstrates the Board of Governors' desire to allow our chapters the flexibility and creativity that all of us recognize exists in our Association. Perhaps nothing can better demonstrate this point than the revision of NYSARC's Real Estate Policies and the enacted NYSARC's Minimum Insurance Standards for all chapters.

Prior to the revision of NYSARC's Real Estate Policies, chapters could not establish or use holding companies unless they were needed for purposes of reimbursement. With the approval of the new policies, chapters can form and use holding companies for any real estate transaction regardless of the reimbursement formulas. In addition, the chapters own Board of Governor representatives can attest to the condition and value of the property as opposed to NYSARC state staff as the old policy called for.

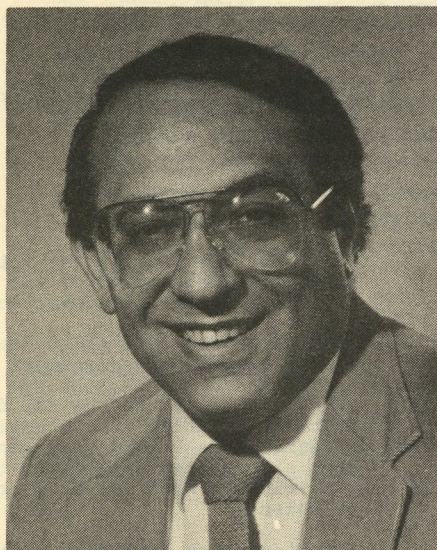
In the NYSARC Policy on Minimum Insurance an Ad Hoc Committee established a set of standards along with the Executive Committee and Board of Governors, allowing for chapters to use their own local brokers or any company they so desire. In addition, the Association was successful in getting the additional premium charges to be reimbursed through our chapters' budgets.

Our Proposed Chapter Model By-Laws is but another example as to how the State Association wants our local chapters to have both flexibility and control of their programs and governance. These are but just a few of the ways in which our Association is attempting to strengthen our chapter's individual management and decision making while providing a secure, safe framework which protects all of our chapters collectively.

While I am fully aware as your President that the many changes taking place within our Association are often times not either understood or felt to be in the best interest of our chapters, I feel strongly that time will reinforce their place in our Association. At times, change can be painful and change for its sake alone is not productive. As your President, however, I feel strongly that the change our Association has embarked upon is not misdirected or unnecessary, but mandatory if we are going to insure that the system and programs established over the

past thirty six years are to remain in existence and insure that persons who are mentally retarded are properly served.

Our Executive Committee recently met with the Commissioner of OMRDD and his staff and I believe that our meeting as well as numerous others that our state staff are and have been involved with, demonstrates how government in this state recognizes our efforts. The actions, the approach, and through the determination of our Executive Director, as well as the integrity and professional capability of our State Association's staff, the Office of Mental Retardation, the Commission on Quality of Care, and other regulatory agencies are turning to our State Association when problems arise, rather than either attacking our chapters individually or embarrassing us publicly. I believe the attitude being shown by all these groups is a strong indication of the correctness of the direction we are going in. Our collective strength is being recognized and respected.



During this past year, I have had the opportunity to work very closely with our Executive Director and to see first hand the dedication and real professional competencies of our State Association Staff. While many may be concerned, many more have over this past year turned to our State Association for technical assistance and guidance in such areas as cash flow problems, rate appeals, budgetary and personnel problems. As President I know I am joined with the vast majority of our Chapters in thanking all of the staff for their efforts and professionalism.

I would like to express a very special thanks to all of our Committee Chairs and Committee members. This past year was most difficult for many of our committees as we changed our process and committee structure. The end result, however, in allowing the Board of Governors to set goals, has given our Committees a real purpose and holds our Executive Director responsible for carrying out these goals

as objectives of our Association. Our Committees remain the backbone of our Association and have effectively functioned through the changes we have made.

While I am most appreciative of all of our Committee Chairs and members, I want to especially thank Warren Heilbronner who chairs our Legal Committee. His time and efforts that he gave to our Association, first in the revision of our State By-Laws and most recently in the drafting of our Model Chapter By-Laws is but one example of the dedication and time given by our Board Members and volunteers. A very, very special thanks also goes to our past Chairperson of our Education Committee, Betty Pendler. After over a decade of dedication, Betty has decided to step down from her chair role. NYSARC, Inc. has been served well by her timeless efforts and devotion to our Education Committee. I know the entire Association joins me in thanking her.

A very special thanks also must go to our Executive Committee. The intensity, sensitivity and dedication of this committee is a credit not only to each member, individually, but to you, the membership, for selecting this dedicated group of individuals.

I would also like to use this brief report to thank the many chapters who have provided me and my wife a cordial and sincere hospitality when the opportunity permitted our visitation to a chapter, a membership meeting, Board of Director meeting, Annual Dinner or other program social event we have also been treated and regarded with respect.

While I feel that overall the Association has accomplished a great many of its objectives during this past year there is much that is before us. One of the major goals will be to address our internal differences and to examine our structure. To this end, I am appointing an Ad Hoc Committee to bring back to the Spring Board of Governors' meeting its recommendations as to any changes or reinforcement to and the manner in which our Association is both structured and how it relates to our chapters.

Communication, as always, is a major process to educate, inform and provide input for and to our Organization, Regional Meetings will be continued, scheduled far in advance. A slide presentation is currently being developed which will enable our Regional Vice Presidents to better explain our Association to chapters in their region.

I have always welcomed the many comments that have been offered regarding any issue before our Association. To those who have written or called me during the year I sincerely say thank you for your concern and honesty.

There are still many problems facing our Association. As President, I am confident that our Association is attempting, in a systematic manner, to approach all these problems with integrity and honesty. My only plea, my only real calling to our members, is that each and everyone of us, the volunteers, the parents and non-parents alike, renew our dedication to our purpose and take a more active role in our Association.

Thank you all for a most interesting year. I hope I have served you well.

David B. Lettman

David B. Lettman

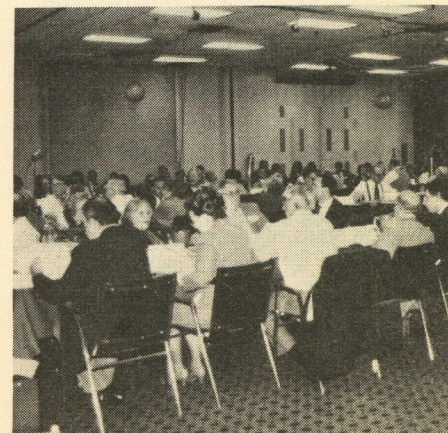
BOARD OF GOVERNOR MEETINGS PRODUCE ACTION ITEMS

The governing body of the NYSARC, Inc., the Board of Governors, met on Thursday and Friday, October 24 and 25, 1985 and again on Sunday, October 27, 1985. The Thursday and Friday meetings reviewed a number of items which were recommended to the Delegate Assembly.

The Thursday night Board Meeting had the majority of time reserved for the purpose of discussion of philosophical issues facing the Association. Over twenty-four Board members presented a variety of issues which will help the Association determine its direction over the next several years.

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

- Adopted the Chapter Model By-Laws.
- Approved a policy on Chapter names.
- Approved the entering into a lawsuit with the State of New York concerning the non-adherence to the law passed for capital development.
- Reviewed and recommended to the Delegate Assembly for approval of the 1986 NYSARC, Inc. Legislative Platform.
- Re-elected Shirley Valachovic as Senior Vice President.
- Elected Warren Heilbronner, Ellen Maroun and Ellie Pattison to be Members at Large to the Executive Committee.
- Adopted a resolution endorsing the concept of self-advocacy.
- Approved the preliminary request for a new chapter from Newark D.C.
- Adopted the 1986 Board of Governor Goals.
- Tabled the discussion on a Proposed NYSARC, Inc. Real Property Development Corporation.
- Approved the guidelines of the new Association's Incident Review Committee.
- Adopted a policy for chapters' use on Human Sexuality.
- Adopted a position on the Community and Family Living Amendments Act of 1985.
- Reviewed the response of the Commissioner of OMRDD to the NYSARC's Annual Report to the Commissioner of OMRDD on the Quality of Care in Developmental Center: A Parental Perspective.
- Approved the Spring Board of Governors' Meeting to take place in Albany.



Members of the Board of Governors' review information for discussion.

Letters To The Editor

Dear Editor:

The article on the Cleburne case in the past issue of OCV missed the major point: The decision is a disaster for the mentally retarded.

By its referral (6-3) to include the mentally retarded as a 'suspect group' we have been relegated for the foreseeable future, to second grade citizenship and indeed, 'suspect' by the community and the legislature who feel free to pass the 'Site Selection' law. It is an insult to every mentally retarded person.

If the Supreme Court had ruled that the mentally retarded deserve the same freedom from discrimination as blacks, women, religious beliefs and point of origin, we would need no one's approval to live where we wished, as all people should have that right. We would not be feared as quasi-lepers, begging, hat in hand, for the right to live in any neighborhood.

Let us never forget the Cleburne decision is a resounding, terrible defeat for the mentally retarded. The Justices (6 of them) have, in effect said, 'Yes, but not in my neighborhood.'

Sincerely,

Joseph T. Weingold

P.S. Cannot we once and for all tell OMRDD that C.R.'s are **not** subject to the same regulations as ICF/MR's? And if they do not modify this stand, we'll see them in court.

In my opinion, only in the Courts will we bring OMRDD to its senses.

OCV Welcomes letters from readers. Letters for publication must include the writer's name, address and telephone number. Because of the large volume of mail received, OCV reserves the right to limit the amount of letters printed.

Quote of the Quarter

"When I hear discussions in Albany about reconfiguring the system, about changing levels of care, about opening new beds and day program slots, I worry about the degree of looking at the human beings as numbers and quotas, as commodities to providers who need guaranteed revenue streams, as barriers to achieving plans of compliance with numerical goals set by court orders or federal plans."

Clarence J. Sundram
Chairman, NYS Commission on
Quality of Care for the
Mentally Disabled

Taken from Keynote Address to the General Session, NYSARC 1985 Convention.

GRAMM-RUDMAN AMENDMENT SIGNED BY PRESIDENT

On December 11, 1985, the Gramm-Rudman Amendment passed in both houses of the U.S. Congress. The next day, the bill was signed by President Reagan. As of this printing of OCV, the precise impact of Gramm-Rudman on programs serving persons who are mentally retarded and developmentally disabled is unknown. However, NYSARC is currently in the process of analyzing this piece of legislation in an attempt to gain a clear assessment of its impact on the citizens we serve.

Generally, the Gramm-Rudman Amendment would seek to balance the federal budget by limiting the size of the annual budget deficit. No similar limitation has previously existed. Rather, the U.S. Congress has been free to propose annual spending levels without regard to the amount of borrowing which would have to occur to pay for government programs. Gramm-Rudman, however, sets 'a maximum deficit limit' which declines over the course of five fiscal years until the amount of the annual deficit is zero and the budget is balanced. In order to accomplish this goal, there must be some combination of tax increases or program spending cuts. For the current federal fiscal year which began October 1, 1985, it is estimated that such spending cuts and tax increases will have to total 11.7 billion dollars.

In the original version of Gramm-Rudman all of the programs critical to the well-being of persons who are mentally retarded and developmentally disabled were vulnerable to substantial spending cuts. Recognizing this danger, NYSARC sent the following correspondence to 60 key U.S. Congressmen. The letter reads as follows:

Dear Congressman:

The New York State Association for Retarded Children (NYSARC, INC.) would like to express its strong opposition to the proposed automatic deficit reduction measure as originally proposed by the Senate known as the Gramm-Rudman Amendment. Preliminary information on this amendment indicates that it would have a devastating impact on long-established programs, services and benefits to the nation's mentally retarded and developmentally disabled citizens and would, for example, slash special education programs by 23% over the next five years.

NYSARC is an Association comprised of 64 chapters which operate programs and services in almost every county in New York State for over 21,000 mentally retarded and developmentally disabled individuals daily, guided by a membership of 46,000 citizens. As a major united service provider and advocacy organization, the well-being of these disabled persons is entrusted to our care.

We understand that select members of the Senate and House of Representatives have conceptually agreed to legislation to be passed by both houses and sent to the President for his signature. Since at this writing we do not know what measures were agreed to and the resulting fiscal impact on mental retardation services, we implore

your support in exempting basic programs of Medicaid, Special Education, Vocational Rehabilitation, Title XX Social Services, Housing-Section 2028, Developmental Disabilities, Supplemental Security Income and Maternal and Child Health from mandated budget reduction cuts.

We strongly urge you to carefully consider the impact of the Gramm-Rudman Amendment on the well-being of mentally retarded and developmentally disabled persons and ask you to ensure their right to a safe and productive life. This office stands ready to respond to any questions regarding this or similar provisions. Please call me at (518) 439-8311 for further information. Thank you.

Sincerely,

Marc N. Brandt
Executive Director

The responses received by the State Office included the following from Senator Lowell Weicker, Jr., Chairman of the Subcommittee on the Handicapped. The letter reads as follows:

United States Senate

WASHINGTON, D.C. 20510

December 9, 1985

Mr. Marc N. Brandt, Exec. Dir.
ARC of New York
393 Delaware Avenue
Delmar, New York 12054

Dear Mr. Brandt:

Thank you for your recent letter on the Balanced Budget and Emergency Budget Control Act of 1985, commonly referred to as the Gramm-Rudman Amendment to the Debt Ceiling Bill.

On October 10, 1985 the Senate approved the Debt Ceiling Bill, which included the amendment proposed by Senators Gramm, Rudman and Hollings. As you know, this amendment sets out a procedure to reduce the net federal deficit to zero by the year 1991. While such a goal is worthwhile, the procedure identified is ill-advised, and would transfer to the President much of Congress' authority to control expenditures in a way that clashes with the Constitution's system of checks and balances.

I believe that this is a very ill-conceived plan. The President currently has all the authority necessary to submit a balanced budget if such were his desire. In addition, the Congress has the vehicle of the current budget process to establish deficit targets. The amendment is thus a statement that neither the President nor the Congress has been able to exercise fiscal constraints.

This amendment was essentially drafted on the floor of the Senate, and its substance was never considered by Committee. It contains broadly-drafted language, the precise effects of which are unknown. It is for these reasons that I voted against the amendment every time the Senate has considered it.

I appreciate your sharing your concerns with me on the potential effect of the Gramm-Rudman Amendment on programs for the disabled. Please be assured that I will keep your views in mind as I continue to oppose this amendment.

Sincerely,

Lowell Weicker, Jr., Chairman
Subcommittee on the Handicapped

IRENE PLATT INSTALLS ASSOCIATION OFFICERS AND GOVERNORS LETTMAN RE-ELECTED AS PRESIDENT

At the Thirty-Sixth Annual Convention, the Delegate Assembly representing the sixty-four chapters and the over 46,000 members of the NYSARC, Inc. elected the Officers and Board of Governor members of the Association.

At the banquet held on Saturday night, October 26, 1985 the Immediate Past President of NYSARC, Inc. and current Commissioner of the NYS Commission on Quality of Care for the Mentally Disabled, Irene L. Platt, Esq. installed the State Officers and Board of Governors.

In her remarks, Commissioner Platt stressed the ever increasing role that Board members play as well as their responsibility to the Association.

The Officers elected for a one-year term

are as follows:

David B. Lettman
President

John Bryant
Vice President - Central Region

Shirley Valachovic
Vice President - Northeast Region

Bernice Volaski
Vice President - Southeast Region

Audrey Strickland
Vice President - Western Region

George G. Hirsch
Treasurer

Mary L. Caniano
Assistant Treasurer

Sadieann Mazzotta
Secretary



David B. Lettman raises his right hand to take an oath as Commissioner Irene Platt officially installs him as President of the New York State Association for Retarded Children, Inc. for 1985-1986.

GENESEE COUNTY NOMINEE RECIPIENT OF 1985 EMPLOYER OF THE YEAR AWARD

Each year, chapters throughout New York State are encouraged to recognize an individual, corporation or business in their communities that have demonstrated outstanding support and assistance in providing services and job opportunities to individuals who are mentally retarded.

This year, P.W. Minor & Son, Inc. nominated by the Genesee County Chapter was selected as the recipient of the 1985 Employer of the Year Award for its meritorious and outstanding efforts on behalf of persons who are mentally retarded.

This organization has been used as a successful work experience site for preparing individuals for competitive employment in the area of leather cutting, stitching and shoe finishing. Duties include cutting leather for soles of shoes, oper-

ating stitching equipment to sew shoes and lacing and dying shoes for completion. P.W. Minor & Son, Inc. has continually supported the Genesee County Chapter by hiring persons with disabilities on a regular basis and providing meaningful work for the Chapter's workshop.

This company has demonstrated a strong and vital commitment to the mentally retarded. The company's caring, unselfishness and willingness to work cooperatively with the staff and clientele of the Genesee chapter have earned the respect and recognition they justly deserve.

Mrs. Dyder Smith, Personnel Director of the P.W. Minor & Son, Inc. (left) and Genesee County ARC Executive Director, Thomas Glair (right) proudly display the 1985 Employer of the Year award.

Mrs. Dyder Smith, Personnel Director of the P.W. Minor & Son, Inc. (left) and Genesee County ARC Executive Director, Thomas Glair (right) proudly display the 1985 Employer of the Year award.



ICF SELF-PRESERVATION: STILL TROUBLESOME

Despite OMRDD's recent communication with the provider community, wherein, the New York Congressional Delegating providers and advocates were praised for their efforts to bring about a resolution to the self-preservation crisis in certain Intermediate Care Facilities, the HCFA transmittal #169, now over a year old, is still the cause of unrest. As of this writing, although the 1985 Life Safety Code has been published in the Federal Register for comment and its adoption is imminent, providers (some of which are NYSARC, Inc. Chapters.) are still plagued with "self-preservation" problems which unfortunately, can only be resolved through legal action or political action.

Our Association commends Senator Daniel Patrick Moynihan and his staff for their tireless efforts to bring an end to this crisis. NYSARC, Inc. credits Senator Moynihan and the Senate Finance Com-

mittee for forcing the Department of Health and Human Services and the Office of Management and Budget to finally publish the 1985 Life Safety Code in the Federal Register. We believe this action was moved by the persistence the staff of our State Office, Faye Drummond of the Senator's staff, as well as the many letters and phone calls to the New York Congressional Delegation from members of the Association and other provider and advocacy organizations.

We have printed Senator Moynihan's response to the Association's efforts in hopes that his staff can be of assistance in resolving any "eleventh hour" problems which may develop prior to the adoption of the 1985 Life Safety Code and also to inform our Association of the understanding and responsiveness of the Senator to this tragic situation.

DANIEL P. MOYNIHAN
NEW YORK

United States Senate
WASHINGTON, D.C. 20510

October 23, 1985

Dear Mr. Brandt:

As you no doubt know, last November the Health Care Financing Administration (HCFA) issued regulations redefining the term "self-preservation" for the mentally-handicapped, and in so doing has required that all residents of any intermediate care facility for the mentally-retarded (ICF/MR) be fully ambulatory and able to move without staff assistance to a safe place in case of fire. Any resident who cannot meet this standard would have to be "promptly relocated." Such guidelines, however laudable in theory, could seriously undermine efforts to place mentally-retarded Americans in intermediate care facilities.

New York State has its own, very strict, fire safety code for these facilities. The New York State code does not require that every patient be fully ambulatory or able to move independently; rather, it requires that all residents be able to move to safety within two-and-one-half minutes after a fire alarm sounds. Through November 1984, New York had successfully placed more than 3,000 mentally retarded persons in ICF/MRs without a single death or injury due to fire.

The National Fire Protection Association recently issued its 1985 Life Safety Code, which is much like the New York State code. New York is now working to incorporate the provisions of the new Life Safety Code in its community residence program. The new code, in my view, properly balances requirements for adequate fire safety in ICF/MRs with the goal of placing more mentally retarded individuals in such community residences.

Thus, on July 25 of this year, I joined 32 members of the New York Congressional delegation in a letter to Secretary of Health and Human Services Margaret Heckler, urging that New York State be permitted to apply its own fire safety code, incorporating the 1985 Life Safety Code, to secure Medicaid certification. I await the Secretary's response with great interest.

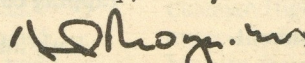
On September 17, I supported the provisions of the Senate Finance Committee amendment to the Consolidated Omnibus Budget Reconciliation Act of 1985, to direct the Secretary to recognize the 1985 Life Safety Code of the National Fire Protection Association.

In addition, Secretary Heckler has acted at our request to expedite the implementation of the 1985 Life Safety Code. This new regulation is currently being reviewed by the Office of Management of Budget.

In the meantime, I have received assurances from the Department of Health and Human Services that no mentally retarded residents of ICFs will be relocated until this serious problem is resolved to the satisfaction of all the parties involved.

Be assured, I will continue to monitor developments in this area very carefully. Please do not hesitate to contact me on this or any other matter.

Sincerely,


Daniel Patrick Moynihan

APPROPRIATIONS AND BUDGET

To support appropriate levels of funding through the appropriations and budget processes of all State programs that affect affirmatively the lives of persons who are mentally retarded and their families

This includes the reviewing and responding to the appropriations for the Office of Mental Retardation and Developmental Disabilities (OMRDD); the State Education Department - Office of Vocational Rehabilitation (OVR), and the Office of Education of Children with Handicapping Conditions; and selected appropriations for the Departments of Health, Social Services, Commission on Quality of Care for the Mentally Disabled and for certain other agencies whose programs affect persons who are mentally retarded.

The NYSARC will initiate a pro-active role that will advise, educate and encourage positive budget construction that will be responsible to the needs of those residents of New York State who are mentally retarded and developmentally disabled.

CIVIL PRACTICE LAW

Client Transfer/Placement

To promote legislation to amend the Civil Practice Law and rules in relation to appeals made by public officers to obtain stays on court orders for client transfer or placement.

This bill deletes the current provision of the law which allows that a state or municipal agency can obtain an automatic stay of any lower court order. This legislation would also amend current law such that the court must hear the case quicker than usual when the appellant is the state or a political subdivision of the state and has been denied a stay.

A.5469 was introduced during the 1985 legislative session. NYSARC supports this endeavor and will work toward obtaining Senate sponsorship.

EDUCATION LAW

A) High School Diploma

To promote legislation which would allow school districts to award to certain students a high school diploma annotated appropriately indicating that it was earned upon the successful completion of an Individualized Education Plan (I.E.P.).

Currently, students who, because of certain handicapping conditions, are unable to achieve competency requirements are denied the awarding of a high school diploma. Presently, the State Education Department allows three diplomas to be issued - a Regents diploma, a Competency diploma and an Equivalency diploma. For those disabled students who are unable to fulfill the requirements for these existing three diplomas, the issuance of an I.E.P. diploma would resolve this present form of discrimination. Therefore, we are recommending the passage of S.4305 and A.5793.

B) Least Restrictive Environment

To promote legislation that will require school districts who contract with the Board of Cooperative Educational Services (BOCES) to provide education for their children with handi-

capping conditions to host BOCES classes, within their district, when appropriate. Furthermore, legislation will be sought to prohibit the placement of children into segregated facilities based upon lack of space in public school buildings.

It has come to the attention of our Association that children with mental retardation as well as other developmental disabilities are finding themselves being educated more and more in segregated settings such as church facilities, office buildings, vacant school buildings as well as centerbased BOCES buildings because of a growing lack of space in public schools. This is no doubt a clear violation of the Least Restrictive Environment.

C) Loan Repayment/Scholarship Incentive

To promote legislation that would create a loan repayment and scholarship incentive program for professionals and students respectively in the clinical areas of speech-language pathology and audiology, physical and occupation therapies.

The New York State Association for Retarded Children, Inc. continues to experience difficulty in the recruitment and retainment of qualified licensed professionals, and in their compliance on a consistent basis with the regulatory requirements in this regard with the State licensing boards of the State Education Department. In brief, the difficulty arises in:

1. the inability to attract to rural areas, qualified licensed professionals in such areas as speech, physical and occupational therapy and psychology,
2. the increasing inability to meet competitive salaries for the required Master's level individual.

The Association proposes to create a loan repayment and incentive scholarship program in the professions of speech-language pathology and audiology, physical therapy, occupational therapy and psychology. These loan repayment and scholarships will be awarded based upon committed practice of the specified profession in human services, not-for-profit agencies which sponsor and operate either day treatment, day training, workshop, clinics, community residences, and intermediate care facilities for persons who are mentally retarded and/or developmentally disabled.

The loan repayment program would allow already licensed individuals to earn loan cancellation privileges for each year of service given in the human service, not-for-profit agency. The expansion of an existing educational loan program would include a 10% cancellation clause for each loan year. In this way, agencies need not wait a four or five year period until potential employees graduate. This would enable agencies to use the current existing work force.

D) Preschool/Summer School

To promote legislation that will begin to address the area of preschool education and to amend education law to allow for the extension of the school year beyond the 180 school day currently allowed for certain students with handicapping conditions.

Early intervention on behalf of children with developmental disabilities is a well-documented fact. However, the availability of the programs, the quality of the programs, and the transportation are but a few of the problems surrounding the edu-



Judith Schelle (left), President of the Fulton County A.R.C. Board accepted the New York State Legislative Resolution commending Lexington Center of Johnstown, New York, on the occasion of its 30th Anniversary, from Senator Hugh Farley (right) and Assemblyman Glenn Harris (center), who jointly drafted the resolution.

FULTON ARC RECEIVES LEGISLATIVE RESOLUTION

Fulton County ARC's Lexington Foundation, the development arm of the Fulton County Association for Retarded Children's Lexington Center, sponsored a dinner attended by over 200 on November 2nd at the Holiday Inn in Johnstown in celebration of Lexington's 30th Anniversary.

Irene Platt, Commissioner of the New York State Commission on the Quality of Care for the Mentally Disabled was the keynote speaker.

Recipient of special honor by the Lexington Foundation was George Madnick, a charter member of the Foundation Board and Past President and current member of the Board of Directors of the

Fulton County ARC. Madnick and his wife Mynn were cited as the parents whose concern initiated the effort that developed into today's Lexington as a response to the needs of one of their own sons who was turned away from the local school system 30 years ago because he was retarded.

With Lexington that evening were Senator Hugh Farley and Assemblyman Glenn Harris who presented a State of New York Legislative Resolution they had jointly sponsored to Judith Schelle, President of the ARC Board. That resolution commended Lexington on its 30 years of service to the developmentally disabled adults and children of Fulton County.

cation of these children.

There are students between the ages of 5 and 21 who because of their handicapping condition need to be in a school program beyond the 180 school days currently allowed under Education Law. Without this type of program these particular children tend to exhibit serious regression. Furthermore, the limiting of an educational program to 180 school days is contrary to the intent of federal law, PL 92-142.

During the last legislative session, S.1246B and A.6973 were introduced. While these bills did not mandate preschool education, they did begin to address some of our concerns. Our Association supported this legislation and will do so again.

E) Vocational Rehabilitation

To promote legislation to remove the Office of Vocational Rehabilitation from the New York State Education Department to a separate office in the Executive Branch called the Office of Rehabilitation Services.

The New York State Association for Retarded Children, Inc. has consistently been concerned regarding the delivery of vocational rehabilitation services under the direction of the State Education Department. The Association supported the program bill sponsored by the Governor to amend the Executive Law to establish a New York State Office of Rehabilitation Services in the Executive Branch of the Government. The bill prescribed the powers and duties of the new office. In addition, the bill called for an increase of funding to the SEP Program of not less than \$2,500 per client per year, with the \$1,000 increase considered "exempt" for purposes of calculating net operating costs under the Mental Hygiene Law.

The Assembly passed 5900-A. Senate Bill 3736 remained in committee. The Association will continue to urge the passage of this legislation.

MENTAL HYGIENE LAW

A) Community Residence

1. Admission Criteria

To promote legislation that will eliminate current practices of discrimination which allows for placement decisions into community residences based upon whether a person currently resides at home or in a developmental center.

Placement into a community residence should be made based upon clinical decisions considering such things as age, sex, medical condition and functioning level to name but a few. Placement should not be made based upon where someone resides.

During the previous legislative session, S.813 and A.2511-A were introduced, with S.813 passing the Senate. Our Association requested the amendment of these bills using the following wording "Admissions criteria for community residential placements shall not discriminate on the basis of prior residence in developmental centers or in family homes."

We will continue to oppose existing language in present bills and work toward the acceptance of our proposed language.

2. Rate-Setting Methodology

To promote legislation that will mandate that final rates be established for community residences prior to the opening of a community residence.

Community residences are now funded through a rate-setting methodology. Serious financial problems of considerable magnitude continue to plague our chapters as a result of having the final rates established well after the residence has opened up.

3. Site Selection

To promote legislation to amend the Mental Hygiene law to reduce the number of days that a municipality has in which to respond when a community residence is being proposed therein.

Currently, law allows forty days for a municipality to approve, suggest alternative sites or to object to the establishment of a facility for the mentally disabled. In many areas, particularly with large populations, it is extremely difficult to hold properties and often the properties are lost because owners do not wish to wait the forty days. In practice, it has been our experience that twenty days seems to be an adequate amount of time for a community to respond.

B) Developmental Centers

1. Co-location

To promote legislation prohibiting the co-location of persons who are mentally retarded and developmentally disabled with persons incarcerated in correction facilities.

The policy of co-locating persons who are mentally retarded with other individuals who are in custody of the criminal justice system commits a gross injustice against those who are mentally retarded. Our Association has worked diligently over the years to educate society to the fact that persons with mental retardation are not people to fear. To locate these individuals side by side on the same campus with persons in the criminal justice system only reinforces a very negative message and consequently does a great disservice to persons who are mentally retarded.

Additionally, having these persons in such close proximity to those incarcerated

poses a possible threat to their personal well-being and physical safety. We will continue to support the passage of A. 957-A and S. 957.

2. Establishment of an Ombudsman

Position in Developmental Center.

To promote legislation that would establish an independent advocacy position in developmental centers.

It has become apparent to this Association that there is a great need to address particular concerns that arise in a more timely fashion. Parents and residents of developmental centers as well as those residing in the community on legal status, need an independent person who they will be able to approach in dealing with matters of concern that they do not seem to be able to resolve through normal channels. It is recommended that these positions be funded and placed under the responsibility of another agency other than the N.Y.S. Office of Mental Retardation/Developmental Disabilities.

3. Termination of Employment/Guilty of Abuse or Mistreatment

To promote legislation that would mandate that appropriate action be taken in cases of proven abuse or mistreatment by an employee of an OMRDD facility.

Parents of persons residing in developmental centers have for many years, been concerned about the continuation of employment of those individuals who have been charged with abuse and/or mistreatment. In many instances, individuals have been able to plea bargain and have gotten their charges reduced or dismissed.

Currently, there is a bill, S.807 that if amended would resolve this concern for us.

C) Interest Reimbursement

To promote legislation to allow for the financing of personal property to be a reimbursable item.

Currently, when a loan is taken out to purchase an item of personal property such as a duplicating machine, washing machine or a van, the interest on said loan is not reimbursable under local assistance. The amendment of Mental Hygiene Law to make interest a reimbursable expense under local assistance will make purchase of those items more affordable to both State and the Chapters and will make the law consistent with laws effecting real property and other types of reimbursement.

PREVENTION

A) Establishment of Temporary Commission on Prevention of Developmental Disabilities and Infant Mortality.

To promote legislation that would establish a temporary State Commission on the Prevention of Developmental Disabilities and Infant Mortality.

One of the recommendations of the year-long Governor's Conference on prevention held in 1981 was to create a commission which would examine, evaluate and make recommendations concerning the prevention of infant death and disability. This commission would also ensure coordination, monitoring and implementation of prevention recommendations and activities.

The Commission would exist for a period of one year with the expectation

that the Commission would be collecting appropriate data during that time to justify the necessity for its continued existence.

B) Fetal Alcohol Syndrome (FAS)

To promote legislation to amend the alcoholic beverage control law in relation to warnings regarding the ingestion of alcoholic beverages while pregnant.

Research has now documented that a leading cause of mental retardation is the ingestion of alcohol by a pregnant woman. Legislation will be sought which will mandate that warnings be placed in appropriate places. As with warnings on cigarette packages regarding danger to one's health, it follows that such warnings should also be required as to the inadvisability of consuming beverages containing alcohol while pregnant.

C) Prevention of Lead Poisoning

To promote legislation which will increase public awareness and will increase the number of existing screening centers to prevent lead poisoning in children.

It is a well-documented medical fact that one of the leading causes of mental retardation is the ingesting of lead by young children. Lead is everywhere in the human environment as a result of industrialization. Hence the sources of lead are many including air, water, food, paint and gasoline. Increased public awareness is essential in the prevention of childhood lead poisoning. Therefore, it is vital that the general public be better educated regarding this most serious problem. Additionally, it is most important that the screening centers which now exist be expanded so that many more children can be tested for lead poisoning.

PUBLIC HEALTH LAW

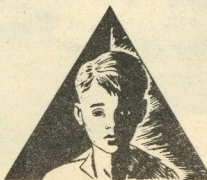
Medical Consent

To promote legislation that would allow a legal guardian of a person who is mentally retarded to sign for medical or dental consent.

Current laws are unclear as to the rights of legal guardians as they pertain to medical or dental consent. Consequently, regulations promulgated by the Office of Mental Retardation and Developmental Disabilities do not recognize the authority of an adult client's legal guardian to give such consent.

This has in the past resulted in undue suffering on the part of many individuals who have had to await medical treatment while permission has been obtained through the courts. Furthermore, this lack of clarification has caused a great deal of frustration on the part of many parents who have gone to the trouble and expense of obtaining legal guardianship on behalf of their adult children only to be told that they cannot provide medical and/or dental consent.

We shall continue to support A.8072 which was introduced during last legislative session which would correct this problem and seek sponsorship in the Senate.



GOLDEN APPOINTED ASSOCIATE EXECUTIVE DIRECTOR

The Executive Director of the NYSARC, Inc., Marc N. Brandt, has announced the appointment of Ben C. Golden as Associate Executive Director. Mr. Golden, for the past six years, served with the Assembly Ways and Means Committee. During that time, he advised the Assembly Committee on Legislative action with respect to the Office of Mental Retardation budget and various other bills effecting the laws of persons who are mentally retarded. Among his accomplishments, Mr. Golden helped the Legislature upgrade staffing standards at developmental centers not covered by the Willowbrook Consent Decree. He was directly responsible for drafting a number of bills that ultimately were signed into law which effect persons who are mentally retarded and/or developmentally disabled.

Mr. Golden holds a Masters Degree in both Social Work and Business Administration. Prior to his service with the Assembly Ways and Means Committee, he was a caseworker with the Eleanor Roosevelt Developmental Services. He is married and has two children.

Mr. Brandt commented that he feels "Mr. Golden will bring to the position, a great deal of insight and leadership skills for our chapters." His appointment began on November 14, 1985.

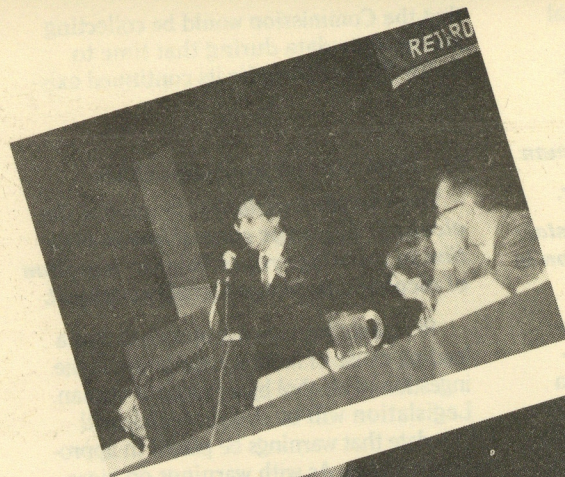
ASSOCIATIONS COMMITTEE CHAIRS NAMED

Immediately following the 1985 NYSARC, Inc. Annual Convention the President of the Association named the committee chairperson. Each committee meets at least twice a year and is charged with the responsibility of addressing the Goals and Objectives of the Association as adopted by the Board of Governors.

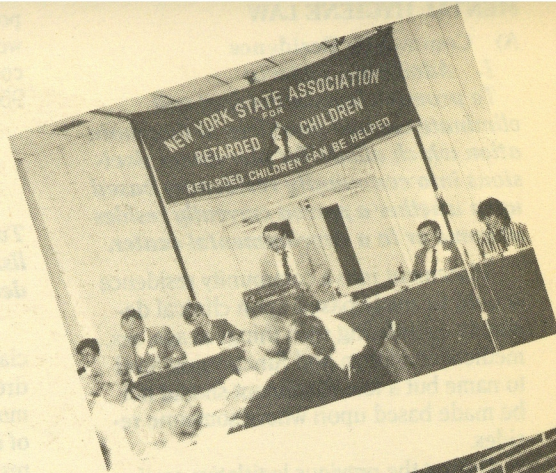
The following are the Committee Chair appointments of the President for the October 1985 to October 1986 period:

Adult Services	John Bryant
Budget and Finance	Robert Meltzer
Community Residential Services	Ellen Maroun
Developmental Ctr.	Bernice Volaski
Education	Janet Calkins
Guardianship	Richard Cohan
Incident Review	Paul Dhalle
Insurance/Pension	Dr. Irving Caminsky
Legal	Marvin Liebergot
	Warren Heilbronner,
	Esq.
Legislative	John Bryant
Nominating	Carroll Stowell
Prevention	Joan Edwards
Public Information	Robert Katz
Research	Robert E. Cooke
Resolutions	Maryanne Bryant
Scholarship & Awards	Kay R. Nogaj
Supplementary Recreation and Special Olympics	Maythorne Winterkorn
Youth	Maythorne Winterkorn

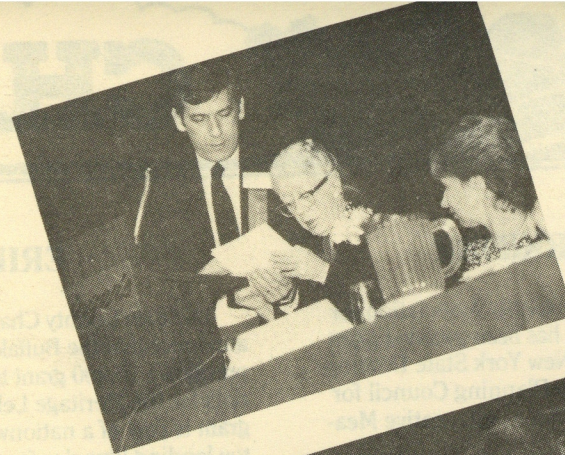
Mr. Lettman praised all those who served during the 1984-1985 term and looks to the committees for 1986 to be productive.



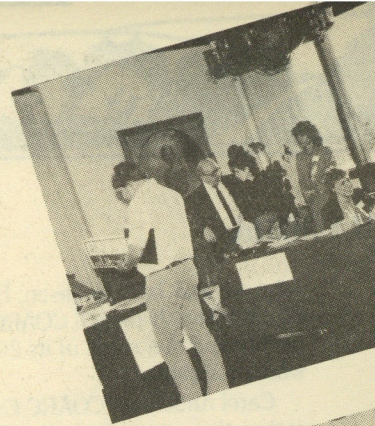
Clarence Sundram, Chairman of the N.Y.S. Commission on Quality of Care for the Mentally Disabled gives the keynote address during the General Session.



David B. Lettman officially opens the Board of Governors' meeting.



Katie Cassidy, a resident of Sullivan County ARC, gives a warm welcome during the opening ceremonies of the General Session.



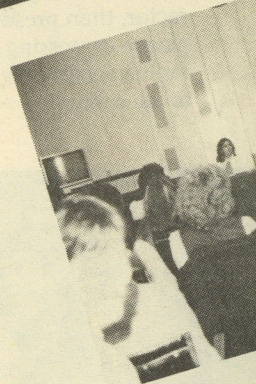
Barbara Levitz, Board of Governor representative from Westchester county responds to the governing body.



Banquet Speaker, Gordon M. Ambach shares his perspective of the future direction of special education programs and services for children who are mentally retarded.



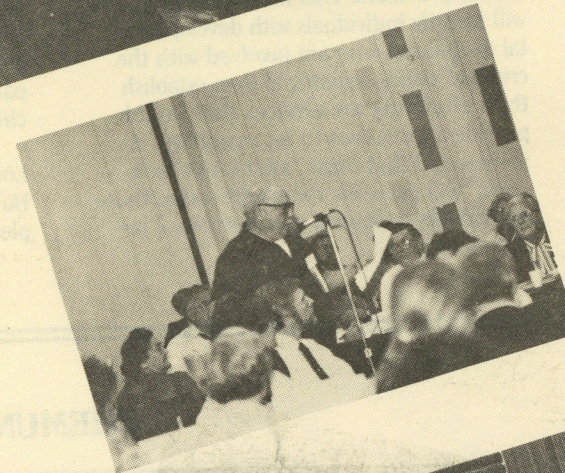
OMRDD Commissioner, Arthur Y. Webb converses with other NYSARC conventioners.



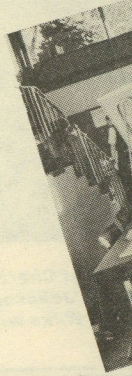
Workshop presenters Patsy Dodge (left) and Pam Cleary (right) take time out along with a young conventioner to enjoy a display of posters entered in the 1985 Poster Contest.



Saturday night banquet.



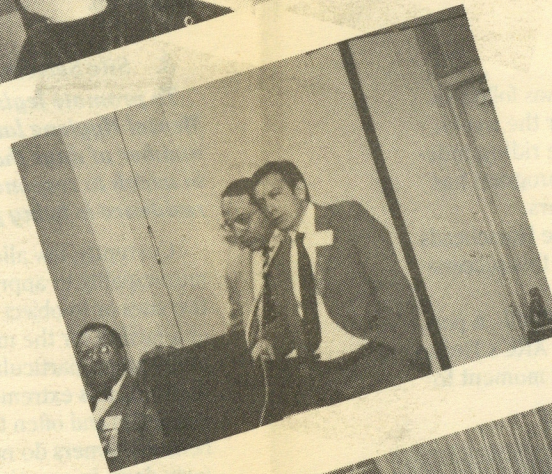
Essex county chapter President and Board of Governor representative Gerald Edwards, raises an issue for discussion.



Westchester County Executive Director, Richard Swierat, accepts a Certificate of Appreciation on behalf of the Bedford Fair Industries.



Representatives of the Board of Governors' are sworn in for the 1985-1986 year during the installation of officers.



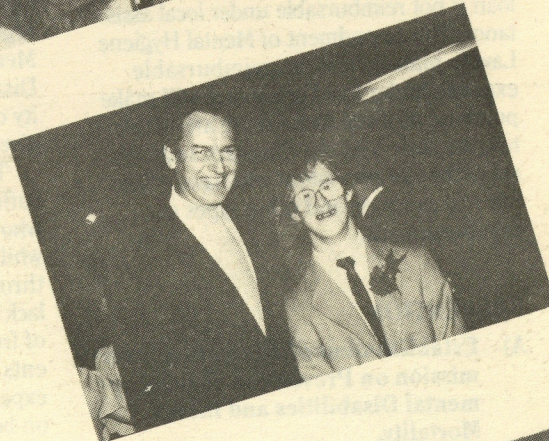
NYSARC Executive Director, Marc N. Brandt, and President, David B. Lettman, direct their attention to issues raised during the Board of Governors' meeting.



Kay Nogaj, Chairperson of the Scholarship and Awards Committee, assisted by NYSARC President, David B. Lettman, presents a Certificate of Appreciation as part of the Employer of the year Awards' ceremony.



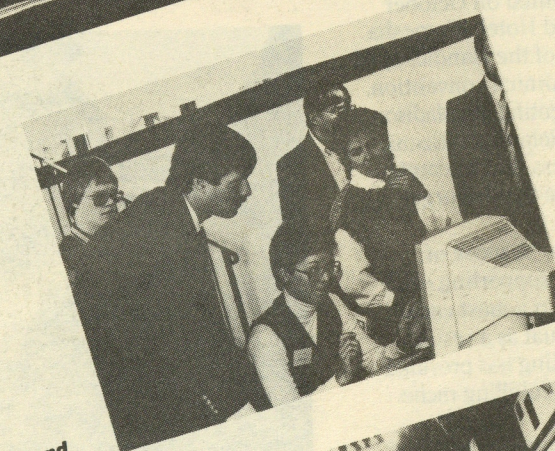
Otsego County ARC Developmental Specialist, Manny Pelligra (right) and NYSARC staff person Peter Vance (left), co-present a workshop entitled "Computer assistance for Membership and Fund Raising Activities."



Commissioner of Education, Gordon M. Ambach (left) and Matthew Wessels, (right) enjoy the Saturday night festivities.



Western region Vice-President, Bernice Volaski and newly elected central region Vice-President, John Bryant officially take office.

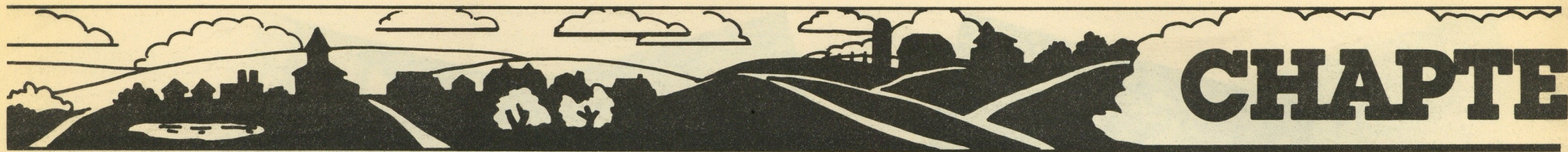


Surrogate's Court Judge Bertrand Gelfand (center) joins Irene Platt, Commissioner from the New York State Commission on Quality of Care for the Mentally Disabled (left) and Joseph T. Weingold, past Executive Director of NYSARC (right), at the Saturday night banquet.

Torren Moore of Data Management Associates, gives assistance with a computer demonstration which was held in the exhibit area.



Marriane Abel, a resident of Sullivan County ARC graciously presents a basket of flowers to NYSARC's 1985 conventioners.



COLUMBIA

During the past two years, workers from the Columbia County ARC have produced several million assembled parts for a new Johnson & Johnson product under a sub-contract arrangement with Charter Supply Company, Inc. Charter Supply is a local plastic bottle manufacturer supplying Johnson & Johnson and other companies.

On Tuesday, September 24, Frank Wilk, Packaging Manager for Johnson &

Johnson and Jake Jacobsen, President of Charter Supply toured COARC's workshop facility and met some of its 200 workers who are disabled.

Carol Anderson, COARC Executive Director, then presented Mr. Wilk with a plaque expressing COARC's appreciation for the opportunity for good work afforded to its workers.



Pictured left to right: Jake Jacobsen, President of Charter Supply; Carol Anderson, Executive Director of COARC, Frank Wilk of Johnson & Johnson, and Doug Casterlin, COARC General Manager, pause briefly as Carol presents Mr. Wilk with an appreciation plaque.

HERKIMER

The Herkimer County Association for Retarded Children has been awarded grant monies from the New York State Developmental Disabilities Planning Council for their proposal known as Alternative Measures.

Utilizing a case management approach, Alternative Measures will focus on the coordination of support services for developmentally disabled youth and adults who are at the pre-trial stage of involvement with the criminal justice system in Herkimer County. Coordination of support services will be done in conjunction with the judicial and corrections system as well as other local and state community-based service providers. This innovative program will identify individuals with developmental disabilities who are involved with the criminal justice system and then establish their eligibility for services that would provide alternatives to incarceration. It is intended that these "alternative measures" will decrease the likelihood of these individuals returning to the criminal justice system.

ERIE

The Erie County Chapter is pleased to announce that the Buffalo Foundation has provided a \$5,000 grant to purchase materials for the Heritage Lekotek. This program is part of a nationwide system of toy lending libraries for families of children with special needs. The Heritage Lekotek will provide services to children from birth to eight years of age throughout Erie County.

By attending the program, parents can borrow toys that are either unavailable or too expensive for them to purchase independently. Some of the materials have been specifically designed for Lekotek or have been adapted to provide play opportunities for the physically handicapped child. The staff is trained to provide guidance and the materials which will help parents to effectively interact with their children through play.

The Heritage Lekotek is located at the Louis J. Billittier Center, 101 Oak Street, Buffalo, New York. For more information, please contact Judie Bonk at 856-4201.

CHAUTAUQUA

A highly successful exercise program has become an important component of Chautauqua County ARC's Continuing Treatment program over the past several months.

The program, called "Move to Health" was developed by the Resource Center's Occupational Therapy Consultant, Cathe Gordon, who is on the faculty at the University of Buffalo.

With their physicians' approval, this group of dually diagnosed clients began a progressive program of aerobic exercises and dancing. The first session began with a 5 minute 'warm-up' and a 5 minute 'cool-down' activity. One dance or exercise routine was added at each of these meetings between the original activities.

With the instructor, the "Movers" then practice the routines and chart their progress. Collages using pictures of their exercises were also made by the participants. Several of the clients have lost weight and all are more flexible.



MADISON

The Madison County ARC's nominee for "Employer of the Year" was selected to receive the annual award presented by the New York State Association of Teachers of the Handicapped, Inc. Burger King of Oneida and its manager, Stan Kozlowski were the recipients of this prestigious award.

The award was presented on October 26, 1985, at the Concord Hotel, Kiamesha Lake, New York, as part of the Handicapped Teachers Association's annual convention.

Greg Goggins, representing the Madison County Association for Retarded Citizens, said "As with any business that attempts to help those in need, we thank Burger King most sincerely."

According to Goggins, "A sense of strength stemming from supporting one's self has been developed in a most capable handicapped individual as a result of employment. Burger King has provided this individual with a self-fulfilling niche in the community."

Jack Campbell, Director of Vocational Rehabilitation Services at ARC said "it's great to see an award that has been dominated by New York City employers finally come to up-state. Particularly gratifying is the fact that the award is a direct result of efforts made by the Madison County ARC."

In the past, Madison County ARC's Employment Service has successfully placed over 140 handicapped clients in competitive employment in the community.

Individuals from Chautauqua County ARC enjoy participating in a new program "Move to Health."

CHEMUNG

The Recreation Program of Chemung County ARC initiated a Horseback Riding Program for adults, which began on July 12th and concluded on September 13th.

Five participants took part in this program at Hunter's Run in Big Flats. Recreation provided individualized staff and Hunter's Run provided volunteers for each rider. Participants learned such skills as grooming, tacking and progressive instruction. A curriculum developed by the New

York State Special Olympics was followed. Participants developed, over the weeks, self-confidence and most are riding independently. In addition, the program has provided therapy for the riders.

A generous donation by the Horseheads Kiwanis Club helped to make this successful program a reality.

Pictured above is David O'Neil, a participant in Chemung County ARC's Horseback Riding Program takes a moment to 'meet' his new companion.



Pictured above is David O'Neil, a participant in Chemung County ARC's Horseback Riding Program takes a moment to "meet" his new companion.

CLINTON

The Clinton County Chapter wrapped up its four week Summer Recreation Program on August 23. The culmination of the program was an overnight campout at Girl Scout Camp Tapawingo at Point au Roche. For many of the 65 children involved in the program, it was their first camping experience.

The Summer Recreation Program started because it was felt by the chapter as well as school officials that developmentally disabled children tend to regress in social skills and some behaviors during

the summer months. The summer program was designed to provide a variety of stimulating activities in a structured environment emphasizing and reinforcing appropriate behaviors. Activities included swimming, community field trips and group recreational activities.

Funding for the program this year, was combined funding from local service organizations and the Clinton County Youth Bureau. The Rotary Club of Plattsburgh was the major sponsor of the project and expects to continue its involvement.



Two young participants in Clinton County ARC's Summer Recreation Program enjoy rolling a large ball as a Rotary Club volunteer cheers them on.

ONEIDA

Oneida County Chapter held their Sixth Annual Recognition Dinner at the Yahnundasis Golf Club, Seneca Turnpike on Saturday, November 2.

The list of honorees included: Ralph Chamberlain, Chairman of the Board, Precise Kit Promotions; Michal Cominsky, President, Chicago Marker Enterprises, Inc.; Joseph DeCuto, Marge Greco, Anthony Hathaway, Werner Kaiber, Partners Composition; Clara Pepe, Thomas Petronio, Rich Smith, AV Works; John Wade, Wademark, Inc.; Mark Warner, Warner Advertising and Bill Williamson, WIBX-WIBQ.

This year's keynote speaker was John Bryant, Central Region Vice-President, New York State Association for Retarded Children, Inc. His talk centered around the importance of volunteerism and the development of advocacy and services in the State ARC system.

This year's Dinner Committee was chaired by Sadiann Mazzotta with help from Pearl Benson, Jack Kowalczyk and Rose Kuzniar. "We had a hard time trying to decide on who to recognize this year, because of the many people and companies who have been so supportive of the ARC in the past year. We would like to thank everyone for their generosity and support," said Ms. Massotta.

ROME DEVELOPMENTAL CENTER

Chapter President Francis Turner, was the recipient of the Dedicated Service Award presented by Calvin G. Bond, Grand Master of the Grand Lodge of Free and Accepted Masons of the State of New York.

Parents Catherine McDonald and Joan Taylor have mounted a letter writing campaign regarding the construction of opaque privacy walls on units 523 and 524, Walsh Medical Building at Rome Developmental Center. These units house a special population of profoundly mentally retarded clients who are medically fragile with multiple handicaps. They feel that there are alternatives to the planned opaque cubicles that are less costly, serve the purpose and will meet the certification requirements of the Federal Health Department.

SCHOHARIE

Schoharie ARC is now preparing to open its fourth community residence. The High Street residence will house eight adults under the 24-hour supervision of two or three ARC staff. The house is expected to open in December of 1985 or January 1986.

WELFARE LEAGUE

On Sunday, September 22, the Mall (formerly the Community Store and Cafeteria) was dedicated to the memory of Yetta Meltzer and the eight other founders of the WELFARE LEAGUE.

Mrs. Reville, chaired the Dedication Committee and welcomed the guests. She spoke of Yetta and her co-founders, who 47 years ago, had the desire to serve the Residents of Letchworth Village and the vision to band together to form the WELFARE LEAGUE to carry forward that dream.

A plaque with the signatures of the original founders of the Welfare League was mounted on the wall of the Community Store now named Meltzer Mall.



Ribbon Cutting Ceremony (left to right) Lou Kaplan, Welfare League Past President, Frances Reville, Welfare League Past President, Leona Greenberg and Sheldon Meltzer - Children of Yetta Meltzer.

DUTCHESS

The Dutchess County Chapter is addressing the question, "What happens when my mentally retarded/developmentally disabled son/daughter reaches the age of 21 years and public education is no longer available to him/her?" A Family Support Service Program has been set up to assist families by offering workshops and lectures on legal rights, services available through the community and how different agencies work toward giving choices to our family. Parent groups are also being formed to share information on how to help adolescents make the transition to appropriate day/residential programs.

COMMUNITY LEAGUE

President Florence Siegel reports that Community League has committed itself to a long range project, that of a park on the grounds of Wassaic.

The chapter feels that this project can be a beautiful, everlasting image of the commitment of Community League toward the quality of care and normalization of every person living at Wassaic. The park will be called the Community League Park. The League has already made a donation toward the start-up of the park. It is hoped the park will have many trees, benches, rest rooms, water fountains and flowers, and all the rest that parks have.

To help raise money to be put toward the construction of the new park the Community League held a raffle for a 19" color television in which the winning name was drawn at their December meeting.

YATES

On September 4, 1985, the Keuka Lake School, a preschool for children with handicapping conditions, opened its doors under the auspices of the Yates County ARC. Housed in the kindergarten room of the former Branchport Elementary School, the school provides specialized therapies based on an individualized program specifically developed for each child.

All services are provided at no cost to the family including diagnosis.

The teacher, Mrs. Rzepski either goes to the child's home or the parents bring the child to her for the initial assessment. The standardized test given as part of an educational screening indicates whether or not further evaluations should be done and/or whether there should be any psychological testing, speech therapy, or physical therapy provided.

The Keuka Lake School fills a gap in a previously underserved geographical area. In the past, preschool children with handicapping conditions from Yates County have been required to spend many hours on a bus in order to take advantage of similar services. The opening of this school provides children with developmental delays and their families with a viable alternative in seeking early intervention.

ULSTER

For the third year, Ulster ARC held a telethon to raise funds for programs provided to citizens who are retarded of Ulster County.

As in the past, a live auction was held which included items up for bid such as a weekend at the Gideon Putnam Hotel in Saratoga, including a limosine to and from the hotel, dinner for two at Stardust in Mount Tremper, two tickets to Little Shop of Horrors in New York City, a cabbage patch kid, a weekend at the Granit Hotel, dinner for two at Bowery Dugout, portable tape player from W.D.S.T. and many more items.

In addition, Nick Walker, star of daytime drama "Capitol" and graduate of John A. Coleman High School made a video tape especially for U.A.R.C.'s telethon. He has also donated, for the auction a script of the show autographed by all the stars.

The telethon netted over \$12,000 which will be used to develop and maintain programs at the ARC.

CHAPTER NEWS

SCHENECTADY

Senior citizens who attend the Maple Ridge Day Treatment Program at Schenectady ARC were invited to tour the Governor's Mansion in Albany on August 8, 1985. Their visit was especially exciting: not only were they shown the official living quarters of the Governor, but his wife, Matilda Cuomo, was their tour guide! She posed

for pictures with the clients, answered their questions and made a special point to speak individually to each and every person. The presence of press photographers gave the clients a taste of being VIP's for the day and it will be an experience they will remember for many years to come.



Senior citizens from Schenectady County ARC stop to pose for a picture with Matilda Cuomo, their tour guide for the day.

SARATOGA

Sewing machine operations at Alpha Industries began less than two years ago - with one sewing machine, a supervisor, a promise of one contract and no client machine operators! Today, rapidly outgrowing its space, there are fourteen (14) sewing machines, over twenty (20) client workers, and more bundles of materials than there is often time to sew.

Initially, thirty-five (35) clients were assessed on the sewing machines, half of whom showed potential to master the craft. Sewing has developed into a full-fledged vocational training program and opens doors for clients to consider competitive employment.

Alpha's Director of Commercial Operations, Ilene Dembo, states that two major contractors are Shamron Mills, Ltd. of New York City and the State of New York. Both contract with Alpha to produce hospital gowns. Other contractors send an assortment of work including X-ray gowns, runner's vests, skirts, nail aprons, BMW headrests, seat linings, and straps; even Santa Claus dolls and wash cloths.

For some of the workshop workers, sewing has been a very successful experience. One of the human success stories,

perhaps says it all. Phyllis, a client worker, was asked to be evaluated on the sewing machine. Reluctantly, because she never operated one before and lacked confidence, she did try. She showed promise and agreed to train. Phyllis's progress was excellent and within one year she reached competitive standards. The Result? Phyllis was asked to consider applying for a position as a regular, full-time employee at Alpha. She did, and was successful in securing the job as a sewing machine operator. Her supervisor sums it up by simply saying "We are proud of her; she is one of the best."



Saratoga County ARC worker, David, cuts ties to be tacked on hospital gowns. Marie, a Saratoga County ARC worker sets a sleeve.

NASSAU



A contribution from the Exxon Corporation's corporate grants program is making possible an equipment purchase at the Nassau AHRC. The check presentation was made by Ed Licence (left), a Nassau AHRC board member and former Exxon employee, to Larry Daniels, who directs the Nassau AHRC vocational training program.

STEBEN

September proved to be a positive month for the Steuben Chapter, as several grant writing efforts were approved, paving the way for important new developments.

In the programming area, two complimentary grants for evaluation and job placement will mean expansion within Steuben Services, its vocational offering. A \$19,000 award from the Tri-County Private Industry Council is to be combined with a \$34,000 award from the Office of Mental Retardation and Developmental Disabilities to establish an off-site training and job placement system. Included in this package is the addition of two new positions, as well as provision for significant expansion of our assessment capability.

In on-site training, a grant for \$25,000 to improve and expand our offset and screen printing programs was received from the Appalachian Regional Commission. Twenty to thirty new participants are projected as a result of the additions, with production speed and sophistication being enhanced appreciably.

Finally, a \$2,500 grant from the Gannett Foundation in response to our capital campaign was also approved. This money will be applied toward the necessary matching funds required for our \$255,000 state aid grant to establish a permanent, broadened vocational site.

WAYNE

The Wayne County ARC Vocational Rehabilitation Center-Key Industries, officially opened their new facility located on Van Buren Street in Newark on September 14, 1985. Barry Guest, a worker employed by the Wayne County ARC was given the honor of cutting the ribbon, giving the ceremony a special touch.

This ceremony highlighted the final day of a four-day open house in which over 300 people took advantage of the opportunity to tour several of the ARC's programs including the Roosevelt Center for Educational Activities, the Day Activities Training Program and Key Industries.



Above Tom Healy, WARC Board Member; Kathy Mouton, Case Manager; Bob Finewood, Workshop Director; Suzanne McGovern, WARC Board President; and Chris Karsten, WARC Executive Director watch as Barry Guest cuts the ribbon.

NYSARC RESPONDS TO PUBLIC HEARINGS HELD ON GUARDIANSHIP

On Thursday, September 19, 1985 a Public Hearing was held in New York City addressing the regulating of appointments, training oversight, authority and availability of Guardians, Guardian ad litem, committees and conservators.

Testimony was presented on behalf of the New York State Association for Retarded Children Inc. by Shirley Valachovic, Senior Vice President of the State Association and long standing member of NYSARC's Guardianship Committee. This public hearing was sponsored by the Assembly Standing Committee on Judiciary and the Assembly Standing Committee on Mental Health, Mental Retardation and Developmental Disabilities, Alcoholism and Substance Abuse.

The following testimony was presented at this hearing.

"On behalf of the New York State Association for Retarded Children, Inc. and myself, personally, as the parent of a son who is mentally retarded, I thank you for the opportunity to speak with you this afternoon.

After a person turns 18, he or she is assumed to be a legally competent adult and able to manage his or her own affairs. This is not the case for many persons who are mentally retarded. Article 17-A of the Surrogate's Court Procedure Act provides for continued legal guardianship of individuals who are mentally retarded even after they reach the age of 18. The initiative of the New York State Association for Retarded Children (NYSARC) was successful in obtaining from the State Legislature in 1969 the legal structure designed specifically to protect persons who are mentally retarded and unable to manage their personal affairs by providing them with lifetime guardianship. Article 17-A accommodates the flexibility of assistance necessary to address the full range of needs of our children from almost total dependence all the way to complete independence. When properly implemented, it retains for these individuals all those rights of citizenship which they can manage for themselves.

The NYSARC Guardianship Program is operated through the Association's 64 chapters and offers families the assurance that future decisions significant to the quality of life of their relatives who are mentally retarded are made in their best interest, particularly in the areas of securing good health care, appropriate housing and satisfactory day and recreational services. This will ensure a focus on health, personal and social development.

With this background and the concerns of parents of persons who are mentally retarded in mind, I present the following comments on the specific areas being addressed at this legislative hearing for your consideration.

I. Establishing in each Appellate Division a screening, training, oversight and evaluation program for conservators, guardians, Guardians ad litem and committees:

It is my understanding that at least 90% of guardianship proceedings (relating to the mentally retarded population) involve parents, siblings, or close relatives seeking to ensure the continuation of care provided in the past into the future. One must wonder what form 'screening, training and evaluation' would take in the situation where a parent is continuing to act in a parental role since the needs of the child have continued into adulthood. To further clarify this point, consider if you will, a typical case of parents applying for legal guardianship of their child who is retarded.

Mr. and Mrs. James are the parents of a daughter who is now 28 years old. Susan, their daughter, has continued to reside with her family, attending special classes in the public school system, and is now receiving vocational training services at the sheltered workshop where she is employed and which is operated by the local ARC chapter under the name of General Enterprises, Inc. The James' have decided, after attending a number of meetings on guardianship, that it is in the best interest of Susan both now and in the future to have the supervision of a guardian. Further, they will take advantage of the provisions of Article 17-A in that they will name standby guardians for Susan in addition to having themselves appointed, thereby providing for continuing care throughout Susan's lifetime. The first two standbys are to be her two sisters in order of age and the last - or ultimate - standby guardian is to be NYSARC with the actual duties of guardianship to be carried out by their local chapter. It is important to note that all of the proposed guardians are knowledgeable with respect to Susan as a person, her needs personally and programmatically, and the agencies providing necessary services.

We would be concerned that any screening, training and evaluations not be presented or carried out in a manner which would intimidate or inhibit a parent, concerned sibling, relative or close friend from assuming guardianship responsibilities.

On the other hand, our Association acknowledges the need for and encourages the development of any training and oversight program which would assist a guardian in his or her role in advocating for a ward in seeking out appropriate services, obtaining necessary and appropriate medical care, etc.

In this regard, the Association stands ready to be of assistance should such a program be seriously contemplated or planned. As NYSARC now has in excess of 46,000 members across the state, has an active Guardianship Committee both at the state level as well as individual chapter committees, and, most importantly, since our Association is currently acting as primary guardian for 70 persons, has been appointed as standby guardian for 160 persons and alternate standby for 187 persons, we feel we have much to offer in terms of experience and insight. We not only are available for information and assistance, but would most

definitely wish to have input into contemplated changes in the current guardianship statute and/or its implementation, as such changes would affect the mentally retarded population of this state.

II. Requiring judges to appoint the appropriate fiduciary from a panel established by the Appellate Divisions:

Since our Association cannot act as guardian of the property of persons who are mentally retarded, but rather only the person, our concern with the requirement of judges to appoint an appropriate fiduciary from an established panel would be that such a requirement would limit the ability of parents to request the appointment of other family members designated by the parents to serve as guardian of the property. We would be most interested to have additional information on this recommendation in order to better evaluate its effect on persons who are mentally retarded and their families.

III. Authorizing conservators, guardians, Guardians ad litem and committees to give medical consent on behalf of a ward:

One of the most critical concerns facing the mentally retarded population of our state, and our Association as a provider of services is the issue of obtaining proper medical and dental care expeditiously. With the enactment of Article 17-A in 1969, it was understood that legally appointed guardians would have the same rights and authority to make these decisions as a parent would have. Indeed, medical consent was and is one of the most basic reasons for parents having themselves named as legal guardians as well as providing for standby guardians.

Unfortunately, we have had and continue to receive reports from our chapters that the interpretation of Article 17-A is inconsistent throughout the state. While in many areas there is little or no problem for guardians in respect to medical consent, in other areas of the state, hospitals and medical personnel have not accepted a legal guardian's consent. The result of such action is one that not only could place the person who is mentally retarded at risk, but can cause unnecessary, severe and/or prolonged pain while awaiting treatment.

Another inconsistency and perhaps a form of double standards in the developmental centers will not accept as valid medical consents by legally appointed guardians other than parents. Parents of children residing in developmental centers are extremely disturbed by this recent development as many had planned on standby guardians appointed by the court to be able to take their place upon their death in securing appropriate and proper medical care.

To address this need for clearer delineation of the rights of guardians to give medical consent, NYSARC has proposed an amendment to the public health law which has been introduced in the Legislature. The amendment, brief and to the point, would permit a legal guardian to give consent for medical and dental treat-

ment. We strongly urge support for the passage of this legislation during the 1986 session to eliminate inconsistencies and provide for timely medical and dental care.

IV. Ensuring that persons with limited assets have access to the services of conservators, guardians, Guardians ad litem and committees:

NYSARC has expressed concern with the current practices of the Surrogate's Courts during 17-A proceedings with respect to the inconsistent application procedures and expenses of Guardians ad litem fees. Not only has the expense of the 17-A proceedings caused hardship, but the additional burden of fees for Guardians ad litem add to such hardship for families of limited means.

The findings of a survey conducted by our Association last year document the inconsistencies from county to county and there is a strong feeling that there needs to be a more standardized approach to all such proceedings and related expenses.

NYSARC is most certainly concerned with ensuring that persons with limited assets have access to guardianship services and since our corporation does act as guardian and is accepting applications for guardianship services on an ongoing basis, we have made it clear that in no way is the financial situation of any parent or person who is mentally retarded to be a consideration with regard to such guardianship services. In NYSARC's Policies and Procedures Manual on Guardianship under the section on Financial Provisions/Planning, it states that, 'No chapter shall charge a parent(s) any fee for obtaining guardianship.'

In summary, in the past two decades profound changes have altered the social attitudes of our society toward persons with special needs and these changes have come about due largely to parental pressures. The establishment of Article 17-A of the Surrogate's Court Procedure Act was significant and it is most important that the original intent of the legislation be preserved. We do feel that the statute needs refinement in order to clarify the authority of a guardian of a person who is mentally retarded to issue medical consent.

Again, NYSARC is vitally interested in the results of this hearing and any resulting legislation or proposed changes in regulations. We offer you our cooperation and commitment, our experience and our expertise as parents and professionals in any way we can to ensure the well-being of persons who are mentally retarded.

Thank you for this opportunity to express our perspective on guardianship and the unique needs of the mentally retarded population."

N.Y.S.A.R.C., Inc. Comments on Community and Family Living Amendments of 1985

On April 3, 1985, Senator John Chafee (R-R.I.) introduced a bill (S.873) to amend title XIX of the Social Security Act. The bill, entitled, "The Community and Family Living Amendments of 1985" is a revision of the 1983 bill (S.2053) submitted by Senator Chafee which our Association studied and did not support.

The thrust of the bill remains unchanged and if passed, would require massive deinstitutionalization by states in response to a gradual yet substantial reduction in federal financial participation (FFP) in the funding of large institutions. The bill also contains financial incentives for the development of small community living facilities as well as provisions requiring state-wide community and family support services.

As indicated in the Association's position on the previous bill, Senator Chafee is to be commended for his recognition of the merits of a well developed community system of care. Many of the principles and goals which Senator Chafee strives for through this bill are those which our Association has fought for and to a large extent, has achieved. Of course, that is not to say that New York State has accomplished everything worthwhile for persons who are mentally retarded, especially those residing in the state developmental centers. On the contrary, New York State can do much more to provide a better quality of life to individuals who are mentally retarded wherever they reside.

The New York State Association for Retarded Children, Inc. has never been silent concerning the care and treatment for persons living in developmental centers. This year, the Association published a report entitled, "The Quality of Care in Developmental Centers: A Parental Perspective." At this writing, our Association is actively pursuing with the New York State Office of Mental Retardation and Developmental Disabilities the adoption and implementation of the recommendations outlined in the paper.

The purpose of mentioning our efforts in this area is to demonstrate and represent the position of a substantial number of parents and professionals alike who strongly believe that the developmental center is an important part of the residential continuum of care. These individuals, reinforced by our Association, are strongly in support of improving the quality of life of individuals residing in developmental centers; are strongly in support of improved direct care and clinical staffing; are strongly in support of improved medical care; strongly in support of the establishment of an advocacy staff position at each developmental center to serve as an ombudsman who will respond to issues raised regarding quality of care; and do not necessarily support the relatively rapid winding down of the developmental center care component.

Our Association, while remaining strongly in support of the continued expansion and improvement of the community system of care in New York State, must also recognize and support the concerns of parents and professionals who remain in favor of "institutional care." Our Association views the developmental center as a necessary part of the residential continuum and strongly supports the improvement of this living component.

The above notwithstanding, the Community and Family Living Amendments

of 1985, which requires massive deinstitutionalization and development of community living facilities, does not address and resolve several impediments to timely, effective program development which has been the experience in New York State. The bill does not contain provisions for a capital grant program with FFP or amendments which would streamline the cumbersome and time consuming HUD application process. In the absence of an effective capital grant program with FFP, states would be committed to massive community development with no assurance of capital construction funding.

The bill does not consider what the impact of extensive development will have on both the voluntary and public providers existing operations, particularly since many providers are having difficulty meeting the federal governments stepped-up compliance efforts in the ICF program. The bill should contain provisions which require the Department of Health and Human Services to de-regulate the ICF program, rescinding all regulations which are unnecessary in assuring quality of care. Such an amendment would allow for the redirection of substantial administrative time and dollars which could be used in development efforts.

The bill requires the availability of suitable living arrangements for all severely disabled individuals who are eligible. Although the language of the bill would seem to include individuals currently living in their natural homes, in practice, it is our belief that with the massive deinstitutionalization required in response to the substantial reduction in federal funding to developmental centers (\$320 million according to the OMRDD analysis) there will be few placements available to such individuals. Further, although Senator Chafee's intentions are admirable and may be most beneficial in other states, the bill will result in a quota system of placement in New York State, the magnitude of which we have never experienced before.

The bill does contain many provisions which would benefit individuals who are mentally retarded. As previously mentioned, the bill strongly supports the development of a community system of care and requires the availability of community and family support services. The bill also requires the development and regular review of a habilitation or rehabilitation plan for individuals receiving services; it requires the provision of case management services by trained individuals not associated with the service provider and thereby independent.

In summary, although the New York State Association for Retarded Children, Inc. cannot support the Community and Family Living Amendments of 1985, we urge Senator Chafee to consider amendments to the bill which would not penalize states for continued operation of those large facilities which provide an acceptable level of care; to include provisions which establish a capital grant program with federal financial participation to accommodate the cost and time frames for development for the great numbers of community living facilities required by the bill; and to include provisions which will remove those regulations of the ICF program which have no relationship to the provision of quality care yet are time consuming and costly to comply with.

Children Target of Delaware Cost Cutting

The young parents from Davenport sat in the foyer of Delaware County Family Court waiting to testify about summer school services their handicapped daughter received last summer. They didn't know why they were there.

Delaware County is challenging 15 petitions for educational services to the handicapped in Family Court. The services provide summer school for students up to 21, and preschool education for children under 5.

Delaware County doesn't want to pay for the services and is making a constitutional issue out of it. Carl Becker, deputy county attorney, is contesting each petition. He declined comment.

Delaware County would rather the state pay the entire bill for services, said William Moon, social services commissioner, who has "a fairly high percentage of these cases that are being funded through one program or another here."

Moon said the county pays 50 percent of the cost of some programs, and 100 percent of others. His department provides about \$100,000 for educational services.

Moon said he knows of no other county that is contesting handicapped education costs in the across-the-board manner of Delaware.

Waiting outside the courtroom, the Davenport mother said her 6-year old daughter has a nervous disorder that prevents her from developing normal emotional and social behavior.

The girl, who also has a seizure disorder, was enrolled in a public school last year, but her handicap prevented her from advancing, said her mother.

"At the end of the school year, we were informed that she had learned nothing."

The couple then sent their daughter first to the Rainbow Project, an Oneonta-based early intervention program of the Otsego County Association for Retarded Children. Then the child was "mainstreamed" from that special program into the TLC program, also in Oneonta.

"We were looking for answers to what was the best environment for her," said Susan King-Elkin, director of the Rainbow Project, who was called to testify.

Jean Stam, special education teacher at TLC, said the girl was socialized through that program to better prepare her for public school life. She is now in a BOCES special education class.

Delaware County doesn't want to pay for \$1,867 cost of the Rainbow and TLC summer schooling. Mrs. Stam said the Davenport girl is one of three children she was called to testify about.

Last year there were 52 petitions filed in Family Court for educational services to the handicapped, said Judge Robert Estes.

He said the county is taking three approaches in objecting to the payments

- Constitutional. The county believes the state should pay for all educational services, since the state mandates them. Also, the county holds that handicaps should be weighed by educators, not through Family Court.

- Proof of handicap. The county says the extent of educational disability must be displayed.

- Program applicability. The program is examined to see if it addresses the educational handicap.

"This is going to cost the county a lot of money," said William Schebaum, attorney for the Davenport couple.

Estes confirmed that one expert witness has been approved for \$1,500, while another charges a yet-to-be-approved \$500.00 fee. "I think it's a large waste of taxpayers' money to go through all this," he said.

Because a high percentage of hearings are for social services clients, counsel is assigned and paid for by the county. Added to that is a sheriff's deputy on duty and a stenographer.

In a letter to the county Board of Supervisors in October, 1985, Estes objected to the new trend of challenging every petition to educate the handicapped. Previously, Becker, as deputy county attorney, reviewed all documents, then initialed his approval.

The new process of hearing every petition leaves the court "hard pressed for time," wrote Estes, who hears about 1,200 Family Court actions yearly. However, he said the full hearing procedure would be applied as requested by Becker, although he hopes the county board would review the situation.

Estes said his main concern remained the inconvenience for county residents.

Stephen Helfgott, director of the Delaware County Association for Retarded Children, said the hearings would have an adverse effect on the parents of handicapped children who are already struggling emotionally.

"We have two parents that are involved in these proceedings and they are very upset," said Helfgott. "They are confused about going into this proceeding, which is an adversarial proceeding. And then they are asked to prove their child has a handicap."

He said some parents of the handicapped may drop the services.

Further, Helfgott said his board will decide if the early intervention program should continue at all, if the hearings are protracted.

Moon said the extra handicapped cost was addressed in the Legislature, and the hearings on constitutional grounds are one way to bring it back to that body.

Rather than rule administratively, as in the past, Estes will now have to rule judicially. Those decisions can be appealed.

Meanwhile, a family from Davenport wonders how it got caught in the middle.

GENTILE NEW EXEC IN NASSAU KAPLAN TO REMAIN ACTIVE AS CONSULTANT

A long time leader and pioneer in the field of rehabilitation and education for the disabled has been appointed Executive Director of the Nassau Association For the Help of Retarded Children.

Frank D. Gentile, a resident of Great Neck and a former vice president of the Human Resources Center, has become chief executive at AHRC which provides daily programs for about twelve hundred mentally retarded children and adults.

Mr. Gentile who started his career twenty-eight years ago in the engineering of electronic and mechanical assembly work for the disabled, holds an honorary doctorate from Dowling College and a master's degree in rehabilitation counseling from New York University. He has lectured widely and has been published in various professional journals including the Journal of Rehabilitation.

As executive director of the Nassau AHRC, Mr. Gentile takes charge of an organization which was founded in 1949 and today numbers twenty-five auxiliaries with 8,500 member-families. In addition to its campus in Brookville, AHRC runs vocational training and sheltered workshops in Plainview and Freeport and a residential camp at Hunter, New York. The organization has over twenty community residences scattered throughout Nassau County and has recently dedicated a day treatment center which joins its school and horticulture program on the Brookville campus.



Helen Kaplan, who has been Executive Director of the Nassau Association for The Help of Retarded Children for twenty-five years, now assumes an emeritus position as Frank D. Gentile takes over as the organization's top executive.

A WORD OF THANKS...

I would like to thank all of the hundreds of friends who sent cards and flowers during my recent illness. Your thoughtfulness meant a great deal to me. I am sorry I missed this year's convention, but I'll be back next year with twice as much fight and enthusiasm!

Mary Caniano
Assistant Treasurer

BOARD SETS COMMITTEE GOALS FOR 1986

At the Annual NYSARC, Inc. Convention held at Grossingers, N.Y. on October 25, 1985, the Board of Governors reviewed and adopted 1986 goals for the Association's Committees. These goals were developed by the various NYSARC committees and reviewed by the Executive Committee of the Board of Governors.

The purpose of developing these goals is to assure that the NYSARC, Inc. committees are focusing their attention and energies on Board of Governor priorities. In addition, the Board of Governors are responsible for developing, reviewing, passing and implementing policy for the Association. It, therefore, follows that the Board of Governors should develop and implement goals and objectives for the coming year as well as on-going objectives.

In essence, then, the goals and objectives become the immediate priorities of the Association. Once adopted by the Board of Governors, the goals are one method of assuring accountability by the chapters that the State Association is addressing the needs as stated. In addition there often are goals and objectives that develop throughout the year that must be met as well as the ongoing NYSARC, Inc. objectives.

The revised adopted By-Laws has established a number of new committees as well as replaced the Vocational Rehabilitation Committee with the Adult Services Committee. Goals and objectives for these committees will be established by the committees and reviewed by the Executive Committee after the Annual Convention when the committees are formed.

The 1986 adopted goals and objectives were developed through the NYSARC, Inc. committee process as well as needs that have been expressed to our State Office. The following are the goals and objectives as adopted by the Board of Governors.

AREA: Residential Services

- A) To review and survey health issues relating to Hepatitis B and recommend to the Board of Governors a process and procedure to address the problem.
- B) To review the Regulatory Certification process, to isolate key indicators and to develop a proposal which would enhance the protection of the quality of life for those individuals residing in residential programs.
- C) To continue to review alternative methods of non-state financing sources for community residences.
- D) Regulatory review process.

AREA: Developmental Center

GOALS:

- A) to take a realistic look at the declining population at developmental centers, to ascertain an appropriate response to the OMRDD plan; and to offer

guidelines for acceptable and humane placement.

- B) To follow through on the Association's quality of care in the D.C. report, and to make the appropriate recommendations to the Board of Governors.
- C) To develop a position statement regarding client abuse and abuse arbitration and submit such statement according to the October 1985 resolution as adopted by the Delegate body of the Association.

AREA: Education

GOALS:

- A) To develop brochures to explain the impact of the Regents Action Plan on special education and to provide information on vocational education.
- B) To continue to assist chapters in developing educational liaisons/ committees and to provide ongoing technical assistance.

AREA: Executive Committee

GOALS:

- A) To review current NYSARC, Inc., policies and procedures and to update where appropriate.
- B) To update NYSARC, Inc., Policy Manual and Chapter Manual to reflect Board action in recent years.
- C) To review and develop an annual process evaluating NYSARC management activities.
- D) To develop an orientation and training program for new Board of Governor members.

AREA: Guardianship

GOALS:

- A) To further update information on guardianship through the NYSARC, Inc. publications on guardianship and wills and trusts.
- B) To begin to explore the development of an audio-visual presentation for dissemination to assure consistency of information regarding the Association's Guardianship Program.
- C) To increase the awareness and importance of the Association's Guardianship Program by increasing the number of active NYSARC chapter guardianship committees by six chapters.

AREA: Prevention

GOALS:

- A) To facilitate statewide dissemination of information regarding prevention through distribution of materials and the establishment of a prevention section in the NYSARC library.
- B) To provide training regarding prevention of mental retardation and developmental disabilities by designing materials for

inclusion in orientation sessions conducted at all ARC chapters.

- C) To provide public education to foster public awareness of prevention of mental retardation and developmental disabilities by developing a slide/tape presentation.

AREA: Public Information

GOALS:

- A) The development of a statewide media effort with a minimum of six (6) releases.
- B) The development of at least three (3) model programs for distribution to chapters.
- C) To explore and make recommendations regarding the possibility of a statewide fund raising and media effort.
- D) To conduct two meetings for chapter public information representatives to further develop cohesive efforts, provide training and exchange information.
- E) To create and manage a communication and development training program to be offered at the 1986 Convention.
- F) To explore the feasibility of organizing regional groups with chapters to provide a common effort for media exposure, covering broad areas by use of radio, daily newspapers and television.

AREA: Youth

GOALS:

- A) To reinforce or expand upon existing youth groups in chapters and to assist five local chapters who have indicated an interest in developing Youth Committees and activities.
- B) To develop a brochure on Youth and Special Olympics' programs.
- C) To present a workshop on Youth activities at the 1986 Annual NYSARC Convention and invite members of local chapters' Youth Committees to participate.
- D) To begin to develop a slide presentation on the Y.O.U.T.H. Program, thereby promoting greater awareness and public relations.

**"An Ounce
of Prevention"
Conference -
Brock University**
St. Catharines, Ontario
June 13 - 14, 1986

A New York State/Province of Ontario conference on future directions of programs aimed at the primary and secondary prevention of developmental disabilities.

For more information call
WNYTF on Prevention of MR/
DD (716) 835-3674.

Publication of Interest

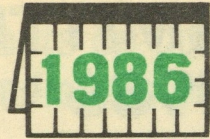
The Human Services Research Institute has recently completed a comprehensive manual on quality assurance. The manual was supported by a grant from the U.S. Department of Health and Human Services and is titled, Assessing and Enhancing the Quality of Human Services: A Guide for the Human Services Field.

The book includes an overview of the concepts of quality assurance as applied in programs for children, elderly persons and persons with disabilities. To order a copy, write to Human Services Research Institute, 120 Milk Street, 8th Floor Boston, MA 02109. The is \$15 plus postage.

NYSARC Prevention Brochure to be Read by College Students

Keuka College students enrolled in a class entitled, 'Introduction to Mental Handicaps' will soon be required to read a brochure on the prevention of mental retardation and developmental disabilities which was developed by the NYSARC Prevention Committee.

The course, taught by Dr. David B. Wiley, is a component of Keuka College's Special Education Pre-Service Teacher Training Program. The brochure will provide the students with interesting facts and information in several areas of prevention including, lead poisoning, fetal alcohol syndrome, prenatal care, automobile safety and a Health Curriculum for Teens.



ASSOCIATION CALENDAR OF EVENTS

JANUARY

- 9 Train-the-Trainer
Delmar
- 10 Training - the IPP
Planning and Implementation Process
Sheraton-Airport Inn
Albany
- 10 Education Committee
Delmar
- 17 Prevention Committee
Delmar
- 24 Executive Committee
Delmar
- 24 Youth and Supplementary
Recreation and Special
Olympics Committees
Albany
- 25 Guardianship Committee
Delmar
- 30 Training - Fiscal Management for the Non-Financial Manager
Hotel Syracuse,
Syracuse.

FEBRUARY

- 6 Public Information Committee
Delmar

MARCH

- 14 Community Residential Services
Committee
Delmar
- TBA Executive Committee

APRIL

- 4 Legislative Committee
Delmar
- 11 Developmental Center Committee
Delmar

MAY

- 2 Formal Dedication of Joseph T. Weingold Building
Delmar
- 2-3 Spring Board of Governors
Sheraton-Airport Inn - Albany

JUNE

- 6 Prevention Committee
Delmar

JULY

- 10 Youth and Supplementary
Recreation and Special Olympics
Committees
Delmar
- 18 Community Residential Services
Committee
Delmar
- 19 Guardianship Committee
Delmar
- 24 Public Information Committee
Delmar
- 25 Developmental Center Committee
Delmar

AUGUST

- 8 Education Committee
Delmar
- 15 Legislative Committee
Delmar

OCTOBER

- 23-26 Annual Convention Fall Board of
Governors' Meeting.
Concord Hotel, Kiamesha Lake

Additional training schedule and dates will be published in our next edition of OCV.

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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Delmar, New York 12054

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