

OUR Children's Voice

Retarded Children Can Be Helped

Five NYSARC Initiatives Become Law

Legislature Passes — Governor Signs into Law, Ombudsman, Scholarship Incentive, Program Development Grants, Building Aid for Special Education Classrooms and Dormitory Authority Funding.

At the October 1986 Convention held at The Concord, the Board of Governors and Delegate Assembly reviewed, approved and

adopted the 1987 Legislative Platform for the Association. Additional legislation, clearly consistent with NYSARC's goals and objectives, was later added to the platform as discussions concerning NYSARC's legislative goals commenced with legislative staff.

In all, 15 bills representing key issues of concern to the Association were printed and introduced in the Legislature for the consideration of both houses. Five of these bills were passed by both the Senate and Assembly and were subsequently signed into law by the Governor. Key to this accomplishment

was the support of NYSARC chapters across the state who actively wrote letters and contacted their local legislators to promote the NYSARC platform.

The results of the Legislature's consideration of our bills are as follows:

1. Education

A. Vocational Rehabilitation — ORS

Goal: Support legislation to move the Office of Vocational Rehabilitation from the New York State Education Department to a separate office in the Executive Branch called the Office of Rehabilitation Services.

Accomplishment: A.5812 by Hevesi passed the Assembly. S.45 by Donovan remained in the Senate Finance Committee. Both bills create a separate Office of Rehabilitation Services.

A last minute compromise was considered which would have created a temporary state commission for the purpose of studying New York State's system of rehabilitation services and making recommendations aimed at its improvement. However, the Legislature and the Governor could not work out the details of such legislation and no bill was printed.

B. Space for Handicapped Children in

Normal Public School Settings

Goal: Support legislation to encourage and require that handicapped children receive their education in normal school settings whenever possible.

Accomplishment: S.315 by Donovan was sponsored at the request of the Association and quickly passed the Senate. This bill increased from \$2,000 to \$3,000 building aid available for the construction of special education classroom space within or connected to educational facilities serving non-handicapped children.

During the 1987-88 budget session both houses of the Legislature agreed to incorporate the provisions of S.315 into the state budget. This action was taken and subsequently approved by the Governor.

Additional legislation was introduced by the Senate and Assembly (S.313 by Donovan, A. 8428 by Serrano) increasing the rental which BOCES can pay for space from \$5.00 to \$10.00 per square foot. This legislation was aimed at providing additional space for handicapped children within facilities serving non-handicapped children.

(continued on page 5)

Governor and Legislature Approve \$7 Million In Start-Up and Operating Funds

Forty-six projects are saved from temporary delay or cancellation

The Office of Mental Retardation and Developmental Disabilities in June of this year informed various chapters and other not-for-profit agencies throughout New York State that various capital projects were to be either temporarily put on hold or cancelled. Approximately forty-six projects were in jeopardy.

On Wednesday, June 17th, the Executive Directors of United Cerebral Palsy (UCP), The Interagency Council (IAC) and our Association met with the Governor's Deputy Secretary for Human Services and the Commissioner of OMRDD regarding the withdrawal of commitments for various development projects across the State. The three major not-for-profit organizations representing persons who are mentally retarded and developmentally disabled expressed their strong concern that such action would delay the establishment of essential services as well as undermine the credibility of the effort to develop community-based services for persons with mental retardation. The Executive Director of NYSARC, Marc N. Brandt, stated that the three groups, "made it clear that funding must be obtained immediately to enable projects to proceed as scheduled."

In responding to questions concerning the reasons for this crisis, Commissioner Arthur Y. Webb explained that it resulted from a more successful than anticipated development effort over the course of the last year. As a consequence, the number of projects capable of coming on line during

FY 87-88 has outstripped available funding by an estimated \$7.1 million dollars.

Additionally, the Deputy Secretary to the Governor for Human Services, Ms. Ilene Margolin, indicated that the Governor was aware of the gravity of the situation and that he was attempting to find a solution.

Numerous letters from parents and providers across the state were sent to the Governor and Legislature requesting that \$7,000,000 to insure the availability of sufficient funding for all committed projects.

During the closing hours of the legislative session the Legislature approved the \$7,000,000 in startup and operating monies for Community Residential and Day Program projects which were in jeopardy. Additionally, the Legislature added language which requires OMRDD to prepare a three year plan estimating the numbers of projects to be completed over that period. This action by the Legislature was intended to insure that in the future adequate monies are available for the funding needs of new projects. The Governor approved the message and the \$7,000,000 was added to the State Budget. While a few of the projects were lost the majority of the projects that were in jeopardy are continuing to be developed.

While NYSARC and the other major providers were delighted that the necessary funds were restored it is the consensus of the Organizations that steps must be taken to assure this problem does not occur again. ■

38th Annual Convention

To Be Held October 15-18, 1987



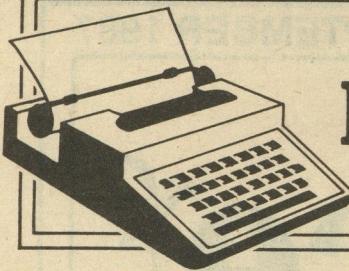
Honorable Stan Lundine, Lieutenant Governor

October 15-18, 1987 marks the 38th Annual convention for the NYSARC, Inc. This year the convention will be held at the Hotel Syracuse in Syracuse, New York. The theme of the convention is "NYSARC Advocacy — Strategies for Transition into the 90's".

Thirty-seven workshops will provide conventioners an opportunity to be informed with some of the most current issues facing persons who are mentally retarded and developmentally disabled.

On Saturday night, October 17, 1987, the Lieutenant Governor of NYS, the Honorable Stan Lundine, will give the Banquet address. The Friday night keynote address will be given by Mr. William G. McMahon, Chairman of the NYS Commission of Correction.

For more details see page 00 in this issue of OCV. ■



EDITORIALS

A Promise Fulfilled – But Not This Year

On Thursday, September 17, 1987, a ceremony marking the closing of Willowbrook (Staten Island Developmental Center) will take place. The event has been named "A Promise Fulfilled." Considering the horrifying conditions that were exposed just a decade ago at Willowbrook the closing of the facility should be noted.

However, it would be a mistake to allow the outward trappings of the September 17 ceremony to cloud the fact, though Willowbrook may be closing, there are many other D.C.s that remain open in N.Y.S. These facilities and their residents experience many of the same problems which have haunted Willowbrook for the past decade.

Furthermore, despite the self-congratulations, N.Y.S. did not volunteer to close Willowbrook. While it is tempting for some to lay claim to this event, it is important to recall why the facility was brought to national attention as a symbol of horror and neglect. It was a small group of courageous parents – along with the NYSARC, Inc. – not a Governor – not a Legislature – not a Commissioner – that filed a suit against N.Y.S. claiming that the conditions at Willowbrook were at a dangerous level, demeaning to the rights of the individual residents, and the nobody but a federal court would listen to their pleas.

It was not the initial intentions of these parents, nor the State ARC, to have the doors of Willowbrook closed. It was the hope and contention of the plaintiffs to bring attention to the Federal Court issues surrounding the overall living conditions of the facility. The overall lack of quality of care, poor staffing ratios, non-existing programs, abuse of residents, poor and inadequate food and clothing, just to name a few, were the main sources of frustrations which the parents wanted to change.

The federal court did listen. Further, it determined that unless N.Y.S. agreed to vastly improve conditions at Willowbrook, it would be the subject of substantial federal penalties. Rather than face such penalties, the N.Y.S. government made a very practical decision and "consented" to vastly improve conditions at Willowbrook. The formal commitment to this goal – the "Willowbrook Consent Decree" – was signed by the state.

The recent decision announced by the state to close additional developmental centers must be viewed with suspicion regardless of the merits that may ultimately be produced by each of the facilities closing. Many of the problems that were of concern to the parents of Willowbrook are still evidenced in many of the state developmental centers. While no one can deny the tremendous improvement of the conditions of the developmental centers since the Willowbrook Decree, it is important to recognize that while change has occurred much needs to be addressed.

Akin to the decision to close Willowbrook, the closing of five additional facilities is

being made by the state for very practical reasons of its own. The state's system of D.C.s is still the subject of ceaseless federal oversight activities. They continue to experience enormous problems and despite an annual client expense of \$90,000 per year they cannot provide decent service at a cost effective rate.

While ceremonies are taking place marking the closing of Willowbrook the conditions leading to that closure are still evidenced in the other twenty developmental centers. Facility after facility are receiving either intermediate sanctions or threat of decertification. Centers are being cited for lack of sufficient clinical services, insufficient staffing, lack of nutritional services and poor programming. In addition a number of developmental centers have had undercover investigators and/or the State Police uncover employee drug dealings and client abuse. While investigating the drug sales being conducted at one of the D.C.s, an undercover detective observed "clients punched around for being obstinate, for not listening or paying attention to commands."

While the vast majority of employees of the state developmental centers are concerned individuals, they are laboring under extreme working conditions. Morale is low and appropriate staff to resident ratios are virtually non-existent.

In addition to their large operating costs and the increasing scrutiny given developmental centers by the federal government, problems like those described are a source of obvious embarrassment to the state. For these very practical reasons, in addition to concern about client well-being, the state has determined to either close or depopulate all of its D.C.s.

The fact that New York State has chosen this policy direction primarily for practical reasons, are not from a sense of pure good will, may come of a disappointment to some. For others this realization comes as no surprise. These persons, many of whom belong to our Association, know that considerations such as cost and even public embarrassment are important factors in political and governmental decision making. For these persons the fact that government often responds to external pressure rather than an inherent sense of goodwill is not an occasion for bitterness. Rather they understand that government was constructed to respond to the forces outside of itself and in particular to the expressed needs and demands of the people it serves. This realization underscores our role as advocates; that is, persons who have taken it upon themselves to represent the needs, wishes and demands of persons who can't speak for themselves.

We should take the occasion of the closure of Willowbrook to remind ourselves that our role as advocates is a legitimate one in our society and one which we must pursue vigorously. We should also note the difficult conditions faced by the residents of the many D.C.s that remain open. For these persons, the promise fulfilled at Willowbrook will not be realized – not this year. ■

Regulatory Reform: Cautious Optimism

The fact that disagreements regularly erupt between regulators and regulatees is not an unusual or surprising event. These two parties after all are often adversaries in a never ending philosophical struggle over the best means to ensure that the process in question – whether it be in the field of mental retardation or any other field subject to regulatory oversight – results in an outcome that is reasonably perceived to be of high quality.

For the regulators part there may be an understandable tendency to embrace the written word as the only means of assessing whether or not quality is actually being achieved. Thus, the specific written requirements of rules and regulations and the production of documentation are critical. There may be neither the time or inclination to look into the more subjective indicators of quality such as staff client interaction or the rely on mere observation to conform that the most commonsense elements of good care are being rendered.

For the regulatees part there is more often a tendency to embrace more subjective and less tangible indicators of quality. Staff client interaction is after all something which the professional lives with every day and something which has become over time very "real" and in that respect verifiable. The regulatee may discount documentation as effort gone to waste proving what obviously exists.

In short the different experiences as well as the different formal roles of the regulator and regulatee have given them a distinctly different view of the world and thus have made a degree of conflict in their relationship something which can be reasonably expected. Just because the regulatee complains doesn't mean that the regulator is behaving inappropriately. Often all it means is that the regulator is doing his or her job. Perhaps this fact is responsible for the sense of futility which pervaded the voluntary sector up until just recently in its struggle to have OMRDD embark upon a meaningful program of regulatory reform.

It took a while for us to prove that we weren't being cry babies when we insisted over the course of a three (3) year period, which included legislative hearings and

letter writing campaigns among other activities, that the conflict between the voluntary sector and OMRDD went far beyond the tensions normally experienced between a regulator and regulatee.

In fact, OMRDD went far beyond reasonable limits in its tendency to embrace the written word as the ultimate indicator of quality. The Division of QA's extreme position in this respect was reflected in its inability to perceive obvious differences in the need to enforce regulations that clearly varied with respect to their relation to client care. That the requirement to have a chair in a clients bedroom was overseen and documented with zeal equal to that applied to regulations requiring basic fire safety, bears witness to the fact that as a regulator OMRDD had lost its sense of perspective. In short, reliance on the written word had eclipsed common sense.

It took the considerable judgement and sensitivity of the Commissioner of OMRDD, Arthur Y. Webb, to be able to look through the conflict between voluntary agencies and OMRDD to see that it wasn't simply a normal consequence of the adversarial relationship between the regulator and regulatee. This is greatly to his credit. As a result of the Commissioner's wisdom we are now cautiously optimistic that Part 686 draft amendments now under discussion not only reflect a renewed and more appropriate sense of perspective on OMRDD's part but will also mark the beginning of a more normal relationship between OMRDD and the voluntary sector.

Part 686 begins the process of discriminating between important and less important regulations. Hopefully it marks a departure from a literalistic interpretation of the written word as the only indicator of quality to an interpretation of written standards in light of sound and good judgement. If this kind of environment materializes it can only heighten the level of trust between OMRDD and the voluntary sector. It will indicate that OMRDD has adopted a more rational system of quality assurance which recognizes both the experience and professionalism which have distinguished care rendered to persons with developmental disabilities in the voluntary sector for so long.

Now both OMRDD and the voluntary field must work together to make Part 686 work. ■

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 persons who are mentally retarded, chartered by the State of New York in February, 1949.

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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

Our 38th Annual Convention is almost upon us. This year's theme, "NYSARC Advocacy - Strategies for Transition into the 90's" seems most appropriate as we rapidly are approaching a new decade. With it brings an opportunity not only to look back at the monumental accomplishments of our Association in the past 38 years, but also a chance to carefully examine current trends and issues which will effect and shape the lives of persons in our state who are mentally retarded in the not too distant future.

We are most fortunate this year to have two outstanding speakers at our convention. The Friday night keynote address will be given by the Chairman of the New York State Commission of Correction, Mr. William G. McMahon. One of the major issues facing our Association is the appropriate planning and assistance to those individuals who are mentally retarded and developmentally disabled who are at risk with the criminal justice system. Mr. McMahon has been discussing this issue with our Association and we look forward to his remarks.

On Saturday night we are most honored to have as our guest speaker at our annual banquet, the Lieutenant Governor of N.Y.S., the Honorable Stan Lundine. Mr. Lundine is no stranger to our Association as his previous role of congressman brought him in close contact with those chapters in the western region of our state that he represented. We look forward to Mr. Lundine's presence and the opportunity of sharing our 38th convention with the Lieutenant Governor.

As President of the NYSARC, Inc. and on behalf of our Association, I invite you to join with us in challenging our ability to provide new and innovative programs and services for all our citizens who are mentally retarded. The highlights of the convention are reported in this issue of OCV and I hope to see many of you at the Hotel Syracuse. ■

David B. Lettman

David B. Lettman
President

NYSARC Slide / Video Program Now Available

An eleven minute program has been produced and is now available for loan entitled "The New York State Association for Retarded Children, Inc." The program provides an overview of the Association through its 65 chapters and highlights some of the monumental achievements of the Association in the past three decades.

The presentation is available in either 1/2" VHS or slides. For more information or to make arrangements to borrow this program, please contact Ms. Susan A. Lyons of the NYSARC State Office. ■

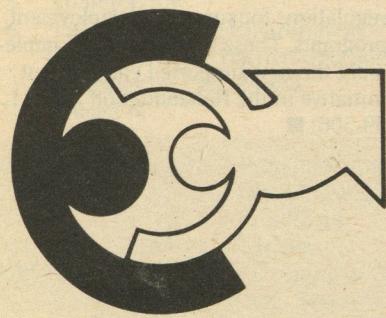
Quote of the Quarter

"In a decent, caring society like the U.S., every individual is important...some of the most talented people in our society are people with disabilities..."

Vice President, George Bush
Before the Association on Handicapped
Student Service Programs in
Postsecondary Education

Annual Convention 1987

See Page 13!



Health Corps Act Amended To Include Employees Of Voluntary Agencies

STATE OF NEW YORK

310-B

1987-1988 Regular Sessions

IN SENATE

(Prefiled)
January 7, 1987

Introduced by Sens. DONOVAN, DALY, DUNNE, FARLEY, FLOSS, JOHNSON, KEHOE, LACK, E. LEVY, N. LEVY, ROLISON, SKELOS, TRUNZO, TULLY, VELELLA -- read twice and ordered printed, and when printed to be committed to the Committee on Health -- reported, and when printed to be committed to the Committee on Finance -- committee discharged, bill amended and recommitted to said committee -- committee discharged, bill amended, ordered reprinted as amended and recommitted to said committee

AN ACT to amend the public health law and the education law, in relation to including health care professionals, employed by voluntary not-for-profit facilities licensed by the office of mental retardation and developmental disabilities, within the New York state health services corps

At the April 3, 1984 Spring Board of Governors' meeting, correspondence was received from our Delaware County Chapter concerning the inability of many of our chapters to recruit and retain qualified, licensed professionals. The letter was referred to the Executive Director who in turn discussed the issue with the NYSARC Legislative Committee. For the last three years, as part of the Association's Legislative Platform, NYSARC has attempted to address the issue.

On August 4, 1987, Governor Cuomo signed Senate Bill 310 (Chapter 583 of the Laws of 1987) which was introduced last legislative session by Senator James Donovan and Assemblywoman Elizabeth Connelly at the request of NYSARC.

Health Corps scholarships are awarded to persons seeking an educational degree in a clinical profession in return for an obligation to work in a specific health care setting. As a result of chapter 583, such health care settings now include not-for-profit agencies serving persons with developmental disabilities.

The following information is a summary relating to the Health Corps.

1) *Description:* The Health Services Corporation administers a scholarship incentive program for the purpose of recruiting clinical professionals into programs operated or licensed by the Office of Mental Health, The Office of Mental Retardation and Developmental Disabilities and the Department of Corrections.

Clinical professions eligible include speech-language pathologist, occupational therapist, nurse, physician assistant, audiologist, physical therapist or other clinical professions determined appropriate by the commissioner other than dentists and physicians.

Scholarships are awarded to recipients in exchange for an obligation to work at a specific program once education is completed. Each year of scholarship funding or portion thereof carries with it an 18-month work obligation.

2) *Awards Process:* The Health Department has developed a needs assessment pro-

cess to screen scholarship applicants. Applicants are evaluated both by the Health Department and the agencies providing eventual employment. Work placements are identified prior to the finalization of awards. All applicants must be received by the February preceding the school year during which awards are effective. The following important facts should be noted:

a) The number of scholarships awarded to date out of an annual level of 300 to 600 initial applications are as follows

85-86 (first year of operations)	30
86-87	137
87-88 (estimated)	165

b) Annual awards have averaged \$ 9,200 per student and cover tuition, room, board and books.

c) Scholarship funds are administered jointly by both the Health Department and the Higher Education Scholarship Corporation.

3) *Availability to the voluntary sector:* "Health Corps" scholarships have already been awarded for the school semester commencing this fall. At the time these awards were made, chapter 583 had not been approved and placement in voluntary programs had not been authorized. Consequently, none of the current recipients is slated for employment in the not-for-profit sector. However, in the event that these recipients or previous award recipients cannot maintain their commitment to work in a state employment setting, they may then choose a voluntary placement approved by the Health Services Corporation. At this time, there are no estimates of the number of award recipients, if any, that will become available in this manner.

Award recipients commencing their education in the fall semester of 1988 will include persons whose employment placement is in the voluntary sector. However, the number of such individuals is *dependent on whatever funds are specifically appropriated for this purpose in the FY88-89 state budget*. NYSARC, Inc. will work hard to ensure that such funds are appropriated. ■

Mid-Hudson ARC Telethon To Air October 25



**Helen Hayes, Honorary Chairperson,
Mid-Hudson ARC Telethon
October 25, 1987**

KINGSTON, N.Y., August 24, 1987 — On Sunday, October 25 from 4 p.m. to 11 p.m., a host of celebrities will participate in a major fund-raising event that will benefit ARCs in Ulster, Dutchess, Greene, Sullivan, Putnam and Orange Counties.

Broadcast LIVE from the Mid-Hudson Civic Center in Poughkeepsie, the event will be carried throughout the region by the

valley's major television station, WTZA, Channel 62, reaching into over 300,000 homes and over 800,000 viewers. Complimentary tickets will be available to anyone calling their local ARC chapters. It is expected that the 2000 seat arena will be filled to capacity.

Miss Helen Hayes, one of America's best loved actresses has agreed to serve as Honorary

Chairperson and Governor Mario Cuomo has filmed a promotional spot to publicize the event.

The seven hour, entertainment packed program will feature such named performers as Rosemary Clooney, Margaret Whiting, Stephanie Mills, Donna Allen, Andrea MacArdle, comedienne Nancy Parker, the rock group Tower of Power, dancer/singer Alysha, Betty MacDonald and Robbie Dupree.

A major media campaign has been planned for the month of October with a countdown to the day of the TELETHON. Area radio stations, newspapers, youth groups, senior citizens groups, church groups, schools, service clubs and organizations, will help call community attention to the worthy cause.

In order to maintain individual community identity, all funds pledged will be designated to the community ARC from which the funds were generated.

In addition to well known celebrities, the programming will highlight each agency's programs and will feature interviews with staff, parents, area dignitaries and others involved in the community.

While this TELETHON is the first joint effort of the six Mid-Hudson Valley ARCs, it will be a fifth run for the Ulster Association for Retarded Citizens who began their TELETHONs over the local cable network which covered only a portion of Ulster County. Executive Director, Peter Pierri, feels that the six-county ARC TELETHON will offer a wider exposure to a greater audience than ever before. "We want everyone to know about the work the ARCs do in their communities. This gives us a wonderful opportunity to reach out to them and to do it in an entertaining and exciting way." ■

Federal Update



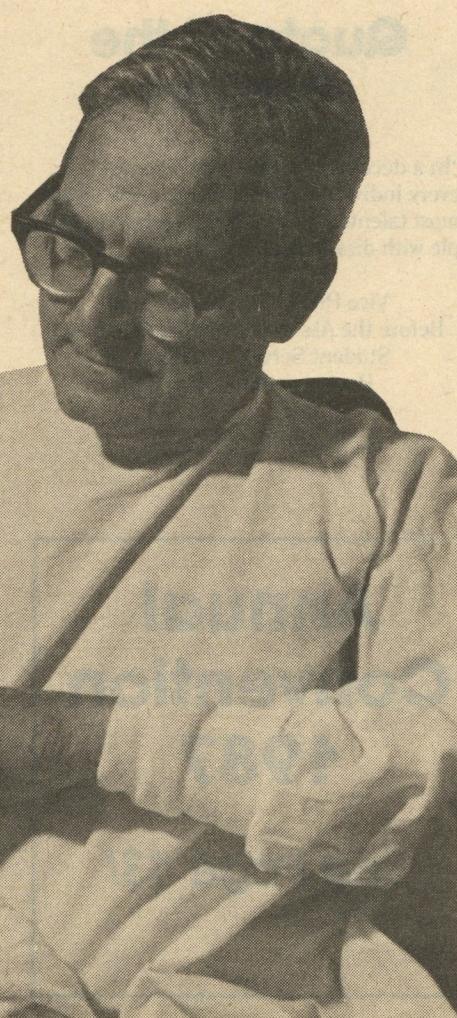
The House of Representatives voted July 15th to approve fiscal 1988 funding for reduced cost mail for not-for-profit organizations. The funding, commonly referred to as the "revenue forgone" provision, was included in a bill to provide fiscal 1988 funding for the U.S. Postal Service, Department of Treasury and other assorted government agencies. The \$517 million appropriation allows a reduced mail rate for not-for-profit organizations. The Senate is now due to begin its consideration of the appropriations bill, H.R. 2907.

Representative Madigan from the State of Illinois introduced in Congress H.R. 1871, which amends the Developmental Disabilities Assistance and Bill of Rights Act by adding Family Support Services to the list of priority services that must be provided. The bill defines Family Support Services as those designed to strengthen the role of the family as the primary caregiver, to prevent out-of-home placement, to reunite families with members who have been placed out of the home and to maintain family unity. The bill also revises the definition of supported employment to include persons with developmental disabilities who are members of groups for which competitive employment historically has not been available or for whom competitive employment has been interrupted due to a developmental disability.

The Internal Revenue Service (IRS) has reconsidered its proposed regulations regarding tax-exempt organizations. The IRS has announced that when final regulations are issued under Section 501 (h) of the IRS Code, they will only apply prospectively (to periods beginning after the date of final publication).

The Civil Rights Restoration Act of 1985, S.557, was introduced in February in the Senate by Senator L. Weicker and 44 co-sponsors. The bill seeks to overturn the U.S. Supreme Court's ruling *Grove City v. Bell*. In the *Grove City Decision*, the U.S. Supreme Court substantially limited the rights of disabled and minority persons by its narrow interpretation of the Section 504 phrase "program or activity" receiving federal dollars. S.577 restores broad definition originally intended by Congress when it passed Section 504. (of the Rehabilitation Act of 1973).

The Department of Education in Washington D.C. has released its proposed regulations for supported employment programs. These regulations will implement the new supported employment initiative in the Rehabilitation Act (P.L. 99-506). ■



Dr. Robert Guthrie enjoys a quiet moment with a newborn infant. Thanks to Dr. Guthrie's research and dedication, newborns such as the one below will enjoy a healthy, normal life.

capped children. S. 313 passed the Senate while A.8428 was held in the Assembly Education Committee. Both houses agreed to consider this legislation during the next legislative session.

C. Scholarship Incentive

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

Accomplishment: At the request of the Association, legislation amending the "Health Corps" act was introduced to make clinicians working for not-for-profit agencies serving the developmentally disabled eligible for scholarship benefits administered by the Health Service Corps. This legislation was introduced originally during the 1986 legislative session but failed to pass either the Senate or Assembly because of concerns relating to the effectiveness of the Health Corps program. During the 1987 session, Health Corps legislation was reintroduced (S.310 by Donovan, A.2975 by Connelly) and this time passed both the Senate and Assembly. On August 4th, S.310 was finally approved by the Governor as chapter 583 of the Laws of 1987.

Since Health Corps Scholarships have already been awarded for the school year commencing this fall — prior to the approval of chapter 583 — persons desiring employment with voluntary providers will become fully eligible to participate in the "Health Corps" scholarship program in the semester beginning in January 1988.

It should be noted that this legislation was originally adopted by NYSARC's Board of Governors at its Spring 1984 meeting at the request of our Delaware County Chapter.

2. Community Residences

A. Timely Response to Rate Appeals

Goal: To promote legislation requiring that OMRDD act upon completed rate appeal applications within a specified time period.

Accomplishments: At the request of NYSARC, bills were introduced in both houses requiring that OMRDD and the Division of the Budget promulgate amended fees within 90 days of the receipt of a completed rate appeal application to amend a fee for an existing program.

S.1629 by Spano passed the Senate while A.2446 by Connelly was held by the Assembly Ways and Means Committee.

Legislative staff indicated that voluntary providers had not voiced concern over the timeliness of OMRDD's recent processing of rate appeals. This observation appears to have been substantiated by the lack of any appreciable chapter response given to a chapter bulletin distributed last summer asking chapters to notify State Office

concerning delays in OMRDD's processing of rate appeals.

Nevertheless, the State Office will continue to monitor this situation and if necessary ask that this legislation be reintroduced next legislative session.

B. Reimbursement of the Cost of Land

Goal: Promote reintroduction and passage of legislation reimbursing the cost of land incurred by voluntary providers to establish residential programs.

Accomplishment: The Association successfully obtained the reintroduction of S.2044 by Spano and A. 2879 by Kremer requiring that fees established for ICF/MRs and Community Residences include the cost of land for newly established residential facilities.

S.2044 remained in the Senate Mental Hygiene Committee. A.2879 was held by the Assembly Ways and Means Committee.

As during last legislative session, this legislation was held in committee since reimbursement of land costs for any type of health care facility is unprecedented. However, legislative staff did indicate that reimbursement of land costs might be considered as part of legislation aimed at securing alternate financing sources for community residential construction. The ability to obtain such financing became a prominent issue at the end of the session when OMRDD announced the cancellation of various projects due to a shortfall in state financing resources.

C. Dormitory Authority Financing

Goal: To authorize the Albany ARC to obtain tax exempt low interest financing provided by the state Dormitory Authority.

Accomplishment: NYSARC successfully obtained passage by both the Senate and Assembly of legislation (S.5861 by Nolan, A.7607 by Conners) to enable the Albany ARC to utilize Dormitory Authority financing. The Governor subsequently signed S.5861 as chapter 250 of the Laws of 1987.

The Albany ARC is expected to utilize Dormitory Authority financing to construct a new day program facility to replace their current facility at 155 Washington Avenue in Albany.

NYSARC will be working with the Dormitory Authority to enable additional NYSARC, Inc. chapters to participate in this type of financing.

D. Goal: To maximize access to Program Development Grants for work on Community Residences.

Accomplishment: NYSARC, Inc. obtained the introduction of S.4409 by Spano and A.6191 by Connelly which deleted the limitation that Program Development Grants (PDGs) be used only for "minor" rehabilitation. This legislation was passed by the Senate and Assembly and subsequently signed into law by the Governor as chapter 441 of the Laws of 1987.

These bills were introduced at the request of NYSARC after it was learned that various control agencies (DOB, the State Comptroller) were beginning to question whether PDGs awarded

to voluntary agencies conformed with requirements contained in the Mental Hygiene Law. Specifically, it appeared that PDGs exceeded the limitation that they only be used for "minor" rehabilitation projects.

Approval of chapter 441 should enable our chapters and other voluntary providers to avoid lengthy administrative delays in the awarding and processing of PDGs.

3. Developmental Centers

A. Ombudsman

Goal: To establish an independent client advocate at each developmental center.

Accomplishment: NYSARC successfully obtained passage by both the Senate and Assembly of A.2455 by Connelly establishing an Ombudsman at each developmental center. The bill was then delivered to the Governor who subsequently signed it on April 22, 1987 as chapter 57 of the Laws of 1987.

This bill was almost passed by both houses during the closing moments of the last legislative session but was killed by Senate leadership which held it in the Rules Committee. Advocacy efforts by NYSARC, including a letter writing campaign to Senator Anderson expressing our great disappointment over the Senate's failure to act on this bill, were then commenced in hope of gaining successful action during the 1987 session. These efforts proved successful.

The Ombudsman is scheduled to become operational by April 1, 1988. At that time, all concerned persons are urged to monitor the effectiveness of the Ombudsman so that whatever measures are required can be undertaken to ensure that the Ombudsman serves the purpose for which it was intended.

B. Co-location

Goal: To promote legislation prohibiting the co-location of persons who are mentally retarded and developmentally disabled with correctional facilities.

Accomplishment: S.3466 by Padavan passed the Senate while A.5290 by Prescott held in the Assembly Mental Health Committee. This legislation does not prohibit co-location from occurring. Rather, it provides a process to determine whether co-location should take place.

In our view, such legislation does not adequately protect D.C. residents and needs to be strengthened since the possibility of co-location remains an ever present danger. This fact was underscored by the Governor's recent decision to convert Rome D.C. into a medium security prison. In all likelihood, such action will lead to co-location of clients and inmates.

In the absence of any clear legal protection against such occurrence, NYSARC has begun to lay the groundwork for legal proceedings to prohibit co-location at Rome D.C. The State Office will continue to provide information on the outcome of such action to our chapters as developments occur.

4. Public Health

A. Medical Consent — Guardianship

Goal: To promote legislation that clearly states that a legal guardian of a person who is mentally retarded is allowed to sign for medical or dental consent.

Accomplishment: NYSARC, Inc. successfully obtained the introduction of A.4941 by Connelly clarifying the right of a guardian to sign for medical or dental consent. However, no attempt was made to obtain a Senate sponsor for this legislation since the Board of Governors at its spring meeting, voted to support a much more extensive guardianship statute introduced at the request of the Commission on the Quality of Care.

The CQC's bill, S.6090 by Spano and A.7994 by Connelly, extended guardianship to all persons with developmental disabilities and clarified the right of a guardian to sign for medical or dental consent. Both bills, however, failed to pass either the Senate or the Assembly. Apparently, various anti-abortion groups advocated against this legislation contending that it could be used to give abortions to persons with developmental disabilities against their will.

In view of the controversy surrounding this legislation, both the Senate and Assembly Mental Hygiene Committees expressed an interest in holding public hearings regarding the subject of medical consent. Should such hearings occur, it will be critical for NYSARC to encourage all persons and organizations who support the right of a guardian to render medical or dental consent to testify.

5. Regulation

A. Key Indicator Proposal

Goal: To promote legislation which requires OMRDD to use "key indicators" to regulate voluntary service providers.

Accomplishment: NYSARC successfully obtained the reintroduction of S.1634 by Spano and A.2452 by Connelly to require that OMRDD submit a plan to the Legislature with respect to regulatory practices conducted by the office. Such plan was to have distinguished critical areas of client care, such as client health and safety, from non-critical areas. Based on such distinctions, OMRDD was to have established separate visitation schedules for all regulations.

Both of these bills were held in committee pending the outcome of efforts by OMRDD to institute regulatory reform through promulgation of revised part 686 regulations.

It should be noted that OMRDD has convened a task force for the purpose of finalizing part 686. NYSARC is actively participating in this process and will inform chapters of any significant developments. Hopefully, part 686 will improve the regulatory environment for Community Residences and there will be no need to continue to seek a legislative remedy to this problem.

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6. Local Assistance

A. Equity of Funding

Goal: To seek legislation consolidating CH620 funding and local services funding.

Accomplishment NYSARC successfully obtained the introduction of S.5866 by Spano and A.7605 by Connelly which makes all persons with developmental disabilities eligible for 100% net deficit local assistance financing regardless of whether they have a history of institutionalization. The aim of this legislation is to eliminate those aspects of the existing local assistance funding system which create an incentive to serve persons who have had a history of institutionalization at the expense of individuals without such a history.

S.5866 was held in the Senate Mental Hygiene Committee while A.7605 was held in the Assembly Ways and Means Committee. This legislation is viewed by the Legislature as extremely costly and in all likelihood will take considerable time and effort before it becomes a reality.

In the meantime, local assistance reform aimed at creating a non-discriminatory funding system which treats all handicapped persons equally will remain a top priority of NYSARC.

7. Prevention

A. Children and Lead Poisoning

Goal: To promote legislation establishing a statewide program to prevent and screen for lead poisoning in children.

Accomplishment S.3541 by Volker remained in the Senate Health Committee. A.5446 by Eve remained in the Assembly Ways and Means Committee.

The Legislature indicated that sufficient funding was not available to pay for the screening and prevention program established by this legislation.

B. Other Bills of Interest to NYSARC, Inc. Enacted into Law

1. Chapter 27 Laws of 1987 (S.3368 by Spano, A.4822 by Connelly) continues supplemental state aid funding to private schools serving adults who are mentally retarded. The bill provides \$1,700 per client until April 1, 1988 and \$2,000 per client thereafter. This legislation must be re-enacted every two years.

2. Chapter 45 Laws of 1987 (S.3181 by Spano, A.4158 by Connelly) authorizes access to a client's clinical records by the director of community services of the director's designee provided that such information is related to the director's statutory obligations.

3. Chapter 249 of the Laws of 1987 (S.5617 by Spano, A.7540 by Connelly) repeals the July 1, 1987 sunset provision thereby making family support a permanent program as opposed to a demonstration program.

4. Chapter 355 Laws of 1987 (S.3603 by Spano, A.6781 by Connelly) establishes the authority of DDSO directors over community services within their catchment area as such authority is assigned by the commissioner.

5. Chapter 538 Laws of 1987 (S.3705 by Spano, A.6787 by Connelly) deletes Westchester and Staten Island D.C.s as "schools" designated for the care and treatment of persons who are mentally retarded and developmentally disabled in order to finalize the closure of these facilities.

C. Other Bills of Interest to NYSARC, Inc. Not Enacted into Law

1. S.5595 by Spano and A.7794 by Connelly require OMRDD to develop a plan for providing services to community-based clients.

S.5995 – Passed Senate
A.7794 – Passed Assembly
A.7794 – Vetoed by Governor

2. S.5998-A by Spano and A.7993-A by Connelly authorizes workshops operated by the Office of Mental Hygiene to manufacture goods for purchase by OMH. The bill has been amended to preserve the preferred vendor status of voluntary contracts.

S.5998 – Passed Senate
A.7993 – Passed Assembly
S.5998 – Awaiting action by Governor

3. S.1343 by Padavan and A.5508 by Connelly require that all medication dispensed in psychiatric centers, developmental centers and ICFs be dispensed by a licensed nurse.

S.1343 – Passed Senate
A.5508 – Assembly Ways and Means

4. S.1637 by Spano and A.2454 by Connelly require personnel working in institutional facilities operated by OMH and OMRDD to report suspected instances of client abuse, neglect or mistreatment to the appropriate commissioner.

S.1637 – Senate Mental Hygiene
A.2454 – Starred on Third Reading

5. S.3602 by Spano and A.7412 by Connelly repeal section 33.17 of the Mental Hygiene Law requiring that providers transporting female clients ensure that such client is accompanied by another female unless accompanied by her father, brother and/or son.

S.3602 – Senate Mental Hygiene
A.7412 – Assembly Mental Hygiene

6. A.5516 by Nadler establishes standards governing the performance of sterilization procedures and requires that in certain instances (i.e. developmentally disabled patients) sterilization cannot be performed without a court order and without a statement from a physician indicating that a future pregnancy would result in death or severe permanent injury.

A.5516 – Assembly Health Committee

7. S.2760 by Padavan and A.3646 by Barraga expands the current applicability of the Site Selection Law in order to govern the establishment of ICFs over 14 beds.

S.2760 – Passed Senate
A.3646 – Assembly Mental Health

8. S.1636 by Spano and A.2450 by Connelly require that board members of organizations dedicated to serving the mentally disabled receive training upon their appointment to such board.

S.1636 – Senate Mental Hygiene
A.2450 – Starred on Assembly Third Reading

9. S.311 by Donavan and A.5365 by Sanders authorize early intervention programs which provide medical rehabilitative and educational services for children with disabilities under the age of five.

S.311 – Senate Education Committee
A.5365 – Assembly Education Committee

10. S.44 by Donavan and A.7689 by Serrano amend the Education Law and Family Court Act to make the State Education Department responsible for early intervention services to children ages 3-5. Such services would no longer fall within the jurisdiction of the Family Court and would become available to all children through a uniform set of standards and procedures.

S.44 – Senate Education Committee
A.7689 – Assembly Education Committee

Wanted: Just One Friend

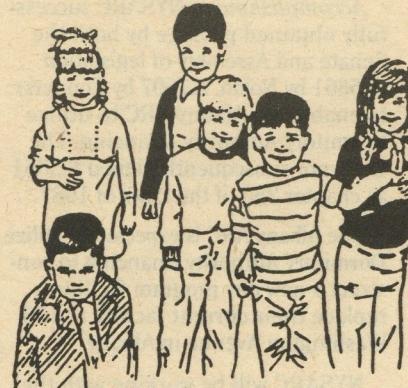
By Carolyn Daniel

How many times I have said, "If my son could make just ONE friend at school, everything would be fine!"

Of course, everything would not be fine. There will always be problems. My son is handicapped, you see. Dealing with OT, PT, IEPs, LREs and the dozen other acronyms we parents face, will always be a problem. But we will deal with them and with the help of the "experts" will hopefully fix what can be fixed.

The social problems our children face are truly heartbreaking. We, parents (who are supposed to be able to "fix" everything), are helpless. Can and should we "buy" them friends? Can a real friend be bought?

My son has cerebral palsy, attention deficit disorder with hyperactivity, and is learning disabled. He is in the fourth grade at our neighborhood school, and the only special education he receives is an ID resource room



for math. He does average (or better) school work, dresses in the latest styles (demanding "hi-top" Reeboks even though velcro had meant independence), loves MTV and Garbage Pail Kids, is well liked by his teachers and the office staff, and... doesn't have one friend at school. No one to spend the night, eat lunch with, or even walk down the hall with.

We have tried engineering friendships with swim parties, overnights, movies and McDonalds, only to have him waiting by the phone for that call that never comes - the invitation to their house.

This isolation takes its toll in many ways. Parents feel helpless and heartbroken. The child begins to lose interest in bringing home the good grades they are capable of. Who cares, anyway? Everyone else at school is talking about "so and so's party last week" and he wasn't invited, or worse, was invited and ignored. It causes emotionally immature LD and hyperactive adolescents to act out

behaviors that usually result in attracting only the principals' attention. It causes a myriad of problems, but mostly a sad, lonely child.

My son is not mistreated by his classmates. On the contrary, they mother him. When I have expressed concern to school personnel, I've been told, "The other children love him - they help him all the time!" I hate to sound ungrateful, but helping and liking are vastly different things!

PL 94-142 gave our children the right to attend their neighborhood schools and receive an appropriate education. It has been enormously successful. But, a far greater battle lies ahead - true acceptance of our handicapped children into their schools.

I sincerely wish this had a happy ending. That he had found that "best friend" we all remember from our school days. That one special friend that shared our innermost secrets, that laughed with us, cried with us, and always was there to play with us. Maybe someday my son will find that person who will see beyond his disabilities and take the time to get to know what a bright and funny little guy he really is.

If I thought it would work, I would run this ad: WANTED: JUST ONE FRIEND. MUST LOVE MUSIC, DOGS, SWIMMING, BIKING, MUD, BUGS, THE FLINTSTONES, COSBY, GARFIELD AND PEANUTS SPECIALS. Approximately 11 YEARS OLD. FOR LIFE.

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Get Well Jerry

As OCV goes to print we have learned that Joseph T. Weingold has suffered a severe heart attack. Our prayers and thoughts are with Jerry.

Dental Treatment For The Handicapped Challenges EDC Staff

By Mary Athey

A visit to the dentist can be a slightly anxious time for the strongest of us, but if you are developmentally disabled, either physically or mentally, the idea of such a trip can take on nightmarish proportions.

Because of the problems relating to treating such patients, particularly children who often require the most frequent care, some private dentists just sidestep the issue by not including such individuals in their practices.

However, an attempt is being made to change that situation in two ways — by making the private-practice dentists more comfortable with handicapped patients, and by making handicapped patients less fearful of dental work.

This attempt is the special project of Dr. Jorge Davila of Brighton, a senior clinical and research associate in the Department of Pediatric Dentistry at the Eastman Dental Center (EDC).

Dr. Davila has devoted most of his professional life to caring for patients with handicaps, and he is especially proud to supervise the EDC program of dental services offered on site and at the Monroe Developmental Center under a contract with the New York State Department of Mental Health.

Dr. Davila is a native of Bolivia. His arrival in this country 20 years ago plunged him into a situation where he had to immediately speak, read, write, and think in English. This abrupt change made him very sensitive to working with people who were also having difficulty dealing with their environments, due to either mental or physical impairments.

He came to the United States to work at EDC with Dr. Basil Biddy, known for his research in fluorides and at that time director of the EDC. Dr. Davila had graduated from dental school in Bolivia and practiced there for a number of years.

He returned to academia in Rochester, earned a specialty certificate in pediatric dentistry from the Eastman Dental Center in 1970, and completed the University of Rochester's master's program in 1972. He continued his research on plastic sealants for children's molars at EDC under the guidance of the late Dr. Michael Buonocore, developer of a sealant bonding technique. This technique has become very common in pediatric practices in recent years.

Drs. Buonocore and Davila also co-authored a report on a bonding technique for repairing fractured teeth.

After two years as an assistant professor at the University of Maryland, Dr. Davila returned to the U of R in 1975 to head the program being established for the treatment of disabled patients at the Monroe Developmental Center, a shelter for the disabled.

Also in 1975, the Monroe Developmental Center hired its first dentists to work on its clients. The center, which had opened its doors in 1973, housed patients with both physical and mental disabilities.

Attempting to soothe both types of patients is the goal for Dr. Davila's team. "We talk to them, always talk, even if they are deaf. It is important to establish human relationships and contact with them. We use touch, eye contact, anything that will put them at ease."

With the violent or aggressive patient, Dr. Davila uses slightly different tactics, but always with great compassion.

"If a patient is violent or aggressive, we try to manage them with more time spent with them, more patience, more touch. If that

"Fear of the unknown is one of our biggest problems in treating handicapped children," says Dr. Davila. "This is especially true of the mentally retarded. We also have problems with those who are physically disabled and whose body movements are uncontrollable, such as those with epilepsy or cerebral palsy. A trip to the dentist can cause their movements to become much more severe."

doesn't work, we do use sedation or general anesthesia, but often, after a few trips, some of these patients lose their anxiety and no longer need this approach."

Because many of the patients are young and have rapid changes occurring with their teeth, yet are unable to care for their teeth properly. Dr. Davila finds a generally low basic oral hygiene among these patients. This is aggravated by the fact that food is used as a reinforcement technique in treating these patients, and, as a result, they are constantly snacking.

Food is so important that even the tools Dr. Davila uses in his care are given food names, such as "crackers" for a mouth prop, and so on.

"When we talk about dental care for these patients, we just want to give them a level of care that will make them happy and give them healthy mouths.

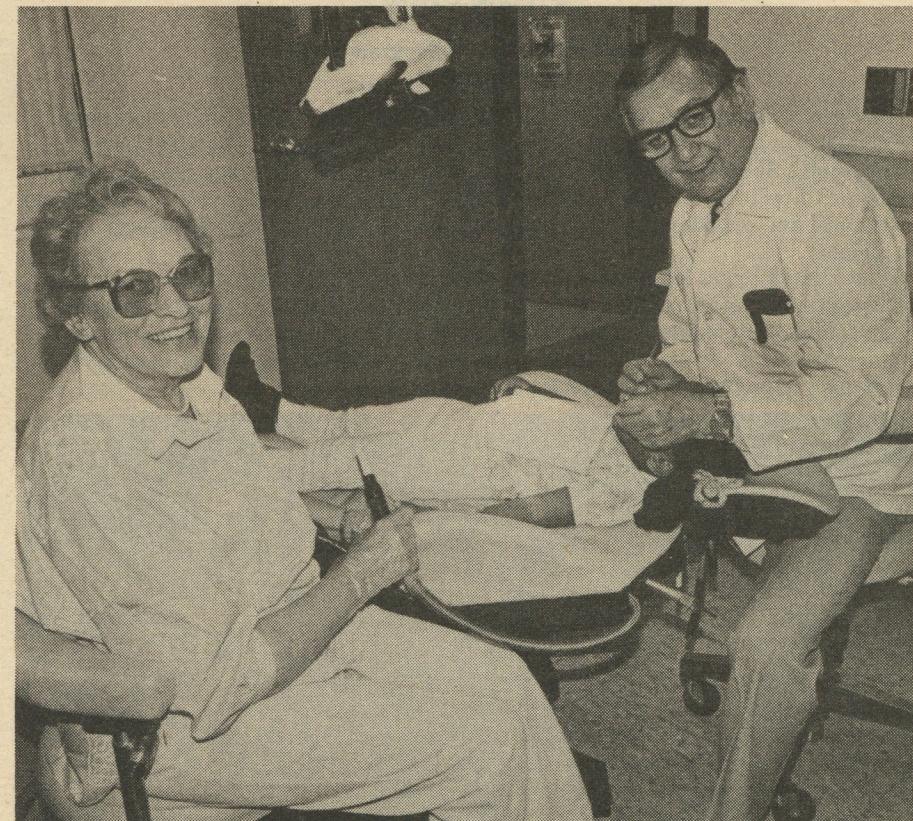
You never know what's going to be the right trigger for pride in these patients. I had one young man who had cerebral palsy. He was in his late 20s and was very difficult to manage. He had a missing front tooth. We replaced it and it gave him so much pride in his appearance that his behavior improved considerably," Dr. Davila reports.

The other side of Dr. Davila's work is, possibly, even more innovative. He has developed, with a grant from the federal government, materials for training dentists in western New York and on Long Island in the management and treatment of the handicapped.

His self-instructional continuing education course is called "Modern Concepts and Techniques in Dentistry for the Developmentally Disabled Patient."

"Many private dentists do not treat handicapped patients for two reasons. First, they lack the experience and are, frankly, somewhat apprehensive about what might happen. Second, there is a tremendous amount of paperwork that accompanies each of these patients, since most of their care is paid for by some governmental agency."

Dr. Davila's course has six booklets with accompanying slides and tapes. A dentist, perhaps in Albion, can study the booklets, view the slides, listen to the tapes, and he-



Dr. Jorge Davila and his assistant, Doris Potter, work with one of the residents at Monroe Developmental Center.

come much more comfortable with the idea of handicapped patients. The course is self-instructional and can be studied not only by the dentist but also by his hygienists and assistants.

These are often the people most closely in contact with the patients, and yet the very ones not in attendance at continuing education courses held by dental groups at some distant site.

"If we can increase the number of disabled patients treated in private practice, it will make an enormous difference in their lives. There are 350 patients at the developmental center that we see. There are many more that need to be cared for. If we can convince every dentist to see just one handicapped patient each week, most of that number will be covered." Dr. Davila believes.

He is currently applying for a new grant that will help in the dissemination of his course, and he is planning a course with the literature and tapes in Spanish.

Dr. Davila has also been working on a program in Rochester to help desensitize children who need to visit the dentist. With the help of two groups, he has been showing a special slide program to children in Rochester School No. 5. One group does not see the program; the other sees happy clowns visiting a dental office, examining instruments, and meeting the dentist. The clown is pleased and made to feel at ease with the entire experience.

The groups are made up of children who are borderline mentally retarded, and have speech impairments and learning disabilities. The reactions of the two groups — measured by heart beats and a subjective evaluation by the dentist — are correlated.

So far, the educational effort seems to be effective.

"We find that if you're honest with these children and go through the steps of care with them, they are more comfortable and less fearful."

Once he has them in his clinic, if a patient is still extremely anxious, various techniques are used. The team often cleanses the face of a patient with lotion to soothe him. The use of perfume helps condition patients to expect a pleasant environment. Sometimes, it's as simple as putting vaseline on chapped lips to make opening the mouth easier, or letting the patient listen to some music.

By tradition, handicapped patients, children and adults, are seen by pediatric dentists. In both cases, the dentist is working with a population unwilling to have treatment and fearful of the procedures. Because of that, a specialist in dentistry for children who is trained to develop management procedures can control those fears and apprehensions.

Therefore EDC is giving great attention to making sure graduates are familiar with handicapped care. EDC students come to the Developmental Center two days a week for 16 weeks as part of their training.

Dedication to the dental care of every handicapped patient is the goal of Dr. Davila and his team. The initial work of convincing people must be done and has started. Now, the task ahead is to teach the "how" to those interested in the program. Jorge Davila is more than ready to take on this challenge. ■

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CHAPTER

CLINTON

Summer Recreation Program Week On Its Way

Once again, through the cooperation and assistance of the Rotary Club of Plattsburgh, the Clinton County Youth Bureau and the Town of Plattsburgh, the Clinton County A.R.C. is providing a Specialized Summer Recreation Program for school age children with disabilities. Now in its fourth year of operation, the program provides five weeks of summer recreational fun to children who have no other program or services available to them during the summer.

There are three sites in Clinton County, Ellenburg, Morrisonville and Chazy, each site serving surrounding areas. The program began July 13 and will run through August 14, with 70 children attending. Transportation is provided for all children. Activities of the program include group recreational activities, community field trips and swimming. Mary Von Bargent is the Director of the program.



Children and Staff from the Clinton County ARC Recreation Dept. enjoy a cool swim while participating in the specialized summer program for school age children.

SCHOHARIE

ARC Celebrates Grand Opening Of New Facility

The Adult Rehabilitation Center of the Schoharie County Chapter, NYSARC, Inc. celebrated the official opening of the Schoharie Day Treatment Center on Saturday, June 20, 1987. The newly constructed facility is located just off Route 30 (Schoharie-Middleburgh Rd.) behind the existing Toe Path Industries. Over one hundred guests and staff attended the open house to celebrate the festive occasion.

The Schoharie Day Treatment Center was designed by the architectural group of Cataldo and Waters to be barrier-free and totally accessible to all persons with disabilities. Ground breaking began in June, 1986 and thanks to the construction firm of Colonie Builders, the facility was ready for occupancy on March 16, 1987. The building has a certified capacity for one hundred clients and approximately forty staff. The design and workmanship are a tribute to the people served and an example of the ARC's commitment towards improving their quality of life environment.

The open house was a well orchestrated event that included tours of the facility, a dedication, ribbon cutting ceremony and refreshments by the Parrott House. Guest speakers included Reverend Jared Van Wagenen, who blessed the new facility, Bonita Bowes, President of the ARC Board of Directors, Ira Gelinson, Executive Director and Master of Ceremonies, and Tony Alvarez, Director of the Schoharie Day Treatment Center.

The Adult Rehabilitation Center of the Schoharie County Chapter celebrates the official opening of their new Day Treatment Center.

WARREN/WASHINGTON

Chapter Celebrates 25th Anniversary

On June 9th the Warren/Washington Association for Retarded Citizens celebrated its 25th anniversary as an operating chapter. A gala party/annual meeting was held at the Ft. William Henry Motor Inn in Lake George where over 250 people including many agency clients and staff gathered for the festivities including dancing to the music of a local group "Revelations" and the annual awards presentation. Outgoing President Mari Gnaide detailed ARC's accomplishments of the last few years and complimented the Board and committee members for their dedicated efforts. Steve Holmes, Executive Director, and Joe Poliquin, new Chapter President, discussed the future of continued growth and fulfillment of the evening's theme "25 Years and Still Growing." Mary Caniano, President of the Albany Chapter, performed the installation of new officers and directors.

The Chapter received a lot of positive publicity in the weeks prior and following the 25th anniversary celebration including an editorial in the Glens Falls Post Star.

The Warren/Washington Chapter also has initiated two new services: a homemaker program funded through the DDSO and a two week summer camp integrated with the local YMCA serving 18 developmentally disabled children.

PUTNAM

PARC Scouts Camp Out

The Putnam Association for Retarded Citizens' Scout Troop 305, along with 15 adults, traveled to Camp Siawaney in Dutchess County for an overnight camping experience on May 29th.

According to Scouting Coordinator and PARC's Director of Intermediate Care Facilities, Richard Zuckerman, "34 scouts who, on a daily basis attended PARC's Day Treatment Program or the Sheltered Workshop for employment, participated in various scouting activities such as cooking, putting up tents, first aid, hiking and all of the usual camping skills."

According to Zuckerman, Scoutmaster Gary Newman and his scouts have been involved in extensive fund-raising activities for the purchase of official scout uniforms.

A successful bake sale was held on April 11th and currently, the scouts are holding a raffle for a color TV to raise those necessary funds.

Newman pointed out that the program is conducted in the same way that all scouting programs are conducted. Badges are presented as advancement takes place and all scouting rules and regulations are in force.

Anyone interested in obtaining more information about PARC's Special Scouts, may do so, by calling 225-5006.

WASSAIC

Community League Basketball Team Competes In Special Olympic State Games

Wassaic D.C.'s Community League, is very proud of the Valley Basketball Team, coached by Bill Thorpe.

During the weekend of March 27th-29th the Valley Basketball Team, coached by Bill Thorpe and accompanied by Mark Russell, journeyed to Elmira to participate in the Special Olympics Basketball Tournament. The team played three games and placed third in their division. The athletes enjoyed their weekend away and celebrated at a Victory Dance in Elmira that Saturday.

We are also proud to announce that seven aspiring horseback riders from the Valley have been participating in a weekly horseback riding program at Roseview Stables. The men practiced mounting and dismounting, half-seat position, posting trot, cantering, sitting trot and jumping cross ties. An important aspect of horse care that the men learned was the "cooling down period" which prevents the horse from becoming ill.

The men had the opportunity to test and display their skills at the Special Olympics Equestrian Games on April 5th.

The Valley Team and its clients as well as Community League have always known how lucky they are to have Recreation Worker Bill Thorpe as a member of their staff. He has always kept the clients of Wassaic actively involved in creative and fun recreational activities.

STEUBEN

Steuben ARC Completes NYS Contract

Steuben Services, the vocational division of Steuben Association for Retarded Citizens (ARC), has recently completed and delivered over 8,200 screen printed shirts for the New York State Department of Parks, Recreation and Historic Preservation.

The shirts, to be worn by all parks' employees, bear the NYS Department of Parks and Recreation logo and were screen printed in Bath by the Handicapped. Steuben Services has also been awarded additional contracts for t-shirts and hats for the Empire State Games, NYS Lifeguards, NYS Senior Games, and Games for the Physically Challenged.

In addition, the Steuben Chapter has recently printed commemorative t-shirts which will be sold in the exhibit area at the 1987 NYSARC Annual Convention.

GENESEE

Chapter Annual Golf/Tennis Tournament Raises \$10,000

A hot day at Stafford Country Club generated a lot of cold cash for the Genesee County Chapter of the New York State Association for Retarded Children on July 13, 1987.

The event was renamed this year in honor of the late Danny Lullo, a longtime promoter of the ARC tourney. His wife, Florence, and daughter, Kathy Earl, attended the awards banquet at the golf course held the evening before.

The tournament not only produced a great deal of proceeds for the ARC cause but also came up with plenty of ice to keep beverages - and players - cool. "We went through about 1,600 pounds of ice to keep the beer and pop cold on the course," Carney said.

In between swallows, Jim Smith of Batavia took low gross honors with a 73, a stroke better than Stafford pro Jon Lynn. Bob Bishop and Chuck Hoover of Batavia and Joe Giordano of Rochester each shot 76.

Dr. Sadegh Danesh had the low net score (64). John Ellingham posted 65 and Phil Call and Bruce Fustino 66.

Among the blind bogey winners were Rich Funke of Rochester and Batavians Charlie Keil and Bob Strang, Jr.

Mark Hoerbelt won the tennis A Flight and Sean Radka was the tennis B Flight champion.

CHAUTAUQUA

The Resource Center's "Special Olympic" Softball Team has been gearing up to participate in the 1987 International Summer "Special Olympic" Games to be held July 31 through August 8 in South Bend, Indiana. The 1987 games will involve the participation of 4,500 athletes from over 60 countries competing in 14 different sports.

SUFFOLK

This year, The Resource Center Softball Team was the only team chosen to represent New York State in this world-wide event. Families and friends share in the joy of our athletes and wish them luck as they "go for the GOLD!"

The Resource Center has expanded its Family Support Services and will now offer an overnight Guest Respite Program to Chautauqua County families of disabled adults and children. The program is designed to provide families with temporary relief from the constant care of a disabled family member. Full day or overnight Respite Care for adults and children will be provided in a carefully selected guest home.

The Respite Care Program is currently seeking caring families to provide good homes for temporary care to disabled individuals. In addition to the personal reward, Respite Home Providers receive training and support from professional staff as well as a per diem fee for care.

New Version of Gilbert and Sullivan Mikado Working in the Hamptons

Several years ago, SSA (Socialization for Special Adults) was initiated in the east end of Long Island and was sponsored by East Hampton and Southampton Departments of Recreation. Helen Rudman, the director of the program, has been meeting with a group of adults on Saturdays when varied activities involving living adjustment are enjoyed.

More recently, Suzanne Plave of New York City, a dramatic director, has joined the group. She is directing "The Mikado in Mime." Excellent musical recording and narration is used resulting in complete understanding and appreciation of the action by "The East End Special Players." These actors are experiencing a challenge never before required of them; they are responding with joy and feelings of self-worth, confidence and pride in themselves.

It is planned that the performance will be shown first on Long Island and hopefully elsewhere as well. Also, Suzanne Plave is very seriously planning a documentary to illustrate the progress made by "The East End Special Players" in presenting themselves as recognized members of the community proud of their accomplishments. The public will be alerted, through the documentary, as to the wide possibilities of effecting the lives of people previously in the shadows.

ALBANY

Albany Clients Participate In Special Olympic Games

Forty-five Albany Chapter clients participated in the training sessions for the Special Olympic games held on May 30, 1987 at the Hudson Middle School Field.

This training involved two hour practice sessions for eight consecutive weeks emphasizing throwing, starting, stopping and tossing skills and more importantly practicing the qualities of good sportsmanship. Volunteer staff, several parents and two Special Olympics coaches assisted during these sessions.

Each of these 45 individuals received a ribbon for their participation in the various track and field games. In addition out of the 12 athletes selected in the Albany County area to participate in the state competition, six individuals were from the Albany County ARC.

As the result of hard work, sore muscles, tears and laughter, Bob Colfels came home from the state games with 1 silver medal and 1 blue ribbon; Sam White came home with 3 gold medals; Jim Hughes and Janet Kandel both won 2 gold medals; and Lenny Brewer and Ricky Hathaway each received a gold medal.

These men and women take great pride in their accomplishments as they continue to wear their medals for weeks following the event. And it goes without saying, the Albany Chapter is truly proud of the effort and positive spirit put forth by all 45 athletes, staff and parents.

Opening Ceremonies of the New York Special Olympics Competition

DUTCHESS

Burger King Joins Work Stations Program At Dutchess County Chapter

For the past few months six clients from the sheltered workshop of the Association of Retarded Citizens, Dutchess County, have been working at Burger King on Rte. 9 in Wappingers Falls.

They are part of the Work Stations program which places clients in the competitive marketplace but with supervision from an agency employee. It is referred to as supervised employment rather than competitive employment. These clients are working with job coach Glenda Chambers. Ms. Chambers supervises the workers and helps them reach their goals. The franchise the workers are in is one that is owned and operated by Carrolls Corporation, the largest franchise in the world of this chain.

The ARC workers are responsible for making burgers, salad bar preparation, and maintenance tasks.



Dutchess County ARC clients with Linda Campbell, Marketing Director and Glenda Chambers, Job Coach at Burger King in Wappingers, a Work Station location.

HERKIMER

Parents Anonymous of Herkimer County Is A Newly Formed Agency

Parents Anonymous of Herkimer County is a newly-formed agency whose main goals are to help the parents of Herkimer County with parenting skills and assist parents and children to break the child abuse cycle.

Parents Anonymous of Herkimer County currently offers parenting classes involving The Nuturing Program, which focuses on learning new parenting skills and new ways of interacting with their children, as well as Parents Anonymous meetings to help potential and confirmed abusers break the cycle of abuse.

In the near future, Parents Anonymous will be forming support groups for parents with teens.

It is the hope of Parents Anonymous of Herkimer County, that any parent living in Herkimer County will be able to reach out and receive the support for their particular need.

In reaching out to our community, we hope to help parents improve their parenting skills, making the future generation free of child abuse.

Without breaking the cycle NOW - the problem only potentiates itself rather than defeats itself.

Parents Anonymous of Herkimer County is currently supported by VISTA-ACTION, whose immediate program supervisor is Jane Markley, Director of Community and Family Services of the Association for Retarded Children of Herkimer County.

If you are interested in joining one of our groups or volunteering, please call Parents Anonymous of Herkimer County at (315) 894-9916 and ask for Phyllis or Sonja. There are no dues or membership fees.

ULSTER

UARC Receives \$60,000 Low Interest Loan From Village of Ellenville

KINGSTON, N.Y. The Ulster Association for Retarded Citizens has received a \$60,000 low interest loan from the Village of Ellenville. The funds, part of the 1987 Small Cities Grant from the federal government's division of Housing and Urban Development (HUD) will be used to repair a badly damaged roof at UARC's Pilot Industries Workshop on Canal Street in Ellenville.

According to Workshop Coordinator, Gabe Cicale, the roof damage has been the cause of many problems at the workshop. "On days we had heavy rains," he explained, "the leaking meant we had to move production areas to drier locations. Our clients would lose half days at a time."

"We also had to replace damaged packaging material and will, after the repairs are made, have to replace insulation," Cicale adds. "And there was the problem of electrical shortages. We are very happy to have received this loan. Bids are going out shortly and we hope to begin work this summer. The sooner the better. I'm not anxious to face another winter with the present roof," Cicale concluded.

According to the UARC Executive Director, Peter Pierri, the loan, when paid back to the Village of Ellenville, will return to an economic revolving fund which will, in turn, be made available to other businesses in need. "The federal government issues HUD grants to promote economic stability and enhance employment opportunities for people," Pierri noted. "The best part of this kind of grant is that the money can be used over and over again."

CHAPTER

SENECA

Ribbon-Cutting For Seneca's Spectrum Industries

A long-awaited moment was celebrated by members of the Seneca Chapter on June 26th with the ribbon-cutting ceremony for Spectrum Industries' newly renovated building. The celebration was held in conjunction with an open house for the 12,690 square foot workcenter facility and the chapter's annual dinner meeting.

In a room filled with proud and beaming ARC supporters, agency and civic leaders saluted Spectrum Industries as a valuable newcomer to the rehabilitation and business communities. Spectrum's early months of operation have brought in jobs from some 15 area businesses, including assembly and disassembly, mailings, shrink wrap and other packaging, pallet rebuilding, and custodial and grounds-keeping work. Through June, 52 clients (capacity is 75) had been admitted to Spectrum, the only service of its kind within Seneca County. Disabled persons who previously had to travel to neighboring counties to receive sheltered

employment/rehabilitation services are finally able to receive them in their home county.

Administrative staff in the workcenter are Tom Hicks, Program Director; Bernard Marshall, Procurement Specialist; Jack Burrows, Supervisor of Rehabilitation Services; and Ron Saracino, Production Supervisor. ■



Seneca County Board of Supervisors' Chairman Frank Saracino and Joseph Adamo of Waterloo cut the ribbon at Spectrum Industries' new facility.

WAYNE

Wayne County Bids Farewell To Exceptional Teacher

A farewell party was held on April 3, 1987 to honor Shirley McNaney after 20 years of dedication and commitment to the disabled children and adults of the Wayne County Chapter, Association for Retarded Children.

Shirley was one of the two original teachers hired when the WARC was formed. During the past 20 years, Shirley has been responsible for helping the agency grow, when she saw there was a program need for disabled teens she helped start one and was the teacher of that group. Then there was a

need for a program for disabled persons over 21 that cannot work in a sheltered workshop or in the community, she helped start the Day Activities Training Program and became the director of that program. Under Shirley's guidance, the DATP has grown from just one program serving disabled adults to a program with three different components, one is to provide education and training in daily living skills and the third is geared to serve the senior citizen population.

The clients and employees of the WARC wish Shirley well and we are glad we had the opportunity to have had her as a friend for so many years. ■

SCHENECTADY

Schenectady Honors Charter Member, Burage Stiles

A special tribute was recently paid to one of Schenectady's "founding fathers." Burage Stiles, a charter member of the Chapter since 1952, was responsible for establishing the first community residence for persons with mental retardation in Schenectady County.

At ceremonies held on May 8th, the Niskayuna residence, 2215 Eastern Parkway, Schenectady, was re-named "the Stiles House." Almost 80 family members, friends, board, staff and political representatives gathered to pay tribute to Burage and recognize the outstanding contribution he had made to the agency over the past 35 years. ■



Burage Stiles surrounded by the clients of "the Stiles House"; Schenectady Board President, Paul Robinson; Executive Director, Linda Lahale; Residential Committee Chairperson, Bella Stuart; and Assemblyman Jim Tedisco, at the re-naming of the residence in his honor.

DELWARE

Local Youth Helps Make Bike-A-Thon Most Successful Ever

The Delaware Chapter conducted its 14th Annual Bike-A-Thon on Saturday, May 2, 1987. One hundred and sixty-seven (167) children of all ages turned out to ride under sunny skies and helped raise \$21,114.43. Riders came from schools in Delhi, Walton, Sidney, Sidney Center, Margaretville and Roxbury. There were also riders from local youth groups as well as programs operated by the Chapter. The all out effort, teamwork, and cooperation exhibited by the riders was commendable. ■

A safe Bike-A-Thon is a successful Bike-A-Thon. In addition to regular patrols by volunteers and the CB Club of Walton, the sheriff and local Constabulary, for the first time this year, insured the safety of the event.

From the total pledged to the riders, \$14,740.43 has been collected. In addition, there were eight (8) countywide sponsors of the Bike-A-Thon, contributing a total of \$4,000, while local sponsors and other business donations exceeded \$2,374. This means that the total donations of \$21,114.43 received to date surpasses the goal of \$20,000.

The record sponsorship and an increase in local prizes by businesses allowed for the introduction of a super countywide grand prize to the riders. Shawn Malcolm of Delhi collected \$1,256.34 and became the super countywide grand prize winner of a trip for two to Walt Disney World (See Super Grand Prize Winner story on this page). In addition, local prizes in each of the four areas consisted of a 10 speed bicycle, a boom box, three personal stereos, five gift certificates, tee shirts to the top 20 riders, and Oneonta Yankee tickets to the top 25 riders. Local and countywide prizes are one of the ways the Chapter shows its appreciation for the riders' efforts.



1987 Bike-A-Thon Winner, Shawn Malcolm, who brought in \$1,256 in pledges receives a Walt Disney World Trip for two from Judy Mostert, Delhi Area Coordinator. In the background, from left to right, George Suess, Executive Director of the Delaware County Chapter and Carmel Banks, President of the Board of Directors, proudly applaud Shawn's superb effort.

YATES

Summer Speech Therapy Group At Keuka Lake School

The Penn Yan Lions Club has underwritten a special speech therapy program being conducted at the Keuka Lake School for a number of Yates County children who, while they could not be considered to be handicapped according to the guidelines established by Part 200 of the Commissioner of Education's Regulations, do have speech disorders. These children have adequate language development, but have disorders of voice, fluency, and/or articulation which can make their intelligibility very poor.

Since such disorders can often cause secondary problems such as shyness, reluctance to try to talk, withdrawal, behavior problems, and/or poor self-esteem, it is important that they be provided with therapy not only to improve their speech, but also to prevent secondary emotional problems which may occur. It is very important that such therapy be given in a group setting where the children have a comfortable setting in which to practice talking to one another. Children who have such speech disorders often feel very inhibited about trying to talk if they are in a group of children who don't have such problems. They need a setting in which they can feel comfortable practicing speaking so that in other settings they can benefit from the role model of peers who have more typical speech development. The only speech therapy available in Yates County to children in need has been individual therapy at Soldiers and Sailors Hospital in Penn Yan.

This summer six children are enrolled in this speech therapy group taught by Alice V. Sherron, Speech Pathologist at the Keuka Lake School. Mrs. Sherron has been on the staff of the Keuka Lake School since it opened in September 1985. She holds a Master's degree in Speech and Hearing from the University of Arizona, and has extensive experience in speech pathology.

The Penn Yan Lions Club has demonstrated its commitment to children with speech disabilities with their donation. It is our hope that this pilot program in Yates County becomes a firmly established service to those children in need. ■

NASSAU



Who says cops don't have a soft spot? In Nassau County, off duty officers got together for a picnic sponsored by the Nassau PBA and served with all the fixings for several hundred children and young people who attended the Nassau AHRC summer day program.

CHEMUNG

Chemung Chapter Honors Former Board Members

Past Board of Governors delegate Harold Bauman and his wife Olive were honored in June by the Board of Directors of Chemung County ARC. The Baumans, each of whom has retired from Chemung ARC's Board, celebrated their 50th wedding anniversary in June.

Board members surprised them with a gift and a large cake at the agency's annual meeting and picnic June 16.

Close to 325 clients, staff members and their families attended the annual meeting. Maryann Bryant was re-elected president, along with Mary B. Krebs, vice president, and Ralph Thompson, secretary. Harry Miller succeeds retiring treasurer Norman Ward.

Among the many awards presented to clients: Off-Site Worker of the Year to Mary Locke and On-Site Worker of the Year to Mary Woodard. Each receives a \$50 savings bond.

Among summer activities planned by Chemung ARC are a baseball clinic for Recreation Program ball players and an Ox Roast.

Held July 24, the pre-game training clinic was put on by the Elmira Pioneers prior to their game against the Utica Phillies. The Pioneers/Red Sox also hosted a picnic reception for ARC ball players prior to the 7 p.m. game.

The Ox Roast, another first for the agency, was planned for August 16 at Grove Park in Elmira. The menu: Beef entree, baked potato, corn pudding, salad, beverage and dessert.

Chemung County ARC also posted a 20% gain in its 1987 membership drive. Membership rose from 444 to 533 members. Betty Butz, a member of the Board of Governors, serves as chairperson of the Community Relations / Membership / Fund-raising Committee.

Events planned for the fall include a tie-in with the Elmira Charity Horse Show Sept. 4-6 at the Chemung County Fairgrounds and a Staff Appreciation Night dinner Saturday, October 24. ■

SARATOGA

New Program To Bridge The Gap Between Day Treatment and The Workshop

Saratoga ARC's Alpha Industries was awarded an OMRDD Initiatives Grant for a prevocational program. The program is entitled, "The Work Training Center" and began operation in October of 1986. The Work Training Center offers a low client-to-staff ratio and clinical support which has not been available in the workshop previously.

The Work Training Center offers a highly individualized vocationally-oriented program offering intensive assistance and training in certain behavioral, social and vocational skill areas. It was developed to help individuals meet the minimum criteria for acceptance into a more normalized working environment through the use of work adjustment. The Work Training Center was developed to overcome the deficits which present barriers to successful employment by maximizing positive work performance according to an individual's program plan.

The Work Training Center was initially formed to serve referrals from the Day Treatment Program who are capable of progressing in a work situation, but need intensive support initially and must have work sites and jobs individually adapted. In its first month of operation, it was found that individuals referred by OVR could be assessed and previously may have been referred to Day Treatment for clinical services. These individuals can now progress to the Work Training Center and not be referred to Day Treatment.

The project's service objectives are:

- 1 to provide clinical and habilitation support to clients preparing for work settings.
- 2 to provide clinical consultation and the modification of work setting and task to allow individuals the opportunity to attain higher levels of productivity; and
- 3 to provide work and work-related experiences as a part of therapy and habilitation.

The following services are provided:

- paid production work
- remedial education
- personal and social adjustment training
- supported job site placement
- physical, occupational and speech therapy
- psychological services
- job and work site adaption ■

ORLEANS

Orleans County Chapter Dedicates New Cabin To Senator Daly

Camp Rainbow, a program of the Orleans County Chapter - NYSARC, was filled with plenty of singing, playing, eating, and smiles July 20 for the dedication of the Camp's new multi-purpose cabin to Senator John B. Daly.

Camp Rainbow was able to purchase the material for Cabin Daly with money raised from the annual Senator's Cup Golf Tournament benefitting Orleans County ARC. This year's tournament takes place on Sunday, August 30.

Cabin Daly houses the Camp's nurse's office, an administrative office, a sick bay, a wheelchair accessible bathroom, and a nursery that is also used for staff meetings.

The new cabin, which is certified as a safe gathering place for campers and staff during thunderstorms, was prefabricated by the Orleans-Niagara BOCES and was erected by inmates from the Orleans Correctional Facility.

It is hoped that this year's Senator's Cup Golf Tournament will raise enough money to cover the \$5,000 Orleans ARC stills owes for the new cabin, with plenty to spare for the constantly rising operating costs of Camp Rainbow.

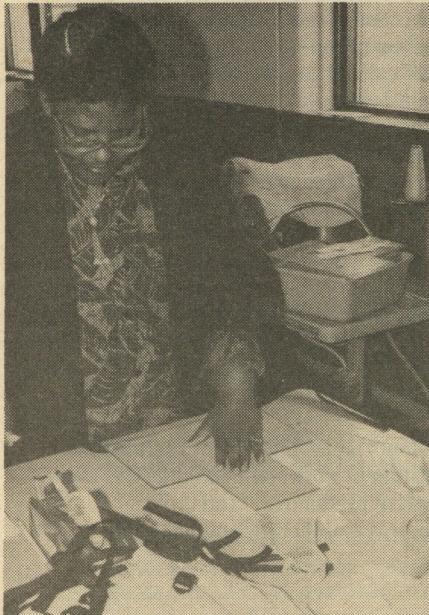
Camp Rainbow has undergone \$30,000 worth of capital improvements this year alone, including the new cabin and walkways that are suitable for wheelchair use. However, as the Senator could tell by the looks on the campers' faces as they lined up to shower him with hugs and kisses. Camp Rainbow is a very special place that is worth whatever it costs to keep going.

Senator Daly said, as he accepted a plaque commemorating the dedication of Cabin Daly. "The real credit for the cabin goes to the people who made the donations of time and money. I don't deserve this, many others have done more. But, I thank you, and this cabin will always be in my memories." ■

Chapter Program Highlights

Oneida Chapter "Invents" New Product

*Don't Be Left In The Dark
Safety Is Affordable*



Bernadeth Nicholas — aligning reflective stripes



Gail Howard — edging Vest-of-Life



Stan Rozyla — sewing Vest-of-Life



Mary Hjdasz, Supervisor — cutting patterns

It's a typical morning. You're on the way to work, traffic is a real pain and to top it off it is one of those drizzly days when you wish you were back home in bed. Suddenly out of the corner of your eye you catch a glimpse of someone jogging and you have to swerve into the other lane to avoid hitting him! Why don't those @ \$&(@?@ joggers wear something so you can see them?

If you have been driving for any length of time, I'm sure you have had a similar situation as described above. With any amount of luck the Oneida County ARC's new prime manufacturing endeavor will help alleviate part of this problem.

"Progress Industries (Oneida County ARC's sheltered workshop) is preparing to market our *Vest-of-Life* safety vest, on a nation wide level early this Summer," said Michael DiNitto, Workshop Director.

The *Vest-of-Life* is a lightweight reflective orange safety vest designed to give the wearer high visibility both day and night. It is the brain child of P.I.'s Industrial Advisory Board.

This board was initiated to help the chapter review quality control procedures, growth potential, efficiency procedures and the production requirements of existing sub-contracts as well as to determine which areas of production could be most readily expanded.

Progress Industries is one of the few workshops in New York State that has a marketing program designed to explore its sub-contracting capabilities through the development of an Advisory Board of this nature.

Each of the industrial representatives was asked to participate as a member of this board because of his/her expertise in a particular field pertinent to the sub-contracting capabilities of Progress Industries because he/she is in daily contact with the manufacturing function of his/her company.

This 18 member board was charged with developing a product in which all phases of production could be maintained locally, according to Jim Coffin, Marketing Director. "We went to the black board with ideas and talked about a safety kit, part of which

would include a vest. The idea was then streamlined to just the Vest," said Coffin.

"We tried several different designs for the Vest while we were test marketing the product," said Coffin. "Originally the Vest had Velcro fasteners but there just wasn't enough flexibility and we finally went to nylon straps with plastic fasteners so now the Vest is adjustable from a 22" waist to a 52" waist making it virtually a one-size fits-all garment," he continued.

The *Vest-of-Life* has been carefully designed so that every garment will be exactly

the same. Reflective lime-yellow stripes are placed precisely five inches apart both front and back allowing space to add on custom printing for commercial buyers.

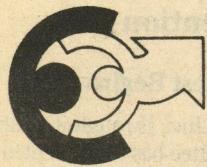
Many local industries have taken advantage of this feature already. One insurance company gave 1,500 Vests as Christmas gifts to its agents around the country; the Lions Club bought 150 for use in American Diabetes Bike-A-Thon; and the Nice and Easy chain recently bought 1,000 Vests to distribute to entrants in the Great American Heart Run. The American Red Cross even used the *Vest-of-Life* to identify its workers at the Statue of Liberty Celebration last Summer.

Patterns for the Vest are cut from large rolls of fluorescent orange mesh. Edges are sewn, reflective stripes are aligned and sewn, tags and straps are attached. Each vest is then packaged in its own handy carrying pouch, which is also made at the workshop.

Future plans for the *Vest-of-Life* include downsizing the Vest to make children's sizes, and the possibility of expanding the line by producing it in different colors, according to DiNitto.

Currently P.I.'s workers are producing 750 Vests a week and production can be stepped up to meet the demands of a large order, according to DiNitto. "As a prime manufacturing contract we control every phase of its production; from cutting the pattern and sewing the garment ... to packaging it for distributors nation-wide. This is just one example of what our people are capable of handling," he concluded. ■

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



Pre-Convention Highlights of the 38th Annual NYSARC, Inc. Convention

"NYSARC Advocacy — Strategies For Transition Into The 90's"



This year, NYSARC, Inc. will be celebrating 38 years of providing support and services to New York citizens who are mentally retarded. The theme of this year's convention — "NYSARC Advocacy — Strategies For Transition Into The 90's" is an extremely important one. Soon we will be entering yet another decade. With it brings an opportunity for us to look back at the monumental accomplishments of our Association and a chance to carefully examine current trends and issues which will effect and shape the lives of persons in our state who are mentally retarded.

The convention will offer an opportunity to share with other families, advocates and providers of service, experiences, concerns and insights toward enriching the lives of children and adults who are mentally retarded and developmentally disabled.

Included in this year's program are 36 speciality workshops. These workshops will offer conventioners an extensive range of topics which will be of interest to professionals, parents and volunteers. We invite you to join with us in challenging our ability to provide new and innovative programs and services for all our citizens who are mentally retarded. Together we can meet the challenges of today and tomorrow. ■

1987 Annual Convention

Thursday, October 15 through Sunday, October 18, 1987, Hotel Syracuse, Syracuse, New York.

Program

THURSDAY, OCTOBER 15, 1987

2:00 P.M. — 6:00 P.M. — Convention Registration
3:00 P.M. — 5:00 P.M. — Executive Committee Meeting
6:00 P.M. — 7:00 P.M. — Dinner
7:30 P.M. — 11:00 P.M. — Board of Governors' Meeting

FRIDAY, OCTOBER 16, 1987

7:30 A.M. — 8:30 A.M. — Breakfast
8:30 A.M. — 12:00 Noon — Convention Registration
8:30 A.M. — 12:00 Noon — Board of Governors' Meeting
12:00 Noon — 1:00 P.M. — Lunch
1:30 P.M. — 5:00 P.M. — Workshops

1. "Children With Special Needs"
2. "Client Participation in the Development of a Work/Social Skills Program"
3. "Understanding and Controlling Environmental Hazards"
4. "Developing a Well-Rounded Recreation Program"
5. "Implementation of Prevention"
6. "Sign Language Programs for Disabled"
7. "A Model for In-Service Training of Parents Whose Children Are Handicapped"
8. "Family Support Services — Ontario Style"
9. "On Our Own"
10. "How to Successfully Implement a Special Event"
11. "Assertiveness Training: Learning to Make Choices"
12. "Advocacy — A Way to Enrich the Lives of Persons With Disabilities"
13. "Scouting — Help Them Be Prepared"
14. "Aging-Out or Transition?"
15. "Volunteerism"
16. "Least Restrictive Environment — A Discussion of the Barriers and Some Strategies for Parents and Educators"

5:30 P.M. — 6:30 P.M. — President's Reception for Workshop Presenters
6:30 P.M. — 7:30 P.M. — Dinner
7:45 P.M. — 11:00 P.M. — Opening of General Session

- Greetings: David B. Lettman, President, NYSARC, Inc.
- Welcome: William McManus, Representing Onondaga County Chapter, NYSARC, Inc.
- Honorable Tom Young — Mayor of the City of Syracuse
- I: Roll Call of Chapters
- II: Opening Remarks: Marc N. Brandt, Executive Director, NYSARC, Inc.
- III: Keynote Address: William G. McMahon, Chairman, NYS Commission of Correction
- IV: Presentation of Awards
- V: Reports of the President, Treasurer, Executive Director
- VI: Report of Board of Governors' Meeting, October 15—16, 1987
- VII: Election of 1988 Nominating Committee
- VIII: Election of State Officers and Governors
- IX: Old Business
- X: New Business
- XI: Resolutions
- XII: Good and Welfare

SATURDAY, OCTOBER 17, 1987

7:30 A.M. — 8:30 A.M. — Breakfast
9:00 A.M. — 12:00 Noon — Convention Registration
8:30 A.M. — 12:00 Noon — General Session Continued
9:00 A.M. — 12:00 Noon — Workshop Sessions

17. "A Model of Clinical Training and Supervision of Mental Health Professionals Treating Dually Diagnosed Clients"
18. "Ulster ARC Sexuality Awareness Program"
19. "Outreach Programs for Aging-Out Students"
20. "Is Physical Therapy an Expensive Luxury or an Essential Service?"
21. "Aging — New Horizons for the Mentally Retarded"
22. "Interaction is the Key: Habilitation Focusing on Communication Development"

12:15 P.M. — 1:30 P.M. — Lunch — Presentation of Awards
— Announcement of Winner of First Annual Convention Logo Competition

1:30 P.M. — 3:00 P.M. — Convention Registration
1:30 P.M. — 5:30 P.M. — Workshop Sessions

23. "Take Your Show on the Road — How to Produce and Market a Slide Show"
24. "Work Training Center"
25. "The Role of the Board of Directors"
26. "Citizen Advocacy — Part of the Solution"
27. "How to Implement an Advocacy System at a Developmental Center"
28. "Preparing Students for Active Participation in Real Life — Selecting IEP Goals That Count"
29. "Mr. Offender — One County's Approach"
30. "Guardianship Information Centers"
31. "Dealing with Low Incidence Conditions"
32. "Individualized Family Treatment Planning"
33. "Prevention and the Mentally Retarded Person — Let's Take Another Look"
34. "Self-Advocacy — What is it Really?"
35. "Children Support Group for Normal Children of MR/DD Parents at Risk"
36. "Community Medical Services Systems Model"

6:00 P.M. — 7:00 P.M. — Cocktail Party
7:00 P.M. — 9:00 P.M. — Annual Banquet

- I: Master of Ceremonies — Arthur F. Kirk, Jr., President, Keuka College
- II: Invocation: Paula Watson — Representing Onondaga County Chapter, NYSARC, Inc.
- III: Welcome: Donna Becker — Representing Onondaga County Chapter, NYSARC, Inc.
- IV: Banquet Speaker: NYS Lt. Governor, Stan Lundine
- V: Installation of Officers and Governors

9:00 P.M. — 11:00 P.M. — Entertainment

SUNDAY, OCTOBER 18, 1987
7:30 A.M. — 8:30 A.M. — Breakfast, Board of Governors
8:30 A.M. — 9:30 A.M. — General Breakfast
9:00 A.M. — 11:30 A.M. — Board of Governors' Meeting
12:00 Noon — 1:00 A.M. — Lunch
1:00 P.M. — Departure

Hotel Information

THURSDAY TO SUNDAY OCTOBER 15-18, 1987

Full American Plan
(Three Full Meals Daily)
Cocktail Party
Entertainment

Rates

2 Night / 3 Day Package
Single: \$157.00

Double: \$119.00 Per Person

3 Night / 4 Day Package
Single: \$235.00

Double: (One Double Bed)
\$178.00 Per Person

Double (Two Double Beds)
\$178.00 Per Person

The above rates include three (3) full meals each day. Gratuities for chambermaids and dining room personnel are included. However, these rates do not include bellmen or other service personnel.

For reservation forms, please contact the State Office immediately.



Banquet Speaker, Stan Lundine



Keynote Speaker, William McMahon

Spotlight On NYSARC Staff



In the next several issues of OCV, we will be spotlighting the staff of the State ARC Office.

John J. Sherman, Jr.

Mr. John J. Sherman, Jr. is the Assistant Executive Director for Fiscal Management. He has been employed at NYSARC since June 18, 1984. John was previously employed by the Niagara County Chapter as its comptroller from February 1981 to June 1984. Prior to that experience, he was the comptroller for Mead Supply Company. John also worked for the Mid-Erie Mental Health Services.

John holds a Masters Degree in Business Administration from Canisius College. He was born in Buffalo, New York.

In his current job capacity, John reviews all requests from the chapters of the Association pertaining to real estate transactions, bank financing, contracts and all other financial matters. Over the past two years, John has been very involved in the development of NYSARC Management Information System.

John has personally visited numerous chapters providing technical assistance and advice in matters relating to financing, business procedures, and financial systems. He has actively worked with the Association's Insurance and Pension Committee and is the State Office liaison to the NYSARC Safety Committee.

Most recently, John has been involved with the newer funding mechanisms such as the rate setting systems and the use of NYS Dormitory Authority Funding. He also has represented the Executive Director on the CMRDD Consolidated Fiscal Reporting Task Force.

John lives in Albany, New York. He is an avid runner, fisherman and outdoorsman. His presence on the NYSARC staff provides the Association with competent and professional financial consultation to our chapters. ■

30,770 New Preschool Students To Be Served Nationally

Throughout the United States about 30,770 new students are expected to be served under the newly authorized preschool special education program created last year. The law passed by Congress and signed by President Reagan, offers incentive grants to states moving toward serving all handicapped three to five year olds.

It has been reported that the 30,770 new children would raise enrollment of handicapped preschoolers by 12 percent over last year's 265,541 served. ■

Lead Poisoning: Past, Present and Future

Do you think lead poisoning and the accompanying dangers of mental retardation, convulsions and behavioral problems are problems of the past?

If so, think again. Lead poisoning, a man-made illness, affects one out of twenty-five children in America. Once considered a health threat to inner-city black children, who were thought to ingest lead by eating lead-based paint peelings from dilapidated homes, today the realization is that the widespread use of lead in everyday products - leaded gasoline, cosmetics, fishing sinkers, storage batteries, tin cans, etc. - makes every child a potential victim. Recent studies by Dr. Robert Guthrie, professor of pediatrics and microbiology at the State University of New York at Buffalo, show that children in suburban, rural, and more affluent families also have serious lead levels in their systems.

Leaded gasoline fumes and lead-based paint are suspected as the major sources of lead exposure. Children living in zones near highway corridors, or on heavily traveled roads, or traffic lights are subject to high concentrations of contaminated air. Though lead has been removed from the newer paints, lead-based paint is still found in many older homes. Dr. Vernon Houck of the Center for Disease Control, estimates there are 80 million lead-contaminated dwellings in the country.

There is a direct relation between low level lead exposure and decreased nerve conductivity. It is possible that any lead in one's system lowers IQ and the more lead, the greater the retardation of intelligence, whether in children or adults. The Maternal and Child Health Service, the Center for Disease Control, the Assistant Surgeon General of the U.S. and the EPA support nationwide testing programs and complete removal of lead from gasoline.

If children who have been contaminated with lead can be found, they can be treated with drugs that eliminate the toxic metal from their bodies. If it is not removed, however, it will eventually damage them neurologically and mentally. Lead poisoning can cause kidney disease, blindness, mental retardation and death.

Since 1980, Dr. Guthrie has lobbied for mandatory, annual blood-screening of preschool children. Blood screening for lead is a simple test. This testing, if done in volume, costs relatively little. We have learned that the legislation for mandatory screening of newborns has effectively reduced the incidence of mental retardation caused by PKU.

Why don't we learn from experience and apply the same principles to annual screening for lead poisoning in all children under five years of age?

Written by: Penny O'Brien and reprinted from the New York Early Education Reporter. ■

Regional Safety Committee

The regional subcommittee of the NYSARC Safety Group Management Committee met during July to present the interests and concerns of the chapters directly to the State Committee. Led by John Rose, each region received an orientation on the organization and conduct of a local safety committee presented by Ctek and an overview of the Safety Group by John Sherman. A perspective on actual losses and risks was provided by the Irwin Siegal Agency in a six month loss summary of the safety group.

Most chapters felt that safety awareness among management and staff needed to be increased and the representatives asked for the Safety Group to support the organization and maintenance of chapter safety committees. Specific training and information was also requested in the area of driving multi-passenger vans, training of van drivers in dealing with client behaviors, infectious disease control, and chemical hazards in the home and workshop.

The overall response was enthusiastic and the result of the regional meetings will be evaluated by the Safety Group Committee in Delmar on August 6, 1987. Persons interested in receiving further information can contact any of the following:

John Rose - Chairman - (518) 842-5080
Tom McDermott - Central -

(315) 735-6497

Nancy Oak - Western - (607) 776-4146

Terry Eisenman - Western -

(716) 731-3540

Brian Shea - Northeast - (518) 272-3800

Henry Villegas - Southeast -

(718) 729-0808

John Sherman - NYSARC - (518) 439-8311

National Employ The Handicapped Week

"Making Employment A Reality"

"Making Employment a Reality" sponsored by the President's Committee on Employment of the Handicapped, is the theme for this year's National Employ the Handicapped Week which will run from October 4 through October 10, 1987.

During this week and the months following, communities will recognize outstanding employers and workers with disabilities.

During the past decade, our nation has seen an increased awareness of the capabilities of workers with disabilities and has demonstrated a greater commitment to the principal of equal employment opportunity for all Americans.

Each year, the first full week is designated as the "National Employ the Handicapped Week." This special week is a time for all Americans to join together to renew their dedication to meeting the goal of full opportunities for citizens with disabilities.

NYSARC chapters are encouraged to participate in this event. For more information, you may contact either Erica F. Berman or Susan A. Lyons at the NYSARC State Office. ■

1988 NYSARC, Inc. Annual Convention

Logo Contest Begins

This year NYSARC, Inc., through its Public Information Committee has implemented the First Annual Logo Competition. This event is open to all ARC employees, parents, members and individuals who are part of ARC's programs.

Next year, 1988, marks 39 years of service by the New York State Association for Retarded Children, Inc. Now anyone can be a part of this special effort by entering the NYSARC 1988 Convention Logo Competition.

The selected logo will be used on all printed materials for the 1988 NYSARC Convention. The winner will receive a \$100 U.S. Savings Bond to be presented at the 1988 Annual Convention. In addition, NYSARC will sponsor the winner's expenses for a nights accommodation at the Concord Resort Hotel during the convention.

Local NYSARC chapters must submit all entries to the State Office by September 15, 1987. ■

Supplementary Recreation Committee To Sponsor ARC Recreational Retreat Day

The NYSARC Supplementary Recreation and Special Olympics Committee will be sponsoring the First Annual Recreational Retreat Day in the Spring of 1988 at the YWCA in Elmira, New York.

This program will be a hands-on, jeans and sneakers day which has been developed for chapter recreation staff who are interested in obtaining new ideas to bring back to their chapters as well as to provide an opportunity for participants to meet other staff persons who provide recreational leisure time activities for children and adults who are mentally retarded.

A nominal fee of \$10.00 will be charged to participants to cover the cost of lunch and facility rental.

For more information, you may contact Susan Lyons, Director of Administrative Services at the NYSARC State Office (518) 439-8311. ■

Disabled Dolls Sold by Mattel

Mattel, Inc. has introduced a unique new collection of soft-sculptured dolls with disabilities in an effort to help children with disabilities develop a positive self-image and to teach non-disabled children about handicaps.

Hal's Pals were developed by Hal O'Leary, the founder of the Winter Sports and Recreation Program in Colorado. Hal, a ski instructor whose left leg had been amputated, has helped hundreds of people with disabilities become good skiers.

Among Hal's Pals are Ballerina Pal who wears a hearing aid, Party Pal who has braces and canes, Outdoor Pal who is visually impaired and Winning Pal who is a speedster in a colorful wheelchair. ■

NYSARC Library Corner

The NYSARC Library, located in the State Office Building in Delmar, New York, is now ready to open its doors to chapters who are looking for information regarding the field of mental retardation and developmental disabilities.

Although the primary purpose of the library is to be a resource library in which interested persons may stop in and spend some time, some of the materials are able to be borrowed for a short period of time.

Our part-time library consultant, Mary Meecham, is available to assist individuals in location information and/or will spend time with them to help so that they may familiarize themselves with the library.

Beginning with this issue, Mary will be providing our readers with two-three interesting reviews of books housed in the NYSARC Library.

To date, several chapters have already taken advantage of the extensive collection of books, journals and other resource materials in the library. We hope that many more will visit! ■

"Financial Planning for the Handicapped"

Written By:
Don P. Holdren

Published By:
Illinois, Charles C. Thomas, 1985

Call Number:
HG179, H593

Here is a book (on what I consider to be a very dull and confusing topic) which is clear, well written, precise in its examples and at times even interesting. Take it from one whose financial expertise is limited to remembering to pay the insurance premiums on time and balancing a checkbook, more or less, I not only enjoyed this book but I could understand it. It has got to be worth your time.

In a complex financial world where TV news programs have money editors as wells as anchormen and the average wage earner is confronted with inflation, recession, the shrinking dollar, IRAs, mutual funds, new insurance regulations, government deregulations and a multitude of investment possibilities, no one is immune to the stress and frustration of trying to provide for a safe financial future. It is not hard, then, to image the magnitude of this problem for the physically or mentally handicapped person or for those responsible for the well-being of a handicapped person.

Don Holdren has put together a unique and comprehensive guide, which zeros in on the special problems handicapped people face when they consider the needs and goals of their financial world for themselves and for their families. The opening quote from chapter one sets the tone of Mr. Holdren's philosophy:

"We are interested in personal financial management because it is the only way in which we can satisfy our lifetime goals. These lifetime goals directly determined our life style, which may also be referred to as our quality of life, standard of living, consumption, spending or our accumulation of wealth in the form of assets. Each of these refer to the comfort in which we live. Being handicapped is not a reason for not living comfortably."

He explains with charts, pertinent examples and sample forms the intricate system of personal financial statements; the mathematics of finance; the place of investment in financial planning; health and disability insurance; life insurance; social security; retirement income and expenses; estate planning; guardianship, wills and trusts. Besides its obvious value to handicapped people, their parents, advocates and social service personnel, the emphasis of this information makes this book a must for such other professionals as financial planners, accountants, insurance agents and lawyers. ■

"Your Child Can Win"

Written By:
Joan Noyes and Norma Macneill

Published By:
New York, Morrow, 1983

Call Number:
HQ773, N69

This book is subtitled, strategies, activities and games for parents of children with learning disabilities and sums up very neatly the contents of one of the most practical and useful books in our collection. After defining learning disabilities, the authors provide concrete procedures, specific examples and practical advice for parents, enabling them to create a growing and nurturing atmosphere for the learning disabled child in their own home.

This is the kind of book you can take to the beach or read in front of the fire on a lazy Sunday afternoon because it is free from jargon-laden reports and is peppered with specific anecdotes. It goes right to the heart of the matter when it explains the common testing procedure; when it prepares parents to get the most out of a meeting with professionals or when it clues parents in on the "how-to" techniques needed when an evaluation of their child's school program is called for. Part two of this book suggests many simple recreational activities and games which parents can start themselves and can enlarge on or alter to coincide with an individual child's growth and needs. These games can be used to improve motor skills, visual acuity, language, body image, spatial concepts, tactile discrimination and to feed the creative imagination.

This comprehensive guide confronts the role parents can play in establishing the individual's self esteem while still balancing the family's right to a normal social and family life. As if to underline their understanding of the day-to-day problems and frustrations these families face, the authors include suggestions and strategies which can be used with the learning disabled teenager — a group too often ignored by experts in this field.

The volume includes a glossary of terms for handy reference, a brief bibliography along with a list of useful commercial games which are available and recommended to encourage learning skills and good social skills as well. Noyes' and Macneill's knowledge of children and their hands-on experience with learning disabled children makes this a required and practical guide for parents and professionals alike. ■

Two Public Hearings of Interest To NYSARC To Be Held

Commission On Quality of Care and Senate Select Committee On The Disabled To Conduct Public Hearings In September

Of interest to our Association, two public hearings will be held during the month of September. The first hearing has been announced by the Chairman of the Senate Select Committee on the Disabled, Senator L. Paul Kehoe. The purpose of the hearing will be to explore developmental disability issues in the Criminal Justice System.

The hearings will be held in Albany on September 15, 1987 in the VanBuren Hearing Room "A", Legislative Office Building and in Rochester on September 17, 1987 at the Monroe County Legislative Chambers, Room 406, 39 West Main Street, both hearings will begin at 10:00 A.M.

The hearings will concentrate on the following problems:

- The lack of services available at the pre-trial and post-release stages of incarceration, which as a result, often further entrenches persons with developmental disabilities into the system.
- The need for statewide coordination of services in both the Criminal Justice and Human Service Delivery Systems.
- The necessity for identifying appropriate screening and assessment tools that if not accomplished, will result in those individuals not being identified as developmentally disabled and thus, placing them at a greater risk of being victimized while in the prison setting.

The second hearings to be held are in the form of five forums to be conducted throughout New York State by the Commission on Quality of Care for the Mentally Disabled. The five forums are intended to allow persons the opportunity to present individual

complaints to the Commission members as well as hear testimony on important issues relating to the rights of and the quality of services for persons with disabilities. The schedule of the forums are as follows:

September 16, 1987

Buffalo, New York
Roswell Park Memorial Institute
Gaylor-Cary Meeting Room
666 Elm Street
1:00 P.M. — 7:00 P.M.

September 17, 1987

Syracuse, New York
Onondaga County Civic Center
Bevard Community Room
590 S. State Street
1:00 P.M. — 7:00 P.M.

September 22, 1987

Albany, New York
Assembly Parlor
Room 306
State Capital
1:00 P.M. — 7:00 P.M.

October 5, 1987

Long Island
SUNY Farmingdale
Student Center — Little Theater
1:00 P.M. — 7:00 P.M.

October 6, 1987

New York City, New York
Jewish Guild for the Blind
15 West 65th Street
1:00 P.M. — 7:00 P.M.

NYSARC plans to give comments at both of these hearings and the next edition of OCV will report on our testimony. ■



NYSARC professional and volunteer leadership travels thousands of miles making friends and influencing people. Michael Limongelli (center), President of the Nassau AHRC, had special greetings at that group's annual Rose Ball for President David B. Lettman and Mrs. Marsha Lettman (left) along with Executive Director Marc N. Brandt and Mrs. Lynn Brandt.

1987 NYSARC, Inc. Convention

"NYSARC Advocacy - Strategies For Transition
Into The 90's
October 15-18, 1987 • Hotel Syracuse
Syracuse, New York

Please return the form with check payable to:

NYSARC, Inc.
393 Delaware Avenue
Delmar, New York 12054

TOTAL AMOUNT ENCLOSED \$ _____

Please type or print the following information. Register only one person per form.
Photo copy form if necessary.

First Name _____ Last Name _____ Title/Position _____ NYSARC Member _____ Yes _____ No _____

Chapter/Organization (if any) _____ Phone # _____

Street _____ City/State _____ Zip Code _____

We would appreciate your assistance in providing us with the following information. Please indicate the position(s) or role (2) if applicable by checking the appropriate box(es).

Board of Governor Chapter President
 Delegate Executive Director
 Chapter Staff Member Parent
 Chapter Board of Director Other _____

Registration Fee Schedule Information

All NYSARC Members and Staff PER CHAPTER

Convention Registration Fee - Please Check Appropriate Box(es)

2nd Registrant (per person)..... \$25.00
 4th Registrant (per person)..... \$20.00
 Subsequent Registrant (per person)..... \$15.00
 Day Registration Only (per person)..... \$10.00

Friday Saturday

All Non-Members of NYSARC

Convention Registration Fee (per person)..... \$35.00
Day Registration Only (per person)..... \$15.00

Friday Saturday

For Non-Registered Hotel Guests

Check (✓) below if you are planning to attend the
Saturday night Cocktail Party/Banquet:

I will be attending

TOTAL AMOUNT

\$ _____

1987 ASSOCIATION CALENDAR OF EVENTS

SEPTEMBER

11th Developmental Center
Committee Meeting
Delmar, New York

16th NYSARC Management Information
System Demonstration
Delmar, New York

OCTOBER

15th Executive Committee Meeting
Hotel Syracuse
Syracuse, New York

15th-16th Board of Governors' Meeting
Hotel Syracuse
Syracuse, New York

16th-17th NYSARC, Inc. 38th Annual Convention
Hotel Syracuse
Syracuse, New York

17th Prevention Committee Meeting
Hotel Syracuse
Syracuse, New York

18th Board of Governors' Meeting
Hotel Syracuse
Syracuse, New York

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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