

OUR Children's Voice

Retarded Children Can Be Helped

Executive 1987-88 N.Y.S. Budget Contains Important Key Initiatives

Governor Proposes Five Developmental Centers to Close — Funds for Salary Enhancement Included — OMRDD Budget Requested Increase to be 9.7%.

On Tuesday, January 20, 1987, the Executive Budget for New York State (April 1, 1987 — March 31, 1988) was submitted to the Legislature by the Governor.

Of major interest to the NYSARC, Inc. were the announced closing of five developmental centers and the beginning of the addressing of the parity issue of the voluntary not-for-profit programs.

While the budget contained many important items which affect programs and services to persons who are mentally retarded

and developmentally disabled, the following is of major interest to our Association:

- A) During 1987-88, the previously announced closures of both Staten Island and Westchester Developmental Centers will be completed.
- B) Concluding in 1991, the State will close the following five developmental centers:
 - 1. Craig D.C. (Livingston County)
 - 2. Newark D.C. (Wayne County)
 - 3. Rome D.C. (Oneida County)
 - 4. Manhattan D.C. (N.Y.C.)
 - 5. Bronx D.C. (N.Y.C.)
- C) A total of 1,607 community residential placements are called for.
- D) The 1987-88 budget includes continued funding for the 96-unit SRU at Newark D.C. and three new sites to be opened in 1987-88. Rome SRU development will be for 144 placements, Sunmount

(continued on page 14)



Executive Director of NYSARC, Marc N. Brandt (right) discusses salary coalition proposals and the proposed closing of five D.C.'s with the newly elected speaker of the Assembly, Melvin H. Miller.



Part of the more than 300 individuals attending the February 10, 1987 Salary Rally.

NYSARC Co-Sponsors Salary Coalition Rally

Eleven Statewide
Organizations
Rally for
Salary Enhancement

On Tuesday, February 10th, representatives from 11 statewide organizations serving persons with mental retardation and developmental disabilities and persons with mental illness met to conduct extensive lobbying activities in the State Legislature on behalf of higher salaries for direct care staff.

The day began at the Albany Hilton Hotel. Nearly 400 persons from across the state gathered to be briefed on the salary enhancement proposal which was agreed upon by the "Coalition for Improving Salaries". Attendees were instructed to advocate for a proposal requiring the State Legislature to appropriate an additional 17,500,000 state dollars (13,500,000 for programs serving persons with mental retardation and 4,000,000 for programs serving persons with mental illness). That proposal called for increasing direct care salaries by an average of \$4,000 per direct care employee.

The meeting at the Albany Hilton concluded with speeches from key public figures. These included Assemblywoman Elizabeth Connelly, Chairwoman of the Assembly Mental Hygiene Committee; Senator Nicolas Spano, Chairman of the Senate (continued on page 2)

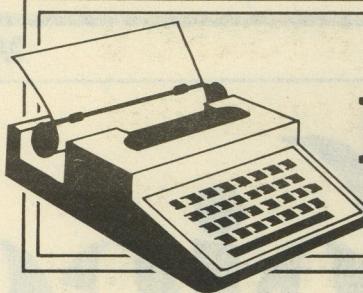
Board of Governors Hold February Meeting — Take Action on NYS Budget, Closing of Five D.C.'s

At the October 1986 Convention held at the Concord Resort Hotel, the governing body of the NYSARC, Inc., the Board of Governors, scheduled an additional Board meeting for 1987. The meeting was held on February 20th and 21st, 1987 in Albany, N.Y. The meeting was scheduled so as to give the Board an opportunity to discuss and to react to the proposed NYS Budget as well as to give the Board an opportunity to discuss philosophical issues.

The meeting was held at the Thruway House in Albany, N.Y. and was well attended. The Board reviewed the proposed Executive N.Y.S. Budget for fiscal year 1987-88 and discussed in depth the proposal to close five developmental centers. A full report on the recommendations that NYSARC has adopted relating to these issues is found in the article on page one relating to the Executive Budget.

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

- Received a report from the Public Information Committee concerning the statewide media campaign.
- Reviewed the proposed NYS Executive Budget as it relates to programs and services (continued on page 7)



EDITORIALS

Governor's Two Key Initiatives Draw Praise

On Tuesday, January 20, 1987, the Governor of New York State, Mario Cuomo, submitted to the Legislature the Executive Budget for April 1, 1987 through March 31, 1988. While the Governor established education as his top priority for the coming year, the proposed budget for the Office of Mental Retardation was up 9.7% and contained increases in almost every existing program.

While the Association has a number of concerns regarding the direction that services are heading, we commend the Governor and OMRDD for two significant initiatives that were contained in the budget submission.

Firstly, the Governor announced the closure of five (5) additional developmental centers including Bronx, Rome, Craig, Manhattan and Newark D.C.'s. The scope of this action is unprecedented and clearly indicates that the systematic institutionalization of persons who are MR/DD is a practice which society has outgrown and which should be relegated to the past. As an organization which has fought for years advocating for the right of these disabled citizens to have the dignity of living within and as part of normal society, we applaud the Governor for initiating this monumental step forward.

Certainly we recognize the risks inherent in attempting such a bold enterprise and we have made our concerns known. Clearly, the movement of so many needy and vulnerable persons is an enterprise which will require a high degree of sensitivity and planning. Yet our expression of concern should in no way diminish or cloud our strong and fundamental support for this initiative.

The Governor also proposed that a special appropriation be approved by the Legislature to enhance salaries for employees of voluntary agencies. Specifically, the Governor recommended \$7,000,000 be appropriated to increase wage levels for all non-administrative personnel.

Most interested organizations felt that it would be necessary to increase salary levels beyond what was proposed by the Governor. However, all agreed that the Governor's initiative established a precedent for recognizing and addressing the wage issue; a precedent which was essential in order to request further salary enhancements from the State Legislature.

The Governor and Commissioner of OMRDD are to be congratulated for addressing both of these critical issues and for taking the lead in public dialogue. ■

The Closing of Five Developmental Centers - The Real Challenges

The Governor's proposal to close Craig, Newark, Rome, Manhattan and Bronx Developmental Centers by 1991 marks the beginning of a long needed discussion on the role of d.c.'s in the future configuration of services. While the announcement to close these specific five facilities came as a surprise the handwriting has been on the wall for years.

Almost nobody has been admitted to a developmental center in this decade. Since the formation of the Office of Mental Retardation there has been a stated objective to move the "system" from an "institutional model" to a "community based system". The statistics speak for themselves. As the number of persons in developmental centers has decreased from 27,000 individuals in 1967 to 12,100 in 1983, to the current 9,900 persons, the number of persons living in community residences and apartments has increased from 12,600 in 1983 to 17,200. OMRDD projects that number will increase to 24,500 by 1991.

Public policy to close developmental centers is not a new theme and is not confined to New York State only. The State of Rhode Island recently announced the closing of the State's only developmental center, the Ladd Center in Exeter. Governor Edward D. DiPrete stated that the closing of Ladd "is one of historic proportions and will make Rhode Island the first state in the country to formulate a public policy of eliminating multi-purpose institutional care for retarded citizens. Through this project we will light the way toward a future in which care for retarded citizens in this nation no longer need include large, impersonal, institutions. This commitment to dignity, quality, and compassion is in the finest traditions of our State."

Congress has also been addressing the role of developmental centers through hearings held by Senator Lowell Wiecker concerning care of d.c.'s and by the introduction of the Community and Family Living Amendments sponsored by Senator John Chafee. The intent of the legislation is to shift the focus of Medicaid reimbursement away from developmental centers and other intermediate care facilities over 15 residents to "community or family living facilities".

While almost all support the proposed closing of the specific five developmental centers almost all have concerns as to how this ambitious goal will be achieved. Therein lies the real challenges.

Of the 1,300 individuals who reside in the five developmental centers slated to be closed many are severely disabled and will need modifications to the existing staffing patterns as well as appropriate programming.

While life in developmental centers has significantly changed for the better over the past decade, real and meaningful programming is still lacking. If community residences for these 1,300 are not to be "mini-institutions" the state must assure a quality of life which currently is not apparent in the large developmental centers.

The support of the closing of these five developmental centers should not be interpreted as a shifting away from the development of needed community development for individuals currently living at home in need of community residence or day program. The challenge for the state here is to balance, appropriately balance, the needs of both individuals (those residing at home in need of a community placement and those living in a d.c.) If the community need is ignored we will find ourselves in a crisis situation a few years down the road as waiting lists swell beyond belief.

The final challenge is to assure that the approximate 7,500 individuals who will remain in developmental centers be given the highest degree of attention. These individuals are the most vulnerable. The success of the closing of the five developmental centers should not diminish the level of care for those who remain behind. In fact, as the "institutional" system becomes smaller the real needs and appropriate program models can be developed and put into place.

The Association has urged the Legislature to establish a review panel to oversee the planned closings and to assure that all placements are both appropriate and in the best interests of the individual. A review panel could assure that the activities which have taken place to date are opened to appropriate oversight and input from responsible persons. Such a panel could indeed accept the real challenges of this initiative. ■

(Salary Coalition continued from page 3)

Mental Hygiene Committee; OMRDD's Commissioner, Arthur Y. Webb and OMH's First Deputy Commissioner, Bruce Feig. All speakers voiced their support and encouragement to the audience for their goal to enhance direct care salaries.

Following the meeting, participants streamed up State Street to the State Capitol for prearranged meetings with their local State Legislators. These meetings were conducted throughout the day. It appears that the number of Legislators visited substantially exceeded 70 different Senators and Assemblymen.

Following their visits, most participants reported that the "coalitions" proposal received vigorous support from those Legislators and their staffs with whom meetings were held. Even more importantly, observers concluded that the events of February 10th had an important impact on the collective awareness of the members of the State Legislature.

Comments from individual Legislators continue to reflect an apparent sympathy with voluntary providers on the salary issue. However, favorable action by the Legislature on the Coalition's proposal is by no means certain. Key decisions concerning state spending must be made by legislative leadership including how much additional spending the state can afford in FY 87-88 and which of the many competing funding proposals now before the Legislature will be addressed.

Coalition representatives have their work cut out for them over the next few weeks to ensure that the Legislature substantially addresses the salary issue when it enacts the budget for the 87-88 state fiscal year. The major NYSARC funding request this year in the New York State budget is the additional sum necessary to provide the staff of our chapters and the field as appropriate wage. ■

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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

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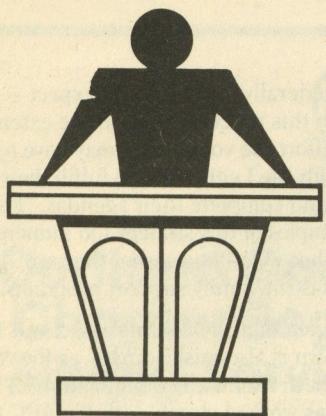
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Subscription to Our Children's Voice is through membership in a local chapter of the New York State Association for Retarded Children, Inc. The publication is also available to the general public at \$ 1.50 per year.

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The President Speaks



At the October 1986 Annual Convention held at the Concord Resort Hotel, the Board of Governors reviewed a major proposal concerning the structure of the NYSARC, Inc. While it was decided by the board that there was no immediate need to change the organizational structure, the need for additional meetings was apparent.

Since the October meeting, additional regional meetings have been held, a Board of Governors' meeting was held in February and a Presidents and Executive Directors' meeting is to be held in March.

The February board meeting provided the board an opportunity to review the proposed New York State Budget and allowed the board enough time to discuss a number of philosophical issues. It is hoped that these additional meetings will allow the chapters in the Association an increased forum to voice their concerns and recommendations.

My remarks to the board at the February meeting were brief but I have been pleasantly surprised by the number of calls I have received reinforcing the concerns that I raised.

As President of the Association, I take great pride in the collective accomplishments that our chapters have achieved. If history has taught us any lesson it is that our objectives can be met if we stand together as one Association in what we as parents, professionals and advocates desire for persons who are mentally retarded and developmentally disabled.

As President, I have had the great pleasure and opportunity to visit with many of our chapters. These visitations constantly reinforce my positive feelings that as an Association, chapter by chapter, we are accomplishing many of our objectives.

My one concern of caution, however, arises out of my feeling that now, more than ever before, we must be careful not to allow popular, political themes to sidetrack our goals and objectives. I sense that some programs are being developed and initiated because the funding is enticing rather than meeting the real needs of persons who are mentally retarded and developmentally disabled. Such occurrences will only lead to elitist types of programs and surely will not provide adequate or appropriate services.

Our Association has always been strong and we have never been more united than we are today. Let us all stand together and reaffirm our original mission which is just as current as the day in 1949 that it was written. ■

David B. Lettman

Quote of the Quarter

...there seems to be an almost universal sense of relief that a decision about Craig's future had been made and that clear and forceful direction is now being provided on the issue. I suppose the reaction should not be too surprising - nobody's comfortable with the burden of uncertainty. People, our course, want to feel in control of their own lives."

Richard C. Merges, Director
Craig DDSO
Sonyea, New York

(commenting on the announced closing of Craig Developmental Center)

NYSARC's Legislative Platform Moving Rapidly

At the Thirty-Seventh Annual Convention held in October 1986, the Delegate Assembly, representing the membership of the NYSARC, Inc., adopted the Association's 1987 Legislative Platform. The platform was printed in its entirety in the December 1986 OCV edition.

At the time of this writing, a number of bills have been sponsored for the Association by the Legislature. Much of the Association's 1987 Legislative Platform is the direct result of chapter requests for needed reform.

As of the date of the printing of OCV, the following is a summary of bills from NYSARC introduced in the State Legislature:

1. A2455 by Connelly and S1638 by Spano, provides for an Ombudsman to advocate for the appropriate care and treatment of individuals residing in Developmental Centers.

*Assembly Mental Hygiene Committee
Senate Mental Hygiene Committee*

2. A2879 by Kremer and S2044 by Spano require that fees established for ICF/MRs and Community Residences include the cost of land for newly established facilities.

*Assembly Mental Hygiene Committee
Senate Mental Hygiene Committee*

3. A2975 by Connelly and S310 by Donovan, make it possible for clinical professionals to receive scholarship ben-

efits in exchange for working in voluntary not-for-profit agencies licensed by OMRDD. This bill amends existing law establishing the "Health Corps" which currently makes these benefits available to clinicians working in state-operated facilities only.

*Assembly Health Committee
Senate Finance Committee*

4. S313 by Donovan, increases the current limitation on BOCES ability to rent space from \$5.00 to \$10.00 per square foot in order to facilitate the use of space in normal public school facilities by children with handicapping conditions.

Passed Senate

5. S315 by Donovan, increases the building aid formula for children with handicapping conditions from \$2,000.00 to \$3,000.00 per pupil in order to facilitate the use of space in normal public schools by children with handicapping conditions.

Passed Senate

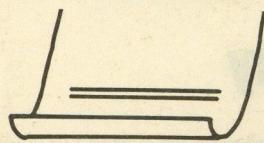
6. A2446 by Connelly and S1629 by Spano establish a procedure to require OMRDD to promulgate amended fees within 90 days of the receipt of a completed rate appeal application to amend a fee for an existing program.

*Assembly Mental Hygiene Committee
Senate Mental Hygiene Committee*



Joseph T. Weingold NYSARC Office Building as it first looked around 1900.

Letters To The Editor



Dear Editor:

I would like to wish everyone in the ARC family a Happy New Year and congratulate you for your continuing advocacy.

In your recent editorial, **An Inequity within New York's Family**, you praise the Governor for his administration's accomplishments. In addition, to those achievements you mention, there are many more that can be highlighted — especially since the ARC Chapters did so much to contribute to our successes.

The ARC family accounts for almost 35 percent of all persons living in community residences and for more than 35 percent of all persons in day programs. ARC chapters receive more than 40 percent of all local assistance funds for day programs. What's even more telling is that the ARC, as a major provider, has grown statewide in the past three years by more than 25 percent.

Perhaps most significantly, we currently have underway with ARC chapters more than 100 projects that will accommodate some 700 persons in community residences, and another 60-plus projects for more than 2,000 persons in day programs.

All of those activities reflect the strong commitment of the ARC chapters.

That tremendous amount of activity however, would seem to argue against what you perceive as a "climate of uncertainty." I would have to say that the development over the past few years — and what is currently going on — hardly reflect a "lack of a state policy" as you stated in your editorial.

Nor is community development being blocked by a "lengthy, confusing development process." Indeed, the situation is the exact opposite.

The ARC chapters continue to be aggressive, OMRDD continues to facilitate and enable, and the Governor and Legislature continue to be supportive.

This is — and will continue to be — an exciting time in our field. Yet I am struck by the dissonance between what you are saying and the reality of all the efforts that are underway in our system.

Wouldn't it be better to take a supportive approach — especially in view of state government's willingness to continue to expand opportunities for the ARC and its clients? It is one thing to express concern about difficulties that may be confronting the ARC — it is quite another, however, to cast a pall over our system by contending that things are uncertain and confusing.

Such gloomy assertions are basically, wrong — and they are unfair to all those who have worked so hard to establish the co-operative partnership between the State and the voluntary provider community.

The reality is that there is more certainty and stability than ever before.

We stated clearly in our three-year plan in 1983 what we saw as the anticipated growth and changes. And we have met the



challenges and met our objectives. We have worked diligently to establish a clear and certain regulatory and reimbursement policy — and we have succeeded in creating the most supportive environment to date. The day treatment fee system, and the new day treatment regulations speak for themselves.

In another area, I was dismayed by your concern with small residential units (SRUs), and by your inaccurate and misleading statement that the establishment of SRUs "clearly demonstrated a lack of a state policy dealing with the residential needs of persons who are mentally retarded." All one has to do is look at the community continuum and the growth of residential beds in the last four years. More than 4,000 such beds were created. The Legislature and the Governor continuously highlight this growth as one of their top achievements. More needs to be done, I agree, but our accomplishments have resulted because there is a clear policy.

In a letter sent to OMRDD on March 3, 1986, it was stated that NYSARC "does not oppose the current plans" of OMRDD, adding that your support of SRUs was contingent upon several items that closely parallel the 1986 appropriation language passed by the Legislature and agreed to by the Governor. Your support was essential to the overall endorsement by the Legislature. The resolution passed at your last convention not only is disappointing, but it is inaccurate, not very pragmatic, and clouded by unrelated aspects. After extensive debate during the Fall of 1985 and on into the 1986 legislative session, the Legislature adopted a practical approach to serving clients, one that is proving to be highly successful. Just look at Newark. It's too bad that NYSARC shifted its position and now apparently will not be an ally in supporting these better living opportunities for institutionalized clients.

I was even more struck by the statements in your editorial about the 1115 Waiver and 5.07 policy papers.

I am perplexed by the statement that the "field is in shock as to the complexity and immediate need for such dramatic and revolutionary change."

First of all, the 1115 waiver is no more revolutionary than the initiatives taken in the late seventies with ICFs/MR and with day treatment. We have almost become matter-of-fact about the dramatic changes that have occurred through aggressive action by state government, and by this agency in particular in concert with the voluntary sector.

The changes envisioned for the future are also responsive to the demands for more services, for greater efficiency and for improved quality of care, similar to the approach taken years ago.

Policy development in this agency has been an open and deliberate process.

No surprises, no shock.

Indeed, during the past several months we have had more extensive discussions and positive recommendations than ever before. One could objectively say that the directions we have put forth have generally been endorsed, but with the appropriate amount of caution and concern that we share. We are trying to achieve the growth and flexibility that all would want, but with a greater degree of efficiency.

We also want to build on our successes so we can maintain a high level of certainty and stability. This is the real essence of the 1115 waiver and the policy papers.

In terms of the politics of budgeting, I am concerned that your editorial leaves the impression that the voluntary sector is a solo flyer in this area. This can't be further from the way it actually works.

The Governor and I recognize the needs of the voluntary sector, and we seek to craft policies and budget recommendations with such concerns in mind.

As you well know, we spend a considerable amount of time at the beginning of, and during, the budget process talking with various organizations, including the State ARC, to compare policy and budget priorities. This is a healthy and politically practical strategy which should not change.

We generally know what to expect — and through this process we learn the extent of the effort the voluntaries may have to put forth with the Legislature to fulfill their priorities and complete their agendas. There are examples of this strategy too numerous to list; but we all know what they are — one success is the family support programs.

The idea that the voluntary sector is left on its own is also misleading — as the ARC knows better than any organization. The State has worked closely with the ARC to resolve some very serious financial and management issues that some of its chapters have faced. We continue to stand ready to meet these challenges whenever they arise.

On the issue of regulatory behavior of OMRDD, while we have been aggressive — which was clearly stated by me as an objective at the beginning in 1983, we have also seen the overall quality of care improve for clients living in the community. In general, the very providers who have been the subjects of this scrutiny responded to a survey in which more than 80 percent of them agreed that the survey process has resulted in an improvement in the quality of care. The leadership of ARC has said a number of times that the regulations themselves are fine. Indeed, it also has been said that more regulations may be needed. The concern seems to be focused on enforcement and on finding ways to separate critical elements from the important ones.

One of the major objectives set forth in 1983 was to improve the consistency of survey teams, to increase the training of surveyors and to standardize the survey requirements. All of this and more has been accomplished.

We believe that the survey and certification function in this agency should be commended for its productivity, efficiency and the quality of its survey process. Other outside oversight agencies — such as the Legislative Commission on Expenditure Review, the Commission on Quality of Care and the regional Health Care Financing Administration — agree with our perspective. This does not mean that we do not need to continue to find ways to keep the survey process in balance with provider capabilities and the regulations themselves. But, you must bear in mind the regulations exist because they express the right things to do, in and of themselves, for disabled individuals. In that light, our main responsibility is to make sure that enforcement activities are conducted in the least intrusive and least disruptive way possible.

We will continue to work with providers and others to find even better ways of achieving accountability.

In conclusion, I trust that the ARC family is ready to embark on the system reforms that are necessary to meet the new demands, similar to what has been accomplished over the years. We are always attentive to working in concert with all interested and affected parties. I hope you will join with us as we seek to achieve our mutual goals.

Sincerely,

Arthur Y. Webb
Commissioner
NYS OMRDD

Editor's Note: OCV welcomes comments concerning this letter.

Task Force Recommends Program and Fiscal Guidelines for Preschool Operation

Dear Editor:

As a paid-up member of the Benevolent Society for Retarded Children, Willowbrook Chapter of New York State Association for Retarded Children, Inc., and for all other reasons, a member in good standing, I have the right to dissent on Resolution #7 as presented by the Resolution Committee at the NYSARC Convention in October of 1986.

Of the eight resolutions that were presented one was deleted because, in the judgement of the Resolutions Committee, it was superfluous. Of the remaining seven, numbers 1, 2, 3, 4, 5, 7, 8, all but #7 were good, acceptable "meat and potatoes" issues that all could approve. However, I had the feeling that Proposed Resolution #7 would have had some difficulty in being accepted as written. So, the committee decided to fortify its position on this issue and they did so with a battery of WHEREAS's. Resolution #7, which purportedly dealt with the issue of SRU's Versus Community Residences, was wrapped in the "flag" of five (5) WHEREAS's. None of the other resolutions had that many to explain their intent... and it seemed to work. The infamous Resolution #7 was carried by a vote of the Delegate Assembly 559 in favor to 445 against. The ambiguity of the language of the resolution made it difficult to separate the wheat from the chaff. The more you studied this #7, the harder it was to understand. Some lawyers write and talk that way.

The preamble to our by-laws imply that the purpose of our organization is to help the retarded because retarded people can be helped. Our letterhead bears the inscription that states with honor... NYSARC, a not-for-profit, tax-exempt organization of parents and advocates to help all individuals who are mentally retarded, wherever they are, regardless of color, creed or age... truly a remarkable statement of purpose. But when you view the issues, you can add "or place of previous servitude". One would think that institutions (now called developmental centers) are not included in our stated purpose.

Resolution #7 should read "Be it resolved that the NYSARC should actively support the right of people with developmental disabilities to live in the community". No one will oppose #7 if that was the way it was worded. A vote of 559 to 445 would have been unanimous in favor if we stressed voting for a positive position rather than a negative one against SRU's.

Once in a while the literature of NYSARC uses the term "philosophically" in referring to some issues. On a politicizing level, you may prevail but "philosophically, I, for one of many delegates, refuse to compromise or be compromised."

I propose that the Board of Governors at their February meeting endorse a proposal to recommend that the 559 to 445 vote of #7 be rescinded and bring a positive resolution to actively support community residences for the retarded and establish unanimity of mind and purpose in NYSARC.

Mannie Barsky
Willowbrook Chapter

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.

Recently a Task Force appointed by New York State Education Department Commissioner Gordon Ambach submitted its final report and recommended guidelines for the operation of preschool programs for children with handicapping conditions. The Task Force which was established in accordance with Chapter 683 of the Laws of 1986, included provider representatives, parents, county government and representatives of statewide organizations including NYSARC.

Chapter 683 does not abolish the current statutory framework set forth in Section 236 of the Family Court Act and Section 4406 of the Education Laws of New York State. However, it does authorize the SED commissioner to establish program and expenditure guidelines and standards for the provision of programs and special services for children with handicapping conditions who are under age five. Additionally, Chapter 683 authorizes counties to perform fiscal audits and to recoup overpayments. Also, it requires that transportation contracts be awarded to the lowest responsible bidder in accordance with Section 103 of the General Municipal Law and that all vehicles used in the performance of such contracts meet the minimum requirements for school-age children as established by the commissioner of transportation.

The Task Force has recommended that the program and fiscal guidelines be considered "conditions of participation" for state aid funding. In so doing, SED would promote greater consistency for children, parents, providers and counties in the provision of preschool programs and special services without disrupting or dismantling the existing service system.

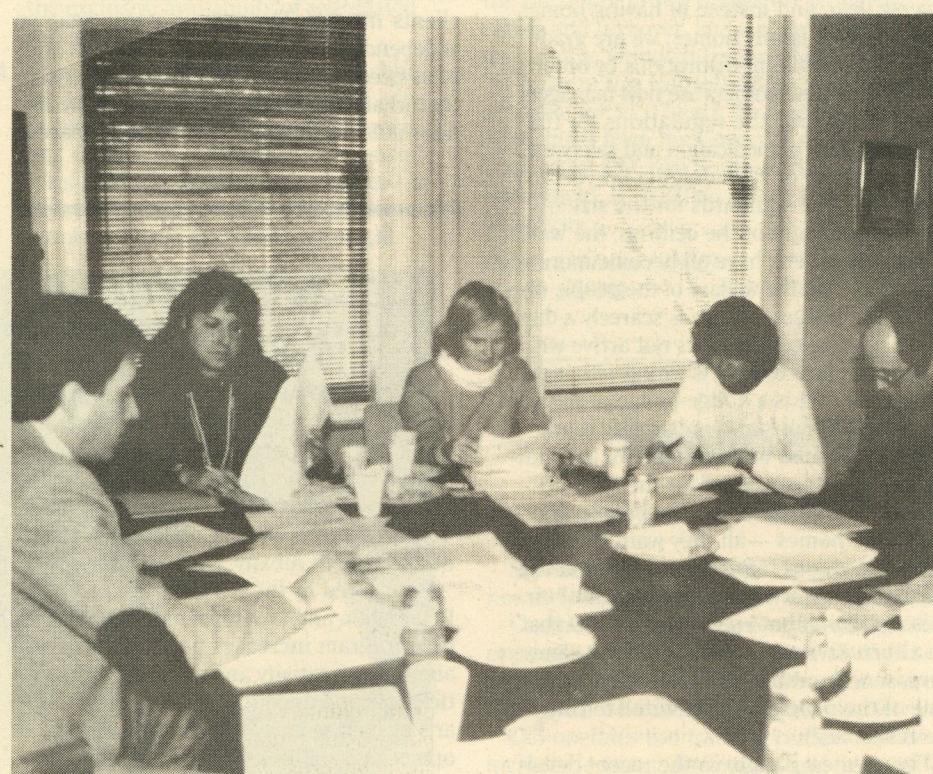
Some of the key recommendations of the Task Force include the following:

1. Transportation - provisions for seat belts and car seats; assistance for children

on and off the bus and into and out of their home; two-way radios and beepers; screening of drivers and aides for history of child-related offenses; parent ability to accompany children; presence of aides and matrons; maximum travel time of one hour per trip.

2. Allowable Cost Manual - the Task Force did not recommend a rate setting system but did specify in detail allowable instructional and non-instructional cost items.
3. Teacher Certification and Mainstreaming - the Task Force recommended modifications to the current teacher certification requirements which would promote the placement of children in the least restrictive environment and would fund the educational and related services costs for such programs.
4. Formulate and Implement "Developmental Delay" Handicapping Condition for Eligibility - while this may require a regulatory change, the Task Force recommends SED take steps necessary to provide for a "Developmental Delay" handicapping condition for eligibility for preschool programs and services. In many cases, the current listing and definitions of handicapping conditions are not appropriate for young children.

Additional recommendations made by the Task Force may be obtained by contacting John Kemmer at the NYSARC State Office. OCV readers are reminded that the proposed guidelines developed by the Task Force are *recommendations* for Commissioner Ambach's consideration. NYSARC is informed that the Commissioner's guidelines and standards will be finalized and disseminated for implementation during the upcoming school year beginning July 1, 1987. ■



Chapter representatives review draft preschool program and fiscal guidelines. From left to right: John Kemmer, NYSARC; Nancy Miringoff, Putnam ARC; Sue King-Elkan, Otsego ARC; Karen Lederman, Rensselaer ARC; Joe Judd, Otsego ARC. Also present but not shown: Annemarie Neubecker, Livingston-Wyoming ARC; Richard Swierat, Westchester ARC; Ray Lewandowski, Madison ARC.

Dr. Robert Guthrie Wins Kennedy Award



Dr. Robert Guthrie a medical researcher of the State University at Buffalo and current member of the NYSARC Prevention Committee, has been named a 1986 winner of the Kennedy International Award in mental retardation.

Dr. Guthrie who developed the screening test for PKU was cited for his contribution in "saving the lives of thousands of PKU babies throughout the world."

The PKU test, now routinely administered to all newborn children in the United States and other parts of the world, can determine the presence of phenylketonuria, an inborn error of metabolism which can lead to mental retardation. Placing the infant on a special diet can minimize or prevent this from occurring.

The Kennedy International Award was founded in 1946 by Joseph and Rose Kennedy in honor of their late son Joseph Kennedy, Jr. who was killed in World War II. This award is the only private award which focuses on mental retardation, in the world.

Announced by Eunice Kennedy-Shriver, she described Dr. Guthrie as a "brilliant innovator who initiated the process of prenatal screening for inborn errors of metabolism which lead to mental retardation." Mrs. Shriver added that "His work has stimulated the entire field of neo-natal screening which, in addition to PKU now includes hypothyroidism, amino acidurias and other genetic disorders."

Dr. Guthrie is one of 9 winners of the award, and was selected from among thousands of nominations submitted from many countries.

Our Association joins the world in congratulating Dr. Guthrie for his contribution to the well-being of our children and unselfish dedication to the field of mental retardation. ■

GUEST COMMENTARY

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

State and Government Funding Dream or Nightmare?

by: Paul Cesana

Throughout the Association, more and more concern is being raised as to how new initiatives are affecting the quality of programs and on-going needs of persons who are mentally retarded and developmentally disabled. Paul Cesana is the Executive Director of the Niagara County Chapter, NYSARC, Inc.



Mr. Bill Stager was the charming and determined individual immortalized by Mickey Rooney in the award winning performance of "Bill", a sensitive and telling television docudrama of an adult who is mentally retarded and who, after years of institutionalization, makes it on his own in the community, touching many a life. I recently had the pleasure to hear at a recent convention the person who was responsible for bringing this story to the general public, Bill's close friend, Barry Morrow. Mr. Morrow revealed how Billy's greatest desires were simply to find a place of his own, to find a job, and to "have a buddy". Bill fulfilled his desires thanks to his best "buddy", Barry Morrow, and enjoyed a life thrilled with the excitement of his community experience, the gratification of his cafeteria work and the hundreds of friends he enjoyed and touched over the years.

All of us at the ARC have had the privilege and satisfaction of becoming acquainted and being touched by many individuals like Bill Stager whose desires are also as simple as his. In recent years, the drastic commitment of state and government funding has assisted us in an unparalleled fashion in providing quality services through housing, staffing and programs which we all believe are offering our clients the needed opportunities to lead a normal life style.

Our clients, parents, friends and agency members need to be alerted, however, that the original simplicity and spontaneity of care and concern has been turned in recent years by these very funding agencies, for better or for worse, into complex systems of organizational professional and political service delivery mechanisms.

The politics of money and government has escalated to new dimensions — those issues of accountability, documentation, and protection from regulatory and legal liabilities. It is beginning to take precedence over those

basic issues of caring, while institutionalizing the manner in which we provide to our clients those basic opportunities for life fulfillment.

Helen Kaplan, one of the founders of the ARC movement and a protagonist of community based services development in the Nassau County Chapter, bemoaned in the recent commentary:

"Now, the goals of the program are in reverse gear, and instead of having homes that replicate family homes, we are gradually becoming mini-institutions by order of OMRDD. Housemothers are now managers pushing papers; the regulations for the administration of medication and safety etc. need a battery of Philadelphia lawyers to interpret. The standards for the size of rooms, the height of the ceilings, the width of stair treads etc. have all become more important than the welfare of the people who live in the houses. There is scarcely a day that a barrage of mail does not arrive with a list of citations of what is wrong with every house. All of it is a hodge-podge of nitpicking gobbledegook and only rarely is any comment related to the welfare of the individual. The "inspectors" for the state obviously do not care about the people who live in the homes — all they want to know is how we record information, and that the information is written according to their prescription, without regard for the fact that an alternative way would serve the same purpose without the wholesale waste of the time of the people who are hired to care for the residents."

The greatest danger in the recent developments in our area of services is that choices or services are gradually, but systematically, eliminated in favor of strict interpretation and enforcement of rigid existent standards. What are proposed as new system "reforms" and "proposals" are but ways to keep the inefficiencies of the funding and regulatory offices intact, while forcing the

cost containment effort onto those providers who have in fact sustained that pressures of providing the key services over the years.

As Marc Brandt, NYSARC Executive Director, commented in a recent testimony presented to OMRDD on the future of services for persons with developmental disabilities "Many of the so-called new initiatives which are being proposed such as Family Support Services, Aging-Out Services, Supportive Work are not viewed by us or the field as 'new'. We have always supported these concepts. In fact, they have been the heart and soul of the voluntary sector for decades. It is almost as if the voluntary sector has ignored children coming of age and needing a vocational rehabilitation program, as if families have been neglected and unserved, and as if nobody was placing into competitive employment individuals who are disabled. It has in fact been the system that has not enabled the true continuum to go forward."

As individuals truly concerned with how our clients are served and will continue to be served in the future, we need to be in touch with these developments and to be prepared to respond appropriately and courageously to the politics of government bureaucracies.

Most importantly we also need to dissipate any complacency with the support of public funding as these monies are vulnerable to political trends and are consistently loaded with expectations and political intents which are not always in the best interest of the clients we serve. Our Board of Directors has made a historical commitment to seriously initiate a Resource Development Program in order to develop local and autonomous resources which can meet our clients' needs according to our priorities and our own clients' interest. The success of this program is dependent on each one of us as each one of us needs to commit our energies to ensure that what we thought had become a dream does not turn into a terrifying nightmare. ■

Exceptional Artworks 1987

Exceptional Artworks, an annual art exhibit that features paintings, crafts, sculptures and photography by persons with mental retardation and developmental disabilities will hold its third exposition on May 4-8, 1987 at the North Concourse, Empire State Plaza in Albany.

Sponsored by the N.Y.S. Office of Mental Retardation and Developmental Disabilities, this program increases public awareness about the creativity and abilities of the participants and encourages expression in the arts by men, women and children with developmental disabilities.

Chapters are welcome to participate in this program. Complete details and exhibit space request forms are available by writing to:

Sally Peyrebrune
OMRDD/Exceptional Artworks
44 Holland Avenue
Albany, New York 12229 ■

Regents Pass Regulations for Twelve Month Programs

The Board of Regents, at their January meeting in Albany, unanimously approved regulations that should, if implemented appropriately, serve children with severe disabilities whose needs are so intense that without a twelve month program would not be able to maintain developmental levels in their school program.

What Children Might Fall Under the Definition of Those With Severe Disabilities?

The regulations to a great degree are specific as to what children should be considered for a twelve month program. They are as follows:

- (1) Pupils whose management needs are determined to be highly intensive and require a great degree of individualized attention and intervention who are placed in classes in which the maximum class size shall not exceed six pupils, with at least one paraprofessional assigned to each class during periods of instruction.
This is often referred to as an Option III Class.
- (2) Pupils with severe multiple handicaps, whose programs consist primarily of habilitation and treatment and are placed in special classes where the maximum class size for those pupils with severe multiple handicaps, shall not exceed 12 pupils. In addition to the teacher, the staff/pupil ratio shall be one staff person to three pupils. The additional staff may be teachers, paraprofessionals and/or related service providers.
This is often referred to as an Option IV Class.
- (3) Pupils who are recommended for home and hospital instruction whose special education needs are determined to be highly intensive and require a great degree of individualized attention and intervention or who have severe multiple handicaps and require primarily habilitation and treatment.
- (4) Pupils whose needs are so severe that they can be met in a seven-day residential program.
- (5) Pupils whose handicapping conditions are severe enough to exhibit the need for a structured learning environment of twelve months duration to maintain developmental levels as determined by the Committee on Special Education (CSE) formerly referred to as the Committee on the Handicapped. These students would be others not referred to in the previous four paragraphs.

*What Children Meet Definition of Paragraph Five?

The CSE in conjunction with the parents will determine at the time of initial placement into school (age five) or at the annual review whether a child fits into this category.

All children whether they are disabled or not suffer a certain amount of regression after being out of school during the summer. The issue to be decided is whether the expected regression is serious enough to warrant a twelve month program. If there is a question in the minds of parents as to whether their CSE will recommend placement in a twelve month program, it may be a good idea for parents to seek an outside evaluation by a private agency.

Responsibility of CSE

The CSE, at either the initial placement or at on-going annual reviews must include in Phase I of the IEP:

- (1) Whether the pupil is eligible for a 10 month or 12 month educational program,
- (2) If a 12 month program, the identity of the provider of services during the months of July and August.

Other points to be aware of are:

- A. Program during summer must be at least 30 days in duration.
- B. For this year, written parental consent must be obtained for all children receiving a twelve month program.
- C. After this year, written parental consent must be obtained for initial placement.
- D. All programs offered during July and August shall be approved by the Commissioner.
- E. If a CSE fails to recommend a twelve month program and the parents feel that such a program is necessary, parents may file for an impartial hearing. For more information regarding how to request such a hearing please refer to:

- (1) Part 200, Regulations of the Commissioner, 200.5 Procedural Due Process, Page 20.
- (2) A Parent's Guide to Special Education, Page 47.
- (3) Guidebook for Committees on the Handicapped in New York State, Page 28.

All of the above publications can be obtained through your local SETRC office or by writing to the NYS Education Depart-

ment, Office for Education of Children with Handicapping Condition, Division of Program Development, Room 1069, Education Department Annex, Albany, New York 12234.

- (4) School year runs from July 1st to June 30th.
- (5) Students who turn twenty-one during the school year are not eligible for an educational program at the end of that year (July & August).
- (6) If a student receives an IEP diploma prior to age twenty-one, that student may be placed in an educational program for the months of July and August following the receipt of that diploma. Please refer to Summer and Winter 1986 editions of Edu-Letter for additional information regarding IEP diplomas.

For legal assistance in impartial hearings you may wish to contact your local Protection and Advocacy (P&A) office. (For complete listing of those offices see page ??? of the Edu-Letter.)

Will Mainstreaming Automatically Exclude a Student From a Twelve Month Program?

If a student is mainstreamed for any portion of the day, will this automatically eliminate the CSE's consideration for a twelve month program? All children labelled as disabled by the CSE must be reviewed for possible twelve month programming.

Some students with severe disabilities are benefitting by having opportunities to be integrated with non-disabled children during parts of their school day. Having this opportunity does not reduce the severity of the condition and consequently would not automatically eliminate the necessity of a twelve month program.

What About the Five Year Old Preschooler?

There are many questions regarding procedures for the five year old child who will complete their preschool program in June. At the time OCV went to press there were many unanswered questions still remaining. It is our strong recommendation that parents who believe their child needs a twelve month program should immediately contact their local CSE for assistance. ■



Public Information Chair, Robert Katz, reviews statewide media campaign.

(Governor's Board continued from page 1)

vices to persons who are mentally retarded and developmentally disabled and adopted a series of recommendations.

- Reviewed the NYS Labor Department Action against Otsego County Chapter.
- Approved the By-law revisions of the Oneida County Chapter.
- Discussed four philosophical issues of concern to the Association:
 - A) Mission Statement of NYSARC, Inc.
 - B) Approaches to Government
 - C) The role of developmental centers in the future configuration of services.
 - D) Least Restrictive Environment.

- Adopted a position statement on the Least Restrictive Environment.

- Adopted a position of support in regards to the closing of five developmental centers but wanted the support to be accompanied by concerns of how the facilities would be closed.

- Approved for those chapters having one Board of Governor representative the use of an alternate when the regular member cannot be in attendance. The alternate would have their expenses reimbursed but could not vote.

- Approved sending chapter offices appropriate information that is transmitted to the Board of Governors. ■



Board member listening to issues being raised.



The Chair of the Legislative Committee, Michael Limongelli, proposes a restructuring of the current committee.

NYSARC Testimony Responds to Proposed Plan to Close Six Developmental Centers

Association Board of Governors Supports Proposal but Urges Legislature to Put Into Place a Review Panel

In this years Executive New York State Budget for fiscal year 1987-88, Governor Cuomo announced the closing of six developmental centers by 1991. The developmental centers to be closed are Rome, Craig, Bronx, Manhattan, Newark and Westchester.

Both the Assembly and Senate Standing Committees on Mental Hygiene held joint public hearings on this matter.

On February 18, 1987, the Executive Director of NYSARC, Inc., Marc N. Brandt, presented the following testimony:

"I am Marc Brandt, Executive Director of the New York State Association for Retarded Children, Inc. As you are well aware, our Association serves thousands of New York residents who are mentally retarded and developmentally disabled within sixty-five chapters, located in almost every county, community and developmental center. We have over 50,000 members and our prime responsibility is to advocate for the needs and rights of persons who are mentally retarded and developmentally disabled whether they are served directly or by our Association or other voluntary organizations or through the state operated community programs and developmental centers.



NYSARC Executive Director, Marc Brandt, giving testimony at recent Legislative Hearing on the proposed closing of five D.C.'s.

Our Association wishes to commend the Assembly Standing Committee on Mental Health, Mental Retardation and Developmental Disabilities and the Senate Standing Committee on Mental Hygiene and their staffs for holding these hearings and affording all parties concerned an opportunity to comment on the proposed OMRDD plan to close six specific developmental centers.

I am here today, representing our Association at the request of the President of our Organization. He wishes that I convey to the joint Committees that while my testimony represents the NYSARC position, the governing body will be meeting this coming weekend and will be adopting the Associa-



Chairs of the Assembly and Senate Mental Hygiene Committees, Assemblywoman Elizabeth A. Connelly (middle), Senator Nicholas Spano (right) review testimony at February joint hearings on the proposed plan to close five D.C.'s. Don Robbins (left), Legislative Associate looks on.

tion's official position at that time. Within a week of these hearings our Association will be transmitting our official position.

We have however, just recently conducted four regional meetings of the Association where this issue was discussed at length. Obviously, the subject matter has been of great importance to the Association and firmly believe that my remarks are representative of our sixty-five chapters. Almost without exception the concern voiced was not objecting to the closings but, rather how the facilities would be closed, why were some of the facilities chosen over others, and most importantly, how are the individuals currently residing in the six developmental centers going to be humanely and appropriately placed?

Clearly, it appears to me that this concern is related to the manner in which the closings have been initiated.

Specifically, the announced closings of the developmental centers came as a surprise to everyone especially since the 1986-1991 OMRDD program-capital plan stated that all of the five developmental centers would be continued and specific capital funding projects were planned for those facilities. This "overnight" turn-around decision to close five state facilities does not demonstrate appropriate planning nor does it clearly articulate a state policy regarding developmental centers.

Parents are nervous, even frightened as to the future placement of their children. Their concern is understandable. This major initiative was not preceded by any visible public discussion or input on the matter. Such apparent absence of forethought was made all the more obvious by the considerable amount of public discussion which was conducted by OMRDD regarding less immediate initiatives. Although hearings were held across the state during the fall and early winter months on topics ranging from medicaid reform to the structure of DDSO's

It must be remembered that whatever their shortcomings are these developmental centers comprise a home for the many persons who live there. These persons and their families often have developed an attachment to these facilities in the course of attempting to make the best out of their individual situations. They have fought to gain for themselves an essential sense of security within their institutional surroundings.

Their feelings must be respected. A careful, well thought out approach to the closure of these developmental centers must be an integral part of the activities which surround this initiative over the course of the next five years. Additional closures must be considered in advance. Decisions to initiate future such actions should not be allowed to materialize as a fait accompli effecting the fate of thousands of persons without appropriate consideration.

Finally the role of the developmental center as a treatment modality must be discussed. Persons who are mentally retarded and their families must know specifically why institutional care is required in certain cases when community based care has been proven so successful.

The state and all concerned persons must answer questions that finally determine whether or not developmental centers have a real and permanent role to play in the care of persons who are mentally retarded. Without answers to such basic questions our uncertainty and anxiety over the fate of literally thousands of persons will persist.

I want to state that our Association's position regarding these closures is not yet officially decided since our Board has not as yet met. I do feel, however, that based upon



Senator Frank Padavan directs questions regarding the proposed closing of five D.C.'s to Executive Director Marc N. Brandt. Assemblyman Samuel Colman looks on.

guarantees can be given by OMRDD that community development for individuals not residing in the community in need of service will not be put aside? What guarantees can be given to individuals currently living at home to insure that their placement needs will also be met?

We urge the Legislature during this year to expand these hearings and to hold state-wide public hearings on the future direction and purposes of developmental centers. The time has now come to develop a meaningful state policy concerning this issue. OMRDD must be held accountable to a plan that has been accepted and adopted by the Legislature.

5) Over the past three years the Association has not received any serious response to the co-location issue. Will the campuses of the developmental centers truly be vacated or will SRU's be next to correctional facilities? We have come so far in our thinking and attitudes toward persons who are mentally retarded that to allow co-location to occur would not only be unjust but hypocritical. We urge the Legislature to hold up the planned SRU's at Rome Developmental Center until a full review can be completed by the Legislature as to the plans of that facility.

6) Finally, in announcing the developmental center closings the Governor stated, "As we develop small community-based programs for mentally retarded and developmentally disabled individuals, it becomes clear that the continued affordability of this policy requires the closure or conversion of inefficient buildings, and, in some cases, entire campuses". Clearly a major laudable aim of the state is to save public dollars. Our Association appreciates this goal since public dollars are the life blood of services to persons for whom we care. Yet, I must use this opportunity to once again implore your committees to take action this budget session to raise salaries paid to direct care employees in the voluntary sector. To close facilities and save state dollars, organizations such as ours will be called upon to supply essential community placements for persons coming out of developmental centers. But to do this job adequately we must be able to pay salaries sufficient to attract the kind of staff who can be entrusted to capably meet the needs of persons who are disabled. Please, take this consideration into account.

The announced closing of Westchester, Craig, Newark, Rome, Manhattan and Bronx Developmental Centers could have been planned and executed in a much more sensitive manner. The shock to the parents, the work force involved, and I am sure to many of the individuals residing in the developmental centers must have been traumatic to say the least. While there appears to be a number of reasons why these particular developmental centers have been targeted to close, we have in New York State an excellent opportunity to demonstrate our real abilities, skills and commitments to a population of our state that is disabled.

Twenty-six years ago former President John Kennedy stated that commitment to institutions and segregation from society was morally wrong. He remarked that if we were unable to prevent retardation, "we must provide for the retarded the same opportunity for full social development that is the birthright of every American".

The Governor has begun that process. In order for that goal to truly be met our Association urges the Legislature to direct OMRDD to carry forth this goal in as humane and sensitive a manner as possible. If that is accomplished we would truly be helping part of New York State's family.

Thank you."■

my conversations with our Developmental Center chapters I anticipate that the N.Y.S. Association for Retarded Children, Inc. will take an official position of not opposing the planned closures; and most likely will support the closing of these facilities, providing proper planning leads to superior living and day programming alternatives to that which is currently being received by the residents.

NYSARC, Inc. has a number of recommendations which it wishes to offer to the Legislature in conjunction with our support. These recommendations are offered based upon our experience and desire to advocate for persons who are mentally retarded.

In order to assure that the highest of priorities is given to the individuals being relocated and not for any other reason, NYSARC, Inc. urges the Legislature to consider the following recommendations:

1) A review panel be put into place with members being chosen by the Legislature. The charge of this committee will be to oversee the planned closings and to assure that all placements are both appropriate and in the best interests of the individual. This would assure that the activities which have taken place to date are opened to appropriate oversight and input from responsible persons. The panel should also review and make recommendations regarding the status of the 15 remaining developmental centers not currently scheduled for closure.

2) NYSARC, Inc. urges the Joint Committee's represented here today to ascertain the real reasons why these five developmental centers are being closed. If one of the prime reasons why Bronx and Manhattan have been targeted to close is due to their many citations of deficiencies by the Federal Health Care Financing Agency, the Legislature should be given an accounting of those deficiencies. We must be made aware to what extent these kinds of deficiencies are indicative of problems throughout the state's entire system of developmental centers.

3) The Association recognizes that placements ideally should be in the geographical area of next of kin or guardian but recommends that the individual needs of the individual take precedence in placement decisions. OMRDD should attempt as much as possible to see that the new location and home is a permanent move. The closing of one developmental center for the sake of closing should not penalize the living needs of the persons who are disabled. Transitional placements must be avoided and individuals should be relocated one time and one time only. It is hoped that in addition good friends and close acquaintances will be able to be maintained so as to provide some stability to the individuals who will be leaving their "home" for a new adventure and opportunity.

4) The time frame stated (1987-1991) is an ambitious goal. While it has been stated that one of the primary reasons for the development of SRU's was to allow a "fast-track" system of development to occur, OMRDD has not made their projected SRU units. The new plan, if the target dates are to be followed, will necessitate all of OMRDD's energies. What assurances and

Federal Update



Employment Opportunities for Disabled Americans Act Signed into Law

On November 10, 1986 President Reagan signed into law the Employment Opportunities for Disabled Americans Act (H.R. 5595). The new law makes Section 1619 of the Social Security Act a permanent program to continue Supplemental Security Income (SSI) and/or medicaid eligibility for persons with disabilities who engage in substantial gainful activity.

Congress had in the past enacted a demonstration program to provide special cash benefits and medicaid coverage for SSI recipients whose continued ability to work depended on these benefits so as to encourage persons who are disabled to engage in substantial gainful activity if they were able to do so. This program began on a trial basis and was slated to expire next year; the new law makes this provision permanent.■

Education of the Handicapped Act Reauthorized

On October 16, 1986 President Ronald Reagan signed into law the Education of the Handicapped Act Amendments. These Amendments were a major expansion of Public Law 94-142.

The action extended for five years the existing provisions, which had created an entitlement to services for handicapped children aged 5-21. One of the major provisions of this new law is the significant increase in incentive grants to states already serving 3 to 5 year-old handicapped children. Those states that elect to receive these funds will be required to serve all disabled children in the 3-5 age bracket by 1990.

The act signed into law also authorizes a new \$50 million early intervention program for handicapped infants and toddlers from birth to age 2 who need services because they are experiencing developmental delays. Services to be provided under the new law include: family counseling, special instruction; speech, occupational and physical therapy; psychological services; case management services; diagnostic or evaluative medical services; early screening services and health services necessary for early intervention services. These services are to be provided in accordance with an individualized family service plan.■

Certification Process of Sheltered Workshops Simplified on Federal Level

In late 1986, Congress passed legislation that simplifies federal supervision of sheltered employment for persons who work at low levels of productivity. The new legislation will eliminate the requirement for separate certificates and programs for sheltered workshops and work activity centers.

The action of Congress will also enable persons to be employed in sheltered workshops even if they work at less than 50%

of the level of productivity of a non-disabled worker performing the same job.

The new legislation states that the wages paid to each worker must be reviewed at least every six months and wages adjusted at least once a year to reflect changes in the prevailing wage paid to experienced non-disabled workers employed in the locality who perform essentially the same type of work.■

President Reagan Releases FY 1988 Budget Request

President Ronald Reagan on January 5, 1987 submitted his fiscal year 1988 budget request to congress. The President's budget proposals marks the process. His proposals, however, does give an indication as to the direction the President wishes to pursue. In his request, the President not only calls for reductions in many domestic programs for FY 88, but also proposed rescissions in some fiscal year 1987 programs.

The following is a very brief review of some of the areas of interest to our Association.

A) Special Education

- 1) *State Grant Programs* would be reduced from \$1,338.0 million to \$1,259,381 million.
- 2) *Preschool Incentives* would be reduced from \$180.0 million to \$85.5 million in FY 88. The Administration is requesting a rescission of \$101.1 million from the FY 87 appropriation bringing it down to \$78.9 million.
- 3) *Early Intervention* would not be funded in FY 88 and the Administration is requesting a rescission of the \$50.0 million appropriated in FY 87.
- 4) *Special Education Personnel Development* would be reduced from \$67.73 million to \$50.0 million in FY 88.

B) Vocational Rehabilitation

- 1) *Rehabilitation State Grants* would be funded at \$1,228.142 million, resulting in a 4.1% reduction from the FY 87 level of \$1,281 million.
- 2) *Independent Living* would continue to be funded at its FY 87 level, \$41.44 million.
- 3) *Supported Employment* would not be funded in FY 88 and the Administration is requesting a rescission of the \$22.1 million appropriated in FY 87.
- 4) *Evaluation* would be reduced 53.8% from its FY 87 level of \$2.11 million to \$0.975 million.

C) Housing Programs — The Administration is not proposing any funds in FY 88 for Section 202, Housing for the Elderly and Handicapped, nor Congregate Housing Services.

D) Developmental Disabilities Program

— The Administration is proposing that it be part of a generic category entitled, "Social Services Discretionary Programs" administered by the Office of Human Development Services. This proposal, if approved by Congress, would give the Administration the opportunity to shift funds within the program among areas such as Head Start, Aging Programs and Developmental Disabilities. Combining the areas proposed by the Administration, the President's request of \$2,210 million would result in a \$34 million decrease from FY 87 funding.■

CHAPTER NEWS

DUTCHESS

and Allsport Join Forces for 2nd Annual Fit-A-Thon

6-21 was set aside for a Fit-A-Thon with the proceeds raised from the Dutchess County Association for Retarded Children.

Allsport members participated. Pledges were collected from clients, and friends for the number of hours they participated in Allsport (jogging, swimming, etc.)

The event opened up to the public.

Awards were awarded for the most hours of workout; the most varied

fundraising.

Prizes of \$5.00 included a commemorative tee-shirt. ■



Second Annual Fit-A-Thon help raise money for Dutchess ARC programs.

FULTON

Fulton Chapter Institutes Television Program

The Fulton County Chapter instituted its first half hour television programming of the Fulton County Parent Club on local WGLV cable TV during February.

The first of the series of half hour presentations featured Sandra Cloud, Director

CHEMUNG

Local Government Visits Chemung ARC

More than 20 representatives of local governments in Chemung County participated in breakfast tours of ARC facilities during January and February and more are planned for other community groups through 1987.

The tour starts with breakfast prepared and served by worker/trainees in the food service vocational program, a videotape of agency operations and remarks by Dr.

Michael A. Doherty, Executive Director and Mrs. Maryann Bryant, President of the Board of Directors.

From there it was on to the assembly area of the Work Development Center sheltered workshop and by van to the Intermediate Care Facility (ICF) for children, the Woodshop work site at Facet Enterprises, a residence for adults and the Spice Rack food service site at the Aetna complex. The woodshop and Spice Rack are examples of supportive employment programs.

Response from county, town and city officials: Terrific!

About 225 guests attended the open house and reception marking the opening of the new adult community residence in Waverly (Tioga County). The former tourist home has been fully renovated and is home for 10 residents from nearby communities. Those of workforce age will be employed at the WDC in Elmira. The ARC is operating the facility in cooperation with Broome-Tioga ARC because their day program sites are closer to Waverly than similar programs in Binghamton.

The year ended with two gifts of \$1,000 each — the first from pledges raised within the community by ARC clients and the second, a matching gift from the Elmira Correctional Facility's Clubhouse Recreation Committee. The latter's check was presented at a dinner for 77 clients, facility employees and their relatives who took part in their respective groups' third annual Bowl-a-thon. ARC clients raised their gifts by circulating pledge sheets for donations per point or per game. ■

ONEIDA

ARC Receives Grant

The Oneida Chapter has received a

COLUMBIA

Columbia Chapter Participates in Winter Ski Program

An average of 15 people from COARC's day treatment center and workshop are participating in a winter ski program at Ski Windham in Greene County.

Skiers attend once a week for ten weeks and train in down hill skiing. Beginning with basic instruction, several now ride the chair lift to the top.

The program started as a pilot program four years ago and is now one of the most comprehensive in the east. Sponsored by Price Chopper, Ski Windham and the Eastern Professional Ski Instructors Association, persons who are developmentally disabled, deaf, blind as well as those with cerebral palsy, amputees, and other medical traumas are learning how to enjoy the popular winter sport. ■



SCHUYLER

Schuyler Celebrates Anniversary of Community Residence

1987 marks the fifth (5th) anniversary of the opening of the Schuyler Chapters' community residence in Odessa, New York. The residence on Church Street in Odessa has been a home for 13 adults and was the first residential facility opened and operated by ARC. Since that time, ARC has opened a ten (10) bed intermediate care facility for adults with severe disabilities in Watkins Glen, New York and two apartments, housing two individuals each, for people who are almost totally independent.

The chapter is planning various activities throughout 1987 to celebrate five years of success and growth in the development of residential programs for persons who are mentally retarded/developmentally disabled. These plans include an open house and celebration in the Spring of 1987, a major feature in the organization's newsletter and an on-going public awareness campaign throughout the year.

Glen Industries, the vocational program offered by Schuyler ARC has received OVR approval and funding as a certified rehabilitation facility. ■

STEUBEN

Nancy M. Cox has been promoted Director of Quality Assurance and S Training for Steuben Association fo retarded Citizens (ARC) in Bath. Cox' pointment is the first step in manage reorganization planned by the age streamline the expanded programs c being offered by ARC.

Cox, who has been employed by S ARC since 1975, was formerly Direc the Residential Program. In her ne tion, she will be responsible for ass quality of service and care to all pro participants through training programs on-site guidance.

A native of Trenton, New Jersey, attended Skidmore College and ear Bachelor's Degree from New York U city. She and her husband, William in Jasper. They are the parents of t children.

Steuben ARC currently operates tional training center in Bath employ developmentally disabled individual also provides residential and trans services to a broad range of the adul capped population in Steuben Cou

ALLEGANY

Allegany Chapter Receives \$90 Grant

The Allegany County Chapter, N Inc. was recently awarded a \$90,000 grant comes from the State Ru Revitalization Program administered Division of Housing and Commun newal. It will provide "bricks and r funds for renovations to the chapter Madison Street Facility in Wellsville, York recently donated by Mr. and Edward Antoon.

The new facility will house a portion of the ARC's work center, PWI. Approximately 70 to 75 individuals will work in the departments that will move to the including light hand assembly, up industrial sewing and the seat weaving department. Construction is scheduled to go out in January 1988, project completion targeted for the 1987.

This is the Allegany County ARC round of funding through the Ru Revitalization Program. We rece

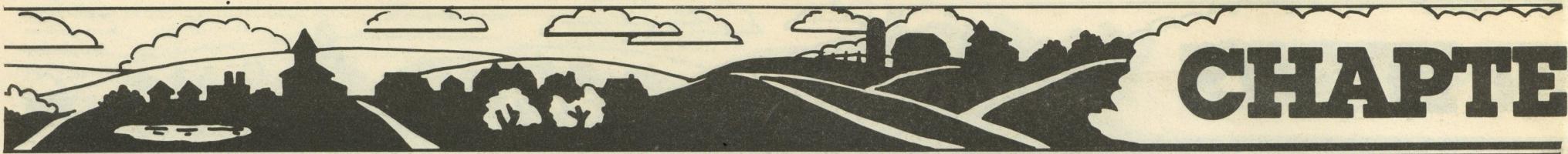
WARREN- WASHINGTON

Chapter Resident Chosen as Member of Self-Advocacy Association

Keith Georgia, a resident of one of Warren-Washington ARC's Supportive Living Apartments, has been chosen as a member of the organizing committee of the newly established Self-Advocacy Association of New York.

In discussing his new post, Keith describes his goals as "helping each person learn to speak up for themselves." The committee is currently planning a statewide conference for the fall of 1987.

Mr. Georgia was instrumental in initiating an internal process that resulted in the chapter board's recent decision to change the chapter's name to the Warren-Washington Association for Retarded Citizens. The change stemmed from adult clients like Keith



WESTCHESTER

The Marriott Corporation, formerly Saga Foods, was honored by Westchester ARC as Employer of the Year at a breakfast ceremony held recently at the Katzenberg Training Center. Representing Marriott were Craig Voss, Food Service Director, Business Food Services and Bill Awad, Food Services Manager. They were presented with a framed certificate of appreciation by Westchester ARC's Executive Director, Ric Swierat.

Marriott has a long record of hiring trainees from the ARC and now has ten Westchester ARC graduates in their employ. According to Mr. Voss, they are very productive and are all earning their pay. He singled out Bobby Ahearn as a genuine success story, saying that Bobby had worked for five years without missing a day of work and adding, "he kept his job because he is a productive employee." ■



Craig Ross (left) and Bill Awad (right) of the Marriott Corporation, formerly Saga Foods, enjoy breakfast at WARC.

SENECA

Workcenter Moves Into Chapter-Owned Building

Excitement is running high at the Seneca ARC as Spectrum Industries, the agency's fledgling workcenter program prepares to move into newly renovated quarters behind the administration/day treatment building. Both buildings have been purchased by the ARC, marking the first time this chapter has owned real estate — the first time, but certainly not the last. Already plans are underway to build a new community residence in Seneca Falls and with the 1991 planned closing of Newark Developmental Center, the need to develop more residences is clearly anticipated. Likewise, plans are in progress to open a second day treatment site which will serve 80 additional clients.

The agency's continuing expansion is also closely tied to the young and thriving Family Support Services program which for many clients and client families is the entryway to ARC services. Parent support groups, guardianship, recreation, case management, information and referral and home services are among the many functions of this invaluable, understaffed and overworked program — which has also run the Seneca Chapter's highly successful Legacy of Love campaign.

Without doubt 1987 will be an exhausting but very rewarding year for the ARC in Seneca County. ■

COMMUNITY LEAGUE

Franklin Physical Abilities Center Trains New Employees in Aquatics Environment

Franklin Physical Abilities Center has developed an Aquatics Module for the education and training of all new employees. Through the module, participating staff receive an overview of the aquatics programs offered at Franklin Physical Abilities Center.

The program developed and conducted by Steve Victory, Aquatics Coordinator, helps the staff to understand the aquatic environment.

As part of the training, new staff members simulate, for themselves, the various disabilities, sight and hearing impairments, cerebral palsy mobility etc., typical of the clients served by Wassaic.

These aspects of the program aid their staff in evaluating the needs of their clients and determining which aspects of the aquatics program can benefit their clients the most. ■

DUTCHESS

DCARC Adds Recreation Program to Services

A recent addition to the continually growing services offered by the Dutchess Association for Retarded Children is a recreation program for the aging out population that is between 15 and 21 and preparing to leave school and attend a day work program.

Gladys L. Boone has been hired to coordinate the program, which was requested by a parent group in the Family Support Services program at DCARC. Ms. Boone's background is in the human services field, primarily recreation services.

The program is funded through a grant from the Office of Mental Retardation and Developmental Disabilities of the State of New York.

The program is open to all children regardless of whether they live at home, attend a school program through BOCES, a public or private residential school in Dutchess County, or a day program such as those operated by DCARC. ■

NASSAU

Santa Visits Chapter

Many stops at the NYSARC chapters were on Santa's list during the holidays. In the downstate area there wasn't any snow so Santa had to improvise when he visited the Brookville campus of the Nassau Association for the Help of Retarded Children. A City of Glen Cove fire truck was commandeered, and when Santa arrived to visit the boys and girls of the Nassau AHRC he was escorted by fire fighters, volunteers from the Glen Cove High School, and Glen Cove Lions, who sponsored his trip. ■



Children from Nassau AHRC visit with Santa who arrived by fire engine due to the lack of snow.

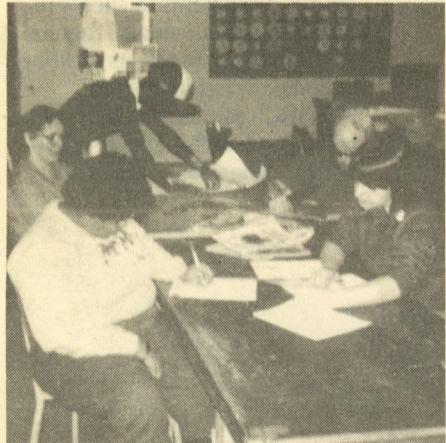
ALBANY

Albany Chapter Sponsors Food Drive

The Albany County ARC sponsored a food drive to benefit the Albany County Emergency Food Task Force from January 19th through the 29th. On the 29th of January, participants from the Day Treatment, Workshop and Community Residence programs presented their donations to Dawn Primeau, Coordinator of the Albany County Emergency Food Task Force, during a ceremony held at the Albany County ARC workshop.

The significance of this event is two-fold. First, those in need in the Albany County area will be the recipients of a variety of nutritious foods. Second, the idea of a food drive was suggested by one of the Albany County ARC's workshop client-employees, Gladys Jones, and the entire Food Drive Committee consisted of four additional client-employee volunteers, George Donovan, Sylvia Hine, Patricia Sammons and Sam White.

Under the guidance of Linda Sacco, Work Supervisor, this committee held meetings, planned the entire event and presented their ideas to staff at various agency meetings. These individuals experienced first hand what it means to be active, responsible committee members. Their enthusiasm, determination and desire to truly help those in need is commended. ■



The Food Drive Committee, comprised of clients from Albany ARC, meet to plan the chapter's food drive to benefit the Albany County Emergency Food Task Force.



This year's plants were available in a variety of colors, and were supplied through Erie County Chapter's greenhouse in Orchard Park, New York, an adult workshop satellite.

SCHENECTADY

Bella Stuart Wins G.E. Community Service Award

In 1963, Bella Stuart, the mother of a retarded son, became an active member of Schenectady ARC. For the past 23 years she has maintained her commitment to the chapter, helping the organization grow from little more than a two-room schoolhouse into a center currently serving over 300 clients.

For her efforts and extensive involvement on the Board of Directors (she was President from 1982-1985), numerous committees, fundraising activities and as a Board of Governor representative, Bella has been named recipient of the 1986 Gerald L. Phillippe Award for Community Services for General Electric's Combined Corporate Components in Schenectady. This award, named in honor of a former G.E. board chairman, is presented each year to G.E. employees who are involved in areas of public service. Along with the award, Bella received \$1,000 which she donated to the ARC.

In the words of Executive Director Linda Lahaie, "It is hard to describe just how much Bella means to us. We have a very active Board of Directors and we count on them to help out in a lot of ways. The fact that Bella has done so much for us only serves to illustrate how much we depend on her." ■

ERIE

Erie County ARC Sets Record with Poinsettia Sale

The Erie County Chapter, NYSARC, sold a record 12,425 poinsettia plants during their Annual Poinsettia Sale in December. The poinsettia sale is the chapter's largest and most successful fund-raising event.

The tradition continued this year, as a record number of volunteers and community members from the Buffalo area lent their support. Participants from Buffalo's business community rose dramatically. Public sales included additional sites throughout Erie County and local shopping malls.

This year's plants were available in a variety of colors, and were supplied through Erie County Chapter's greenhouse in Orchard Park, New York, an adult workshop satellite. ■

CHAUTAUQUA

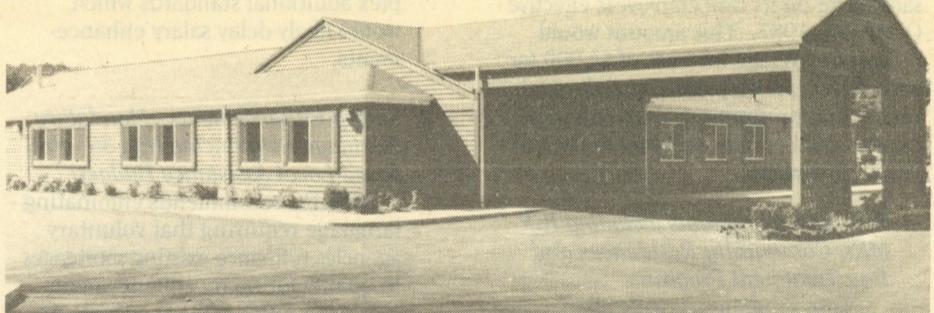
Chautauqua ARC Catalog Offers Adaptive Communications Devices

A large part of our disabled population is severely physically handicapped. The extent of their disabilities may prohibit them to adequately communicate. This makes them passive observers who feel that they must rely on others for their every need, and justifiably so. However, technology has improved to the point where we can adapt mechanical devices, through any number of switches, built to overcome a person's disability. To accommodate the wide range of physical disabilities, the Resource Center's Rehabilitation Engineering Department has built a variety of switches. Each switch is operated by the individual's body part that has the most consistent movement — this may be their head, foot, arm etc. When the switch is pressed by a body part, the person is rewarded by the device being activated. Switches come in all shapes and sizes such as tug lines, squeeze toys, ring pulls or head bands with mercury sensitive switches.

Aside from other uses, these switches can be used to activate children's toys. Toys offer an excellent way to improve particular motor movements in disabled children. For example, if a child is working on improving his strength for grasping, then a squeeze switch with a toy attached is a very motivating method for achieving that goal. If a child sees that he can control a toy, it may urge him to communicate his wants and needs to gain other things he desires.

Providing "alternative" communication to individuals who can't speak is the main goal of the Resource Center's Regional Communication Center. Their rehabilitation engineer has been constructing adaptive devices to meet the skills and needs of the clients. Through the use of adaptive devices, many vital speech, occupational and physical therapy activities can be taught and provide persons with physical handicaps with the freedom to use items they previously could not operate.

The Resource Center has recently compiled a catalog describing a collection of toys, switches and communication devices produced by their Rehabilitation Department. These items are available for purchase upon request. For more information or to obtain a catalog, you may contact the Chautauqua Chapter. ■



One of several new ICF homes recently opened by Chautauqua ARC.

DUTCHESS

DCARC Hires Sanchez to Coordinate Family Support Services

Lisa Sanchez, an Albany native, has been hired by Dutchess County Association for Retarded Children to coordinate their Family Support Services Program. The program works with the families of mentally retarded and developmentally disabled teenagers and adults.

Prior to coming to DCARC, Ms. Sanchez worked at Albany ARC as a teacher in their Day Treatment Program. She has worked as a fund raiser for Muscular Dystrophy in Albany and served an internship in the Legislature during college.

She has a BA in Political Science and Public Affairs from Albany State and graduate credits in business and education.

She currently resides in Esopus with her husband who is a student at the Culinary Institute of America in Hyde Park. ■

YATES

Yates ARC Initiates Strategic Planning Project

On January 20 and 21, the process of strategic planning for the Yates ARC was off to a running start. Fred McDonald of the McDonald Management Training Group met with the Steering Committee for Strategic Planning to begin the development of a data base. Two intensive evenings were spent by both board and staff members working towards a long-range plan for development. First, the factors impacting the quality and delivery of service by the Yates ARC were analyzed. Next, the weaknesses, opportunities, threats and strengths of the Yates ARC were analyzed. Board and staff members worked independently on these problems and then came together at the end of each evening to synthesize their results. The strategic planning project, ably headed by board member John Rathfon, is intended to bring into focus the work of the Yates ARC and to give planned direction for its future growth and expansion. ■

Budget (continued from page 1)

SRU will be for 48 placements and J.N. Adam SRU will be developed for 72 placements. The budget also calls for the continued SRU development of Long Island D.C. (144 placements).

E) The sum of \$7,000,000 is being recommended for "the first of a two-year phase of salary adjustment for non-administrative positions in voluntary operated not-for-profit residential and day programs."

After a careful review and analysis of the proposed budget, the Board of Governors at their February Board meeting adopted the following recommendations for the fiscal year 1987-88 state budget.

1. Office of Mental Retardation and Developmental Disabilities

A) Funding Request - NYSARC's budget request to the Legislature for FY 87-88 is limited solely to the issue of salary enhancements for direct care employees. Our chapters work in a labor intensive environment. The absence of wage scales sufficient to attract adequate direct care staff threatens to undermine the entire voluntary system of services to persons who are mentally retarded and developmentally disabled. In recognition of the gravity of this situation we are asking the Legislature to focus its funding efforts for our field entirely on this issue.

1. \$13,500,000 in Additional State Share to Enhance Salaries for Direct Care Employees.

An additional \$13,500,000 in state share above the \$7,000,000 recommended by the Governor is requested to enhance salaries for direct care employees effective October 1, 1987. This amount would provide an average increase of \$4,000 for each direct care employee in all day and residential programs. Salary enhancements would provide funding to the following programs:

a) Rate driven programs including ICF MRs, Community Residences and Day Treatment Programs

These programs provide all of NYSARC's residential services and day services to severely disabled individuals.

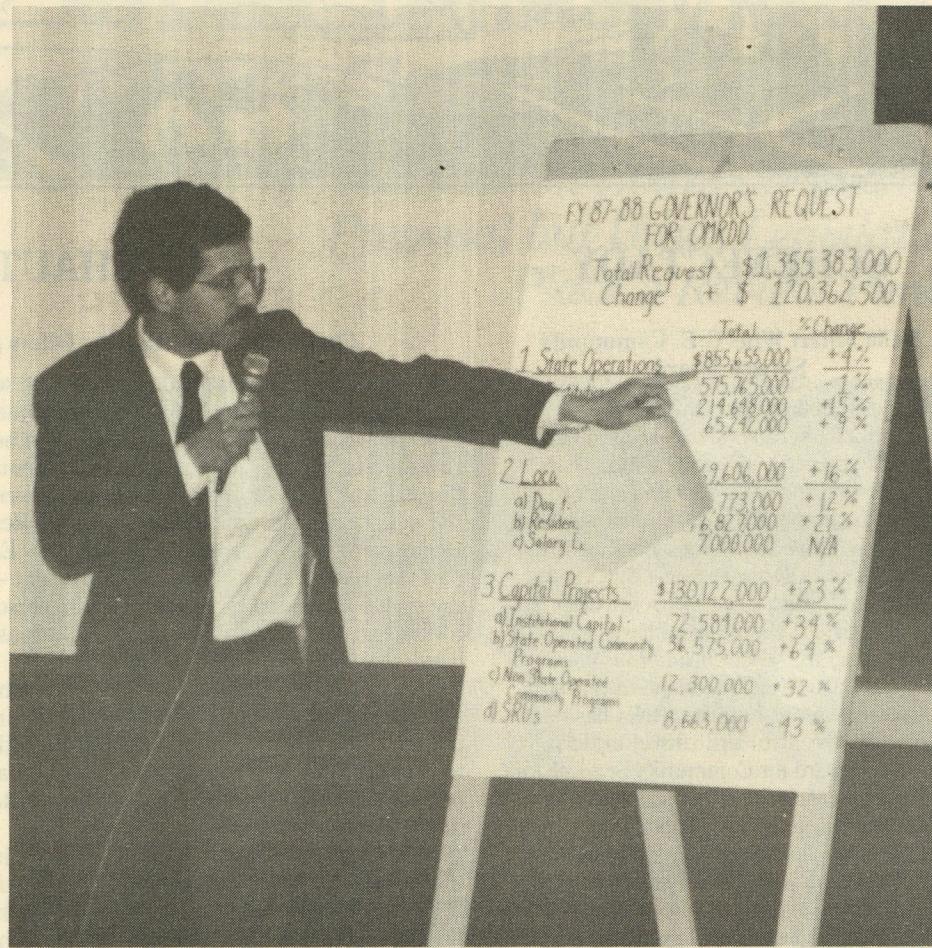
b) Basic Local Assistance Day Programs (Chapter 620, Local Services, Unified Services, Direct Sheltered Workshops)

Funding increases in these programs have been restricted almost exclusively to new development over the past five (5) years. As a result, cost of living increases, including salary increases, have remained unacceptably low. The FY 87-88 Executive request continues to recommend minimal increases for inflation and wage levels. The effect of enacting such requests without additional funding will make it impossible to make any significant improvement in employee salaries.

B) Language Deletions

1. Salary Enhancements - Means Test (Pg. 84 - Proposed Local Assistance Budget)

This language requires that a means test be constructed in order to target selected agencies for salary enhancements. Such language presupposes that existing wage scales are problematic in only limited in-



Ben Golden, Associate Executive Director, presenting 1987-88 NYS Executive Budget.

stances. This requirement should be eliminated since it fails to recognize the fact that the salary problem is a severe, statewide problem affecting all providers. Existing payment mechanisms already contain reimbursement standards. These can be used without the development of complex additional standards which would likely delay salary enhancements.

2. Salary Enhancements - Mandatory Mortgage Refinancing (Pg. 85 - Proposed Local Assistance Budget)

NYSARC recommends eliminating language requiring that voluntary agencies refinance existing mortgages to qualify for salary enhancements. Mortgage refinancing is acceptable but not as a precondition for clearly justified wage increases.

3. New ICFMR, CR Cost Limitations (Pg. 82 - Local Assistance Budget)

The Executive Budget recommends adding new language which would arbitrarily cap fees paid to newly established ICF/MRs and Community Residences regardless of costs which are necessary to meet client needs. Existing procedures already screen costs to ensure cost efficient rates. NYSARC recommends that the additional restrictions proposed by the Executive Budget be eliminated.

4. Mandated Project Designs (Pg. 38-39 - Capital Projects Budget)

NYSARC recommends eliminating language requiring that new projects designed after April 1, 1987 be based on prototype architectural designs developed by OMRDD. Such designs are untested and will likely delay development. Further, prototypes will limit the ability of new residential programs to blend in with and be accepted by individual communities. Utilization of such designs should be permissive and not mandatory.

2. Staffing Standards

NYSARC, Inc. recommends the Legislature reinsert language contained in prior year budgets requiring minimum staffing standards at non-Willowbrook class developmental centers.

However, it is also recognized that such minimum standards do not take into account critical factors effecting either the actual presence or staff (i.e., employee absenteeism) or existing client disability levels. Thus, NYSARC also recommends that the Legislature add language requiring OMRDD to evaluate current staffing needs and to recommend revised and intensified staffing levels for legislative consideration.

3. Humane Developmental Center Closure Policies

The Governor's FY 87-88 budget recommends closure of six (6) Developmental Centers (Bronx, Manhattan, Newark, Craig, Rome and Westchester) by 1991. The demands of meeting this timetable must not be allowed to create an insensitivity to the placement needs of individual clients. To safeguard against such possibility, NYSARC recommends the addition of budget language requiring that mechanisms be established to monitor and guard the movement of and due process rights of all clients and in particular the rights of non-correspondent clients.

4. Community Placements

a) Closure of Developmental Centers will create additional pressures upon state government to devote a disproportionate share of community placements to clients residing in developmental centers at the expense of clients residing at home. It has long been NYSARC's philosophy that such policies are unfair and discriminatory. Therefore, it is recom-



O.D. Heck representative, Robert Taylor speaking to the staffing ratios of d.c.'s.

mended that NYSARC advocate for the addition of budget language stating that "placements of individuals into community residential facilities shall not be denied or approved based solely on considerations relating to such individuals place of residence."

b) Finally, to facilitate community placements cost guidelines for new projects should recognize necessary regional costs.

2. State Education Department

Least Restrictive Environment

It is recommended that NYSARC advocate for initiatives aimed at encouraging the placement of handicapped children in public school settings housing non-handicapped children. These initiatives include:

- Increasing the building aid formula for the construction of special education program space from \$2,000 to \$3,000 per pupil when such program space is constructed so as to integrate handicapped children with non-handicapped children.
- Increasing statutory limitations on BOCES ability to rent space from \$5.00 to \$10.00 per square foot provided that such space facilitates the integrated education of handicapped and non-handicapped children.
- Extent to BOCES the right of first refusal for program space made available for rental by school districts. Such right would increase the availability of "integrated" program space for handicapped children.

The next issue of OCV will report on the final adopted New York State Budget for April 1, 1987 - March 31, 1988. ■

Governor Reintroduces Independent Office of Rehabilitation Services

For the fourth consecutive year, Governor Cuomo has introduced legislation creating an independent Office of Rehabilitation Services (ORS). This initiative would combine the Office of Vocational Rehabilitation (OVR) in the Education Department and the Commission for the Blind and Visually Handicapped in the Department of Social Services to form the nucleus of a new, independent, cabinet-level agency whose sole mission would be the provision and coordination of rehabilitation services.

In his remarks reintroducing the ORS Bill, the Governor stated, "The establishment of an Office of Rehabilitation Services has been a continuing priority of my administration. We are committed to improving services for the disabled population of this state and there is no better way to do this than to create a single office dedicated to improving services for persons with disabilities.

Despite the virtually unanimous support which this proposal has received from people with disabilities, service providers and disability advocates and overwhelming support in the New York State Assembly, the New York State Senate has consistently refused to move this initiative. ■

Board of Governors Statement on LRE

Twelve years ago, President Ford signed the Education of the Handicapped ACT (PL 94-142). This law guarantees the provision of a free and appropriate education to children and youths, and mandates specialized and individualized services to meet each student's educational needs in the least restrictive environment.

Philosophically, NYSARC has always supported the idea of public education. That position has been proven over and over again as local chapters have handed over their school-aged programs to the public sector. This has never been done lightly but always with assistance to parents of the children to ensure that quality programs continue for their children in the public sector.

At the February Board of Governor's meeting, the Board discussed the issue of the Least Restrictive Environment (LRE). The following Position Statement was recommended by the Education Committee and adopted by the Board concerning the Least Restrictive Environment:

1. Development and acceptance of a state-wide commitment to integrated special education services, available in typical schools and other community environments in proximity to non-disabled peers, as a goal for all citizens with disabilities who are for school age.
2. This commitment should be reflected in the New York State Department of Education Plan as a goal with stated guidelines for attainment of that goal.
3. That integrated options for all students with disabilities, regardless of categorical diagnosis or severity of handicapping condition, should be available to all special education schools in their local districts and neighborhood public schools, and that placements in these options or any alternative options are truly based upon individual needs rather than being dictated by the absence of services in integrated environments and the exclusive availability of segregated services.
4. That information, training and technical assistance be provided to local education agencies, directed to both special and regular educational constituencies (professionals, parents and children) to assist them in the design and implementation of these integrated options. ■



Florence or Beverly? - Our Community League Chapter is well represented.

Publication Reports on Impact of Group Homes on the Surrounding Neighborhood

Neighborhood opposition to the establishment of group homes for persons with developmental disabilities is largely based on myths about the impact such a home and its residents will have on property values, neighborhood stability and safety. The American Planning Association has recently published a study conducted on behalf of the Governor's Planning Council of Illinois that provides officials in that state with concrete evidence that:

- (1) Group homes do not affect the value of residential property in the surrounding neighborhood, and
- (2) Group homes do not affect the stability of the surrounding neighborhood, and
- (3) The crime rate for persons with developmental disabilities who live in Illinois group homes is substantially lower than the crime rate for the general Illinois population. Therefore, these group home residents pose no threat to safety in the neighborhood surrounding the group home.

The findings of the APA study are consistent with those of more than twenty other studies of the impact of group homes on the surrounding neighborhoods. "Together these studies form one of the most exhaustive bodies of research on any specific land use," says Daniel Lauber, author of the report. "They offer sound evidence that group homes do not adversely affect the surrounding community."

The report includes five appendices which describe statistical tests used to evaluate the data, information on the more than 2,000 group homes studied, a list of control neighborhoods, information on other studies of the impact of group homes on property values and turnover, and a copy of the form used in the "Criminal Involvement Survey."

Copies of this valuable 36 page report are available for \$1.07 each (to cover the cost of postage) from the Governor's Planning Council on DD, 840 South Spring St., Springfield, IL 62706; phone (217) 782-9696.

*Reprinted from LINKS
March 1987. ■*

Rhode Island to Close Ladd Center

The Governor of the State of Rhode Island, Edward D. DiPrete, has recently announced the closing of the Ladd Center in Exeter. While Rhode Island has only one developmental center, the closing of Ladd will mean that Rhode Island will be the first state in the country to eliminate multi-purpose institutional care for persons who are mentally retarded.

In 1985 the Governor requested that the Department of Administration Office of Strategic Planning review the feasibility of closing the Ladd Center. While the Office of Strategic Planning was given the responsibility of writing the report many governmental and non-governmental organizations worked together to produce the final recommendation to close Ladd. The Department of Mental Health, Retardation and Hospitals, the State Budget Office, advocate groups, appropriate unions, and the Town of Exeter where Ladd Center is located all worked together to produce the final report.

Governor Edward D. DiPrete formed an implementation planning group and directed them to consider the following initiatives:

1. To create a mix of additional group homes for 175 of the residents still at Ladd, to create cluster facilities for 50 more severely disabled clients, and to transfer 25 residents who require hospital level care to Zambarano Hospital.
2. To create a staffing plan which integrates personnel into those new arrangements and makes alternative provisions for continued employment of all current Ladd Center staff.
3. To create a land-use plan for the property which establishes limits and types of permissible development and also takes into account environmental issues, and reflects the concerns of the Town of Exeter.

Mr. Thomas Romeo, Director of Mental Health, Retardation and Hospitals for the State of Rhode Island stated that, "This significant public policy decision supports a long-term commitment by Rhode Islanders to our mentally disabled citizens." ■

Service Dogs Aid Persons with Disabilities

Service dogs, that is dogs that aid persons with disabilities in activities of daily living, are now helping more and more individuals lead more independent lives.

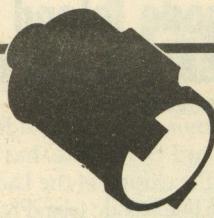
Canine Companions for Independence (CCI), a California-based not-for-profit agency, is presently the only group that trains dogs to help persons who are disabled. To date, there are approximately 200 dogs throughout the United States, Canada, Holland and Israel with three of these animals being used in New York State.

CCI operates two training centers located in California. A two week training session which includes lectures, discussions and field work with the dogs is mandatory for all participants.

The dogs are taught 89 commands which takes two years and costs approximately \$5,000. Nine different breeds of dogs are used including standard Poodles, Border Collies, Golden Retrievers and Labradors.

- The companion dogs are able to assist their "masters" in endless ways such as turning on light switches, picking up fallen objects off the floor, pulling wheelchairs, hanging up coats onto coat hooks or putting a glass into a sink.

Service dogs are not included within the provisions of law that apply to guide dogs and hearing dogs. ■



Chapter Program Highlights

Monroe Chapter Launches Unique Program Special Sitters for Special People

Mr. and Mrs. Smith would like to attend their daughter's school concert, but they face a usual dilemma. They have no babysitter with whom they feel comfortable leaving their son who is developmentally disabled. The boy doesn't communicate well, and the neighborhood youth who sometimes sits appears to be ill at ease with him. Rather than leave their son in this situation, Mr. Smith stays home. Mrs. Smith goes to the concert alone.

Finding a suitable sitter/companion is a problem families of individuals who are developmentally disabled face continually. When a caregiver would need knowledge of special equipment or dispensing medicines or handling seizures, or where there is only one parent, the problem is even more acute.

In Rochester, N.Y., the Monroe County Association for Retarded Citizens is launching a project designed to address these needs. The "Special Sitters" project will train area youth to serve as sitter/companions for the developmentally disabled. Once training is completed, the sitter/companions will be listed in a directory from which families may request names and numbers of sitter/companions in their area. Parents will then call the sitter/companions to arrange preliminary interviews, negotiate hours and wages, transportation and responsibilities.

Funding for the program comes from an 18-month grant of \$40,000 which the

includes instruction in first aid and home safety, sign language, and use of adaptive equipment. Professionals describe disabilities such as mental retardation, autism, cerebral palsy and epilepsy in general terms. Specific problems and needs will be worked out between individual parents and sitter/companions.

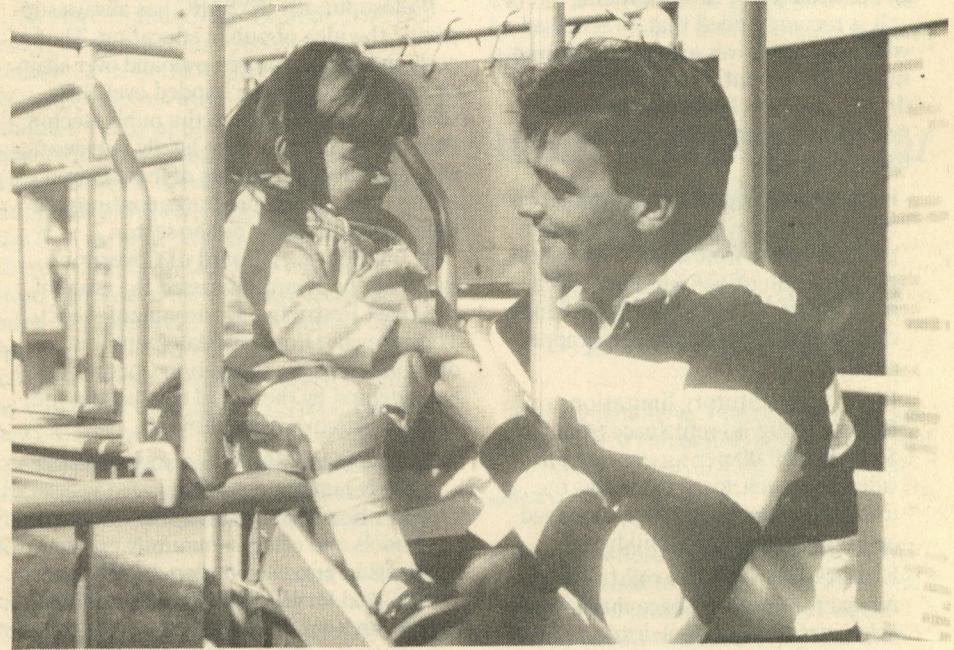
In pairs or small groups, the trainees engage in role-play exercises to learn about verbal and non-verbal communication and about sensitivity to others. A discussion of age-appropriate creative activities is included in the training.

In addition, sitter/companions are trained in communicating with parents. They are taught to say "no" to any responsibilities they feel they cannot handle.

A March of Dimes film featuring four children who are disabled, speaking for themselves won rave reviews at the pilot program. "It gave me direct insight into the feelings and needs of the handicapped," said one participant.

A luncheon with individuals who are disabled and their families, highlights the final day of training. "Fun, fulfilling, rewarding, and meaningful," are words that appear in evaluations again and again in regard to the training and especially the luncheon.

The project provides for evaluation, to be solicited from sitter/companions once the



attracted communications interns. The interns helped to prepare a video which is used for recruitment. In addition, the communications students taped all presentations given by experts at the pilot session. Some of the training by necessity will be provided when the students are not in school — weekends, holidays and evenings. Because of this, professionals may not be available. Therefore, the tapes made by the volunteers are invaluable.

While several trainees were already members of YOUTH-ARC an ARC-sponsored program for teen volunteers who work with the disabled in social and recreational activities, the pilot program inspired others to join.

All pilot trainees were enthusiastic about the new skills, insights, and friendships,

they acquired during training.

What parents gain will be "empowerment," a theme which is all-important to Monroe County ARC's Director of Special Services, Jodi Rosenschein-Atkin.

Says Rosenschein-Atkin, "The Special Sitters program empowers parents because it gives them a chance to make choices and judgments on behalf of their children that they would naturally make if their children were not handicapped. If a parent is looking for respite care, often some of the choices are not really choices at all."

Along with empowerment, comes assurances for the families that the sitter/companion they have hired brings competence, skills and perhaps above all, enthusiasm and insight to the job.

Written by: Robin Pulver ■



Monroe County ARC received in July 1986 from the New York State Office of Mental Retardation and Developmental Disabilities. According to grant provisions, families will pay a one-time \$5.00 fee to use the service.

Doris Cohen, coordinator of the project, announces that the goal is to train 75 sitter/companions to serve 125 families in 1987.

Recently fourteen area high school students participated in a three-day pilot program which will serve as a model for monthly training sessions to be held throughout the area. Cohen is currently busy spreading the work with recruitment talks at churches and public and private schools in the area.

The three day-long sessions of training offer a carefully wrought curriculum, which

service has been provided. Families are also responsible for signing Emergency Medical Treatment and Liability release forms and completing evaluations.

Sitter/companions must be at least 14 years old. They must have parental permission and two written references. Eventually the program may include adult trainees.

By involving local students and perhaps eventually adults, the community benefits through greater awareness of the unique problems and potentials of individuals who are developmentally disabled.

Students interested in careers in medicine, health, therapy, and education have an opportunity to explore those interests. Some of those in the pilot program came from career intern programs. The program even



Cortland County Chapter Begins Sibling Services

The A.R.C. (Advocacy, Recreation and Community Living Services), the Cortland County Chapter of the New York State Association for Retarded Children, sponsored its first Sibling Conference at the Cortland Holiday Inn. The focus of this Sibling Conference was "the forgotten child" — the brothers and sisters of children with disabilities. Twenty-one families, the majority from Cortland County, attended this two-day event.

The conference was coordinated by Chris Gratz, ARC Family and Recreation Services Director, who was assisted by several excellent helpers from SUNY College at Cortland and other community volunteers.

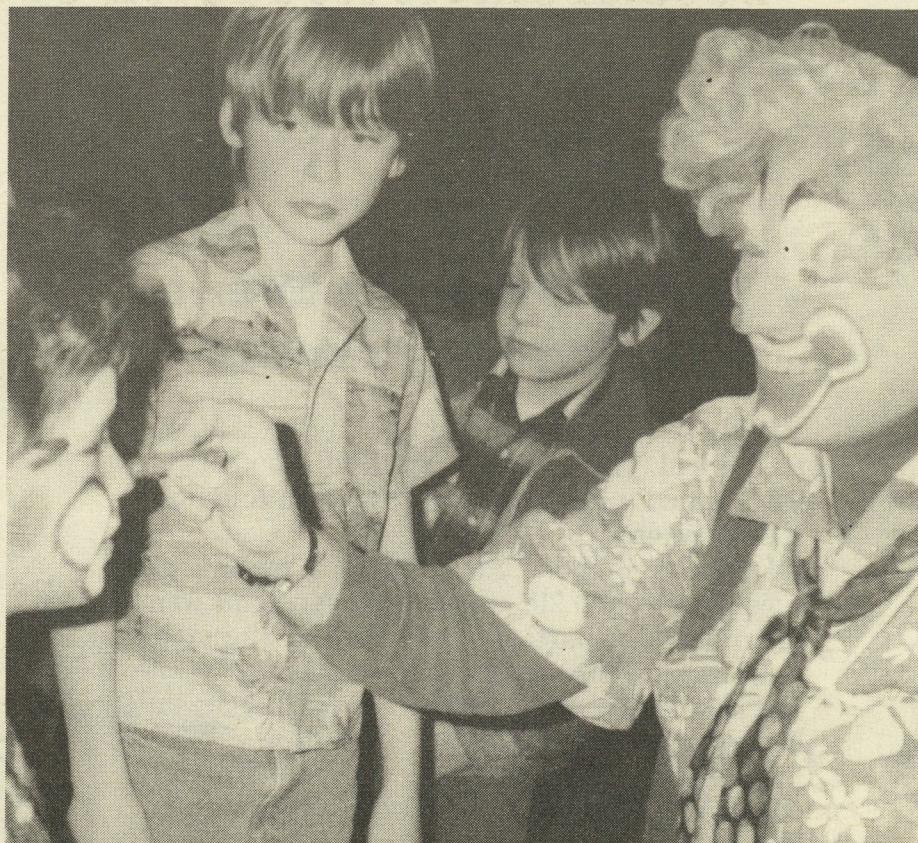
On Friday evening, the conference began with a pizza party and a visit from Astral P. Clown. Astral performed magic tricks. Several of the children learned to juggle and became part of the act. Many of the children also eagerly got their faces, arms and hands decorated with bright body paints.

Later in the evening, Hugh Gratz, a family therapist from Syracuse Catholic Charities, spoke on communication within families. A demonstration using the youngest conference participant, a 7-month-old child, and the oldest participant, a 60-year-old parent, illustrated that all family members can communicate with each other. However, this demonstration also illustrated the changes in the way individuals communicate as they get older, from the simple and natural reactions of a baby to the more restricted and controlled actions and words of an adult.

Maria DuBois, a public health nurse and massage therapist, then spoke about the demonstrated healing touch. Members of different families volunteered to receive massages so that Maria could illustrate simple massage techniques such as foot, hand and shoulder massages which could be done by even the younger members of the families. In response to a question from a parent, Maria indicated that massage was a good way for family members to help each other relax and to provide some special attention to each other. She also said that even the family member giving the massage usually finds it relaxing.

At the end of the evening, some families stayed for the night at the Holiday Inn, while others chose to go home and to return to the conference on Saturday morning. However, 24 non-disabled siblings shared rooms and stayed over-night at the Holiday Inn. After everyone was settled in their rooms, the non-disabled siblings told about their experiences and shared their feelings about living with a brother or sister who is disabled.

On Saturday after breakfast, all the families joined together and enjoyed the Holiday Inn's pool and health club facilities. Many of the children had their first experience with a "hot tub". Everyone then had lunch together. In the afternoon, there were separate workshops for the parents, the older (ages 11-16) siblings and the younger (ages 7-10) siblings. During the workshops,



Siblings enjoy having their faces painted as they participated in Cortland ARC's first Sibling Conference.

the children with disabilities participated in a variety of recreational activities.

Esther Spinelli, a registered nurse who has a brother with multiple disabilities brought a composite videotape of interviews with several Syracuse families (first, the non-disabled siblings and second, the parents) about their experiences and feelings as families with disabled family members. The videotape was shown to the parents and followed by a discussion among the parents lead by Esther Spinelli and Donna Funk, a special education teacher who grew up with a sister who is mentally retarded.

The workshops for the older siblings included an opportunity for the siblings to explore disabilities first hand. Using various props such as eye patches, ear plugs and wheelchairs, they attempted to do a variety of tasks and activities. They then talked about how they managed to figure out how to do almost all of the things even though they were disabled. Their conclusion was that people with disabilities are still capable to doing a lot of things.

Maria DuBois and Evelyn Stevens, social worker with the Special Children's Center lead the workshops for the younger siblings. These siblings learned more about and practiced simple massage techniques. They also had an opportunity to act out their feelings through role playing several situations.

The conference concluded with a discussion of networking possibilities for families and suggestions for future events. The siblings prepared stories and pictures for a sibling newsletter.

During the month of December, a meeting was held with Dr. Ed Haddad, Sibling Network Coordinator from N.Y.A.H.R.C. and several staff and board members for our Cortland ARC. We discussed sibling support systems throughout the state and options for our county. Dr. Haddad described a program in New York City that provided both respite and sibling support. This led to the design and implementation of our new Saturday Respite/Recreation program for children with disabilities and their siblings. It is held every other Saturday at the YMCA and includes swimming, crafts and games. The siblings have enjoyed the opportunity to see some of their conference friends again.

In January, a "Sibling Issues" dinner was held. Parents, older siblings and board members were invited to attend. Dr. Ed Haddad was the key speaker. Representatives from other concerned community agencies attended (Seguin, Special Children's Center, Murray Center, Onondaga-Cortland-Madison BOCES, SETRC) and discussion groups produced several concrete goals on which to work towards in the coming year. ■

*Do you have a program that you would like to share?
Let us know!*

A Special "Thank You"

The NYSARC Library in Delmar would like to thank all those who so kindly responded to the request for donations to our collection.

Several people sent stray copies of back issues of the OCV and by combining them with what we already had, we can now boast four complete sets from 1949 (Vol. 1 #1) to the present issue.

One of the goals of the library is to house as complete a collection as possible of the history and memorabilia of the New York State Association for Retarded Children, Inc. so we were particularly gratified with the invaluable memos, personal correspondences, newspaper articles and early convention records which were given to us.

Our thanks are especially extended to Ann Greenburg of New York City; Lois Jones of Madison County; Louise Cooke of Lewis County; Rudolph Hormuth of the Health Resources and Services Administration in Rockville, Maryland and Harriett Cooper from the New York State Institute for Basic Research in Developmental Disabilities located in Staten Island.

NYSARC Welcomes New Executive Director

The Board of Directors of the Herkimer County Chapter has announced the appointment of Ms. Lulu B. Donaldson to the position of Executive Director. Ms. Donaldson served as the Director of Residential Services for the Onondaga County Chapter. Our entire Association joins in congratulating Ms. Donaldson in her appointment and wish her the best of luck in the months ahead.

Canadian Journal of Rehabilitation

Canada's first referred interdisciplinary journal of rehabilitation will be published beginning September 1987. CJR will provide a national forum for researchers and practitioners in all rehabilitation related disciplines to exchange information on research and theory in habilitation and rehabilitation, primarily from an interdisciplinary perspective.

Annual subscription rates for individuals and institutions is \$40.00 CDN (\$35.00 CDN if received prior to July 1, 1987).

Submissions or inquiries may be directed to:

Dr. James Vargo
Editor-in-Chief
Canadian Journal of Rehabilitation
13325 St. Albert Trail
Edmonton, Alberta, Canada T5L4R3

Legacy
of Love

ARC Awareness Week

The week of February 7th to 14th has been proclaimed ARC Awareness week by the New York State Association for Retarded Children. The Wayne County Chapter, N.Y.S. Association for Retarded Children, will be reminding the public of the care and love it gives to persons who are mentally retarded and developmentally disabled when they offer the "Legacy of Love" Valentine Roses.

The proceeds from the "Legacy of Love" Valentine Rose arrangements \$3.50 each, will be given to the

Proceeds

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NYSARC COMMITTEES

... AT WORK

... IN ACTION

Insurance Safety Group Committee

The NYSARC Safety Group Management Committee adopted its mission and organizations statement at its February meeting. The committee is comprised of chapter staff representing the four NYSARC regions and a member of the State Office staff. The purpose of the committee is to promote safety and health, accident and loss prevention within the Association. It is the group's goal to be able to develop safe work practice recommendations and guidelines which result from the study of the causes of accidents claims and from direct request of chapters. The committee will also help chapters organize effective chapter safety committees and implement training and educational programs and develop materials oriented to improving the safety of the work environment.

The group will meet at least quarterly. Its regional representatives will be contacting chapters directly to obtain the names of individual representatives. The meetings are open to all and chapters are asked to forward any questions, suggestions or requests directly to the regional representatives. The committee will be seeking additional representatives from each region.

This is a first effort in the involvement of chapter staff below the executive director level directly with a standing Board of Governor Committee, the Insurance and Pension Committee. The Safety Committee will report its proceedings and suggest policy development or guidelines to the board for implementation. Any questions can be referred directly to John Rose, Chairperson of the Montgomery Chapter or John Sherman at the State Office. ■



NYSARC's Education Committee meets to discuss summer school regulations.



Representatives from local chapters met at the State Office to discuss plans for the convention Call For Papers, program book and registration "gift". Pictured above from left to right are: Joe Merenda (a sales representative); Barbara Jay, Columbia ARC; Gene Allen, Oneida ARC; Manny Pelligra, Otsego ARC and David Lewis, Schenectady ARC. Also present at the meeting was Debra Kiskis from Albany ARC.



Standing: left to right - Fred Bence, Howland Laclair Agency; Susan Mara, Jefferson; Robert Lane, Continental Insurance Company; John Sherman, NYSARC State Office; John Rose, Chairperson, Montgomery; Henry Villegas, New York City; Donna Simonson, Steuben; Thomas McDermott, Oneida; Howard Siegel, Irwin Siegel Agency.



The NYSARC Supplementary Recreation and Special Olympics Committee plan for their first regional workshop to be held in April of this year. Pictured above left to right are Corlous Fisher, Susan Lyons, Maythorne Winterkorn and Marc Mercadante.



NYSARC Youth Committee members, George Oakes, Christina Johncox, Glenna Gleason-Pitarresi and Chairperson, Maythorne Winterkorn, review the revised organizational manual for YOUTH-ARC which will be distributed to local chapters within the next couple of months.

Guidelines Available for Twelve Month Program

"Guidelines for Twelve-Month Program for Eligible Students with Handicapping Conditions"

This is a new publication, dated February, 1987 which provides in-depth information about twelve-month educational programs.

Write or call a local SETRC or the N.Y.S. Education Department, Handicapping Conditions, Division of Program Development, Room 1069, Education Department Annex, Albany, New York 12234. ■

Upcoming Conferences

1) New York State Association for Retarded Children, Inc.

Theme:

"The Turning Point"
Down Syndrome: A Symposium for Parents and Professionals

Date:
March 20, 1987

Place:
Ramada Renaissance Hotel
Saratoga Springs, New York

For more information contact:
NYSARC, Inc.
393 Delaware Avenue
Delmar, NY 12054
(518) 439-8311

2) New York Association for the Learning Disabled

Theme:
"Transition - A Lifelong Process"

Date:
April 2-3, 1987

Place:
Americana Inn, Albany, NY

For more information contact:
NYLAD
155 Washington Avenue
Albany, NY 12210
(518) 436-4633

3) Young Adult Institute

Theme:
"Transitional Issues for Community Coalescence: Promoting Integration and Dignified Services for People with Developmental Disabilities."

Date:
April 29 - May 1, 1987

Place:
New York Hilton Hotel, N.Y.C.

4) N.Y.S. Commission on Quality of Care for the Mentally Disabled

Theme:
"A Conference on Quality of Care for the Mentally Disabled"

Date:
May 6-8, 1987

Place:
Americana Inn, Albany, N.Y.

For more information contact:
N.Y.S. Commission on Quality of Care
Suite 1002
99 Washington Avenue
Albany, NY 12210
(518) 473-7378

For more information contact:
YAI
460 West 34th Street
New York, NY 10001-2382
(212) 563-7474

5) University of Alberta

Theme:
"Severe and Multiple Handicaps Alternative Futures Conferences"

Date:
May 6-8, 1987

Place:
Edmonton, Alberta, Canada

For more information contact:
Dick Sobsey, Conference Coordinator
Dept. of Educational Psychology
Faculty of Education
University of Alberta
Edmonton, Alberta

6) Cerebral Palsy Center for the Disabled

Theme:
Children in the 80's A one day conference on critical policy and clinical issues affecting children for Educators, Social Workers, Psychologists, Therapists, Nurses, Administrators and other child-care professionals.

Date:
May 8, 1987

Place:
Albany Hilton Hotel
Albany, New York

For more information contact:
Dorie Godfrey
Center for the Disabled
314 S. Manning Blvd.
Albany, New York 12208

7) Citizens Task Force on Aging Out

Theme:
"Aging-Out"

Date:
May 11-12, 1987

Place:
Cultural Education Center
Albany, New York

For more information contact:
Barbara J. Spoor
Statewide Coordinator
NYS Citizens Task Force on Aging Out
One Empire State Plaza
10th Floor
Albany, New York 12223
(518) 473-6007

8) American Association on Mental Deficiency

Theme:
"In Pursuit of Excellence"

Date:
May 24-28, 1987

Place:
Los Angeles Hilton Hotel
Los Angeles, California

For more information contact:
AAMD
1719 Kalorama Road
N.W. Washington D.C. 20009
1-800-424-3688

9) Northeast Rehabilitation Association

Theme:
"Rehabilitation on the Northeast - Moving Boldly into the 90's"

Date:
June 11-14, 1987

Place:
Plymouth, Massachusetts

For more information contact:
Northeast Rehabilitation Association
29 Fessenden Road
Arlington, MA 02174

10) N.Y.S. Association of Day Treatment Providers

Theme:
Annual Symposium

Date:
September 16-18, 1987

Place:
Fallsview Hotel, Ellenville, NY

For more information contact:
David Mealy
Intensive Services Program
130 South Street
Auburn, New York 13021
(315) 255-2271



ASSOCIATION CALENDAR OF EVENTS

April

8 Supplementary Recreation/
Special Olympics Regional
Workshop

17 Developmental Center Committee
Meeting
Delmar, New York

25 Southeast Regional Meeting
Nassau County Chapter, NYSARC

May

1-2 Board of Governors' Meeting
Thruway House
Albany, New York

1 Incident Review Committee
Meeting
Thruway House
Albany, New York

13 Chapter Public Information
Resource Persons Committee
Meeting
Delmar, New York

June

5 Youth Advisory Committee
Meeting
Delmar, New York

14 Supplementary Recreation/
Special Olympics Regional
Workshop

24 Youth Regional Workshop

August

21 Prevention Committee Meeting
Delmar, New York

September

18 Developmental Center Committee
Meeting
Delmar, New York

18 Youth Regional Workshop

October

15-18 Board of Governors Meeting and
38th Annual Convention
Hotel Syracuse
Syracuse, New York

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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