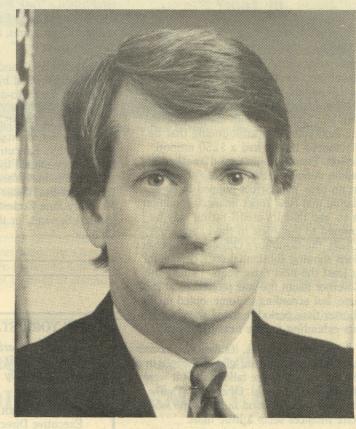
Children's Voice Retarded Children Can Be Helped

Elin Howe Named Commissioner of OMRDD Arthur Webb Takes New State Position





After six colorful and controversial years, Arthur Y. Webb has left his position as the Commissioner of OMRDD to become the head of the State's drug prevention agency. Mr. Webb had the longest tenure of anyone yet to serve as OMRDD's Commissioner. He was appointed in 1983 by Governor Cuomo.

On Tuesday, February 13, 1990, the Senate confirmed Mr. Webb's appointment to the position of Director of the Division of Substance Abuse Services. Governor Cuomo the next day nominated Ms. Elin Howe to be Commissioner of OMRDD. Ms. Howe has been the Executive Deputy Commissioner of OMRDD since 1984.

Senator Nicholas Spano, Chairman of the Senate Mental Hygiene Committee held a public hearing on Ms. Howe's nomination. NYSARC's Executive Director, Marc N. Brandt gave testimony on behalf of the Association which is represented in this edition of OCV. Senator Spano's Committee recommended to the Senate Ms. Howe's appointment and the State Senate confirmed her appointment.

In announcing his nomination of Elin Howe, the Governor stated, "For nearly

20 years, Elin Howe has served with distinction in various positions within the State Department of Mental Hygiene and the Office of Mental Retardation and Developmental Disabilities. She has demonstrated a special sensitivity to the needs and concerns of persons with mental retardation and developmental disabilities."

"She played an important role in bringing the Willowbrook Developmental Center into compliance with a Federal Court order that signalled New York's State's formal commitment to developing a community system of care for those in our institutions."

The Governor added, "As Commissioner, she will provide me with valuable insight and expertise in developing policies to meet the needs of OMRDD clients and encourage their full participation in society."

Ms. Howe has served in the field of developmental disabilities since 1972 when she worked with the Department of Mental Hygiene as a personnel administrator. In 1976, she became the Business Officer of the Brooklyn Developmental Center and in 1977 was appointed Director of Staten Island Developmental Center by then OMRDD Commissioner Thomas Coughlin. From 1980 through 1983, she served as Associate Commissioner of the southeastern County Services Group until she became the Executive Deputy Commissioner of OMRDD in November, 1984.

Ms. Howe is a graduate of Massachusetts State College and holds a Masters Degree in Public Administration from the State University of New York.

She is widely respected by key individuals throughout New York State in the field of developmental disabilities. Marc N. Brandt, NYSARC's Executive Director stated that she "is deeply trusted by parents and professionals alike. She has been in this field for a long time and has a solid working relationship and understanding of the field and its constituency."

NYSARC, Inc. wishes Ms. Howe the very best in her new position and looks forward to working with her.

Proposed Executive 1990-91 New York State Budget Presented By Governor

On Wednesday, January 3, 1990, Governor Mario Cuomo welcomed the Legislature back to Albany with his annual State-of-the-State message. The State-of-the-State serves as a platform for the Governor to outline his policy goals for New York during the upcoming fiscal year. But, most importantly, it serves to give the Legislature and the public a preview of what the Governor intends to present in his budget recommendations for the upcoming fiscal year.

On Tuesday, January 16, 1990, the Governor presented his fiscal year 1990-91 State budget proposal to the Legislature. While it received decidedly mixed reviews, programs for persons with mental retardation fared well in the face of gloomy expectations.

While funding issues have been dominating the budget debate, the budget also addresses certain programmatic changes that have been widely anticipated.

The budget transfers the entire Sheltered Employment Program (SEP) to OMRDD from the State Education Department. Such action is part of the reorganization of the State's vocational rehabilitation system agreed to by the Governor and the Board of Regents. The transfer of SEP realigns responsibilities: OMRDD will be charged with the administration of long-term placements for persons with disabilities while SED's newly created Office of Vocational Educational Services for Individuals with Disabilities (VESID) will develop new placements, especially in supported work.

In keeping with this scheme, almost \$3,500,000 in supported work funding was transferred from OMRDD to VESID. These funds, in addition to \$1,299,000 in new monies, are expected to enable VESID to develop an additional 400 supported work placements during FY 90-91.

Other specific budget actions of interest to NYSARC contained in the Governor's budget recommendations are:

- Maintenance of existing developmental centers' staffing standards.
- An ICF/MR Trend factor of 7.51%: This includes 5.51% for inflation and an additional 2% "super trend" to compensate for changes in the ICF/MR rate setting methodology.
- A Day Treatment Trend factor of 7.51%: This again includes 5.51% for inflation and an additional 2% "super trend."
- A Local Assistance Trend factor of 4%
 Maintenance of the basic SEP payment

(continued on page 4)



The Right Choice

Undoubtedly, the departure of Arthur Webb represents the end of a long era in the short history of OMRDD. He was the agency's fourth commissioner; he served longer than any of his predecessors; program growth, as measured by the budget, tripled during his stewardship; and in many ways he was brilliant and, of course, controversial.

Mr. Webb's replacement is Elin Howe. As OMRDD's first Deputy Commissioner, she immediately assumed the role of Acting Commissioner and, among others, was a candidate for the Commissionership. On February 15, the day after Arthur Webb was confirmed in his new position by the State Senate, Elin Howe was formally nominated by the Governor to be the sixth Commissioner of OMRDD. We think that the Governor made the right choice.

Ms. Howe comes from a very different background than Mr. Webb. Mr. Webb hailed from the state's correctional and social services system: two large state bureaucracies that have evolved with minimal input from their constituencies criminals and the poor. Ms. Howe, on the other hand, is steeped in the history of OMRDD: a state agency whose evolution has been uniquely dominated by the political activity of advocates, consumers and their families. In 1977, she was appointed by Commissioner Coughlin as the Director of Willowbrook and in that role could not have had a better opportunity to learn about the problems of the system, why it needed to change and, most importantly, the concerns of parents and family

Not surprisingly, Ms. Howe - through her combination of experience and personal comportment - has earned widespread respect at the grass roots level of the mental retardation field. Parents trust her: providers respect her; and advocates sense that she is motivated by what is in the best interests of persons with mental retardation. And professionally, she was reared during an era when the term "partnership with the voluntary sector" really meant just that: a relationship between the state and not-for-profit organizations that occurred on equal footing and was based on mutual respect.

This is important. The field of mental retardation in New York State is really unique. Few other consumer groups and advocates are as much a part of the make up of their respective state bureaucracies as the consumer group and advocates in mental retardation. For someone coming into OMRDD from the outside this is not easily appreciated.

But Ms. Howe does come from the inside and has developed a keen appreciation of the sensitivities and very special needs of persons with mental retardation and their families. She is also a competent manager, honest and hard working. That is why we believe that she is uniquely qualified to be the next Commissioner of OMRDD.

For a while some felt that the Governor might, in view of the coming election year, view the OMRDD Commissionership as a plum to be given to someone on the basis of political expediency. That did not happen. The Governor made the right choice, not the expedient one. Elin Howe is uniquely qualified to be the next Commissioner of the Office of Mental Retardation and Developmental Disabilities.

Just That Time of Year?

Lately New York State appears to be on the verge of bankruptcy. The dreary fiscal news of the past two years seems to only get worse. Within the last two weeks of this writing it started to snowball. First the Governor invited legislators to sit down with him and cut his own budget proposal for next year after announcing that he discovered that it had a \$250 million deficit. Then he announced another \$1 billion deficit for the current fiscal year. In no time Wall Street jumped in by declaring that New York's financial condition is so bad that its credit rating may be lowered to the worst in the nation. And finally, the Governor's Office issued projections showing substantial state deficits for at least the next three years. Usually the Governor issues five-year projections at this time, but according to some, opted for the shorter time period to avoid showing deficits extending for the next half decade.

In view of all of this, it's easy to succumb to all of the doom and gloom. People in the State Capital are talking as if it were the end of the world. Of course, it's like this every year around budget time when state finances seem a little tight.

The question then is: Is it just that time of year again or are things as bad as they seem? The answer, we think, is that things are as bad - or almost as bad - as they seem. The facts are too overwhelming; they go far beyond the kind or level of pessimism we have heard before.

The next question then is: What are the implications for mental retardation services? The answer to that question is not quite as easy. Right now things look okay. The good news is that despite everything the budget under consideration for our programs for the fiscal year beginning April 1, 1990 is remarkably sound. The bad news is that everyone knows how sound it is, especially the mental health providers and advocates whose budget is so austere that it looks like it was submitted by another Governor.

Still, we believe, at this writing, that this year's budget for our programs will probably be okay when all is said and done. But it is not this year we are concerned about: it is next year and the year, or years, after that. If the state's fiscal slide continues, as the Governor's projections suggest, everybody who looks to the state for financial assistance is going to suffer. And though we are considered to be among

the "vulnerable populations" over which the Legislature is very protective, there are many other groups that are falling into this once exclusive category. AIDS, homelessness, poverty, drug abuse and mental illness all seem to be growing acutely worse and are demanding more of the state despite the fact that the state has less money to give them. This cannot go on for much longer without something crashing down. We are of course, determined that it won't be us.

A political scientist once wrote that budgeting is the "authoritative allocation of values." If that is true, it would appear, at least this year, that mental retardation services have become valued by the Governor, and hopefully, the Legislature. Needless to say, we hope that we do not have to eat those words when this budget is finally passed. And should it hold up, our celebration will be short lived.

New York State may be entering a dangerous period; right now it certainly seems that way. But then maybe its just that time of year again. As another person said of budgeting, "its a method of worrying before you spend rather than after." If that is the case, we are certainly doing our job.

Small Community Residence Task Force Established by OMRDD

In response to legislation initiated by NYSARC, Inc. and signed into law by Governor Cuomo (Chapter 445), former Commissioner of OMRDD, Arthur Y. Webb established a Task Force to recommend "the development of small community residential programs, including programs of ten beds or less.

On December 7 and 8, 1989, thirty individuals appointed by Commissioner Webb met for a two-day retreat in Rensselaerville, New York. The Task Force was chaired by Ms. Barbara Hawes, Deputy Commissioner of Program Operations. NYSARC, Inc. Executive Director, Marc N. Brandt represented the Association along with Mr. Michael Mascari, Executive Director of the Nassau County Chapter and Ms. Mary Jane Eccleston, Director of Residential Services for the Oneida County Chapter.

The Task Force heard presentations from OMRDD staff concerning financial compliance and research issues. After the presentations, the Task Force members were assigned to four separate groups to discuss issues pertaining to the requirements of the legislation. These issues must be addressed as part of a report for submission to the Legislature by January, 1991 and include: adequate operating costs capital reimbursement methodologies, the needs of individuals who are severely disabled and compatibility of residences with local neighborhoods.

The groups reported their findings to the entire Task Force which developed final recommendations. Ms. Hawes stated that OMRDD would develop a draft report and that the Task Force would reconvene to review the report prior to submitting the recommendations to the Commissioner.

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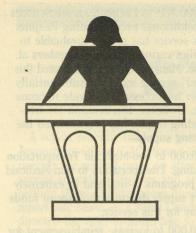
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From The **Executive Director's** Desk



by Marc N. Brandt Executive Director





The President **Speaks**

Self Advocacy: A Tool of Survival

Why we asked years ago, should mental retardation be tantamount to a virtual prison sentence for persons with mental retardation? Professionals objected to the analogy. They maintained that there wasn't anything imprisoning about an institution: that persons so limited could not be expected to want or enjoy the same surroundings that normal people are accustomed to; that it was safer and more reasonable for everyone concerned - parent and child - to send the individual to "someplace where they could be taken care

I remember that: "someplace where they could be taken care of." It had a euphemistic ring to it. In the same breath it sounded benevolent and sadistic. Long ago when I first heard it, it bothered me but I didn't understand why. Today I understand. Well-meaning professionals did not know that institutions were prisons because they didn't appreciate that shutting a person with mental retardation away really took anything from him or her. There was, they thought, nothing to take.

Almost 20 years of massive deinstitutionalization is sufficient evidence to prove that we all realize that this isn't true. Persons with mental retardation can enjoy, learn and grow by being in society with everyone else. They have the same need to be in control of who they are, what they say and what they do. Deinstitutionalization, normalization and least restrictive environment reflect a common movement toward this end.

But its not always easy to determine where this movement should reasonably take us next. Each step - integrated classrooms, fringe benefits, even accessibility - is greeted by the furrowed brow of many a well knowing individual who has long since accepted deinstitutionalization. Of these next steps, one of the most recent, and perhaps most controversial, is the notion of "self-advocacy."

Even mentioning the term elicits moans from individuals who think that this is a misguided attempt to make it possible for persons with profound retardation to, for example, argue for their constitutional rights in a court of law. After all, advocacy has implications for legal and intellectual tasks well beyond the capacity of many of the persons we serve.

But, such reaction to "self-advocacy" is simplistic. It does not acknowledge the fact that self-advocacy includes an extremely broad range of activities: activities that anyone, who participates in any facet of society, must learn if he or she is to survive. "Self-advocacy" may simply mean saying no, for one reason or another, to an invitation to partake in an activity. It may mean asking for something as basic as food and water; it may mean warding of the unwarranted intrusions of others into an individual's "personal space"; it may mean going to the boss to ask for decent treatment as an employee; and it can mean a thousand other things that we all must insist on if we are to preserve ourselves physically and emotionally.

Interacting in society makes us all, by definition, self-advocates. As deinstitutionalization has brought persons with mental retardation into the community; as we have sought to give them employment; as supported work and placement into regular classrooms has become increasingly commonplace, self-advocacy has become a necessary tool of day-to-day existence; not someone's unrealistic wishful or, even worse, fashionable thinking. To me, this is irrefutable.

To be sure, however, self-advocacy must be embraced carefully. It must occur in light of reasonable expectations for the persons whom we serve. But, having done this, self-advocacy is both reasonable and important: it is the logical next step.

The author, Lis Harris tells a story about a little boy who was playing chess with his father. The father had just set up the chess board and the little boy said to him, "Why must the board always be just like that? Why couldn't we move the kings and the rooks over here and the pawns over there?" And the father answered, "We could do those things but then the game wouldn't be chess anymore."

Many of us see the rules of the game change so much that we wonder what game is being played. As we moved our children from seclusion, we did it at times enthusiastically, and at times guardedly. We worked at partnerships with professionals and earned our right to be recognized as our children's advocates. We are now entering a new era, that of self-advocacy, and many of us do it with trepidation. I believe that self advocates have a great deal to teach us about sensitivity, values and choices. I applaud their strength and determination and I know full well that when time and again decisions are made for one it is often unbearable. It should come as no surprise that as a parent, it is the risks that accompany independence that give me concern. I worry about the ability of our children to anticipate the consequences of actions taken. I worry about those who may take advantage of them. I worry about governmental agencies using self-advocacy for their own purposes. I worry that the game isn't chess anymore – but, then again, maybe I'll enjoy checkers more.

Sincerely,

Blanche Fierstein

Thanks

I would like to thank everyone for their kind messages following the passing of my mother, Barbara Weingold. Your thoughtfulness was truly appreciated.

> From. Jonathan Weingold

Thank You

For all of our ARC friends who have supported us with an outpouring of notes and cards in recent days, there is an apt description by Henri Nouwen in his book, "Out of Solitude."

ourselves which person in our lives mean the most to us, we often find that it is those who, instead of giving much advice, solutions, or cures, have chosen rather to

"When we honestly ask share our pain and touch and bereavement, who can our wounds with a gentle and tender hand. The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief

tolerate not-knowing, notcuring, not-healing, and face with us the reality of our powerlessness, that is the friend who cares."

Ned & Ellie Pattison

(continued from page 1)

of \$2,500 per individual including \$1,000 in exempt income.

A reduction of \$2,500,000 to local governments for their administrative expenses attributable to Local Assistance funded programs.

- An addition of \$2,699,000 for Family Support Services to fund services to 1,000 additional families.

- An addition of \$1,571,000 to fund a "Model Waiver Program" that will use Medicaid to provide in-home care to children with complex medical needs who would otherwise require institutionalization.

After a review of the Governor's budget recommendations, the NYSARC, Inc. Executive Committee at its March 2, 1990 meeting adopted the following recommendations:

Office of Mental Retardation and Developmental Disabilities

- \$1,460,000 to net deficit funded programs to provide an inflationary increase of 5.51%. The Governor's request currently includes a trend factor of 4% which is below the expected rate of inflation.
- \$2,200,000 to partially restore the Governor's recommended reduction of \$2,500,000 in administrative funding paid by the State to local governments. The amount requested is intended to restore administrative funding to counties providing assistance to mental retardation services.

- \$1,500,000 to Family Support Services for additional Free-Standing Respite. This service has proved invaluable to families caring for family members at home. Many parents have indicated this "hard" service makes it substantially easier to successfully provide in-home care. However, the demand for free-standing respite has overwhelmed the existing supply.
- \$300,000 to non-Medicaid Transportation Funding. Transportation to non-Medicaid day programs is vital and in extremely short supply due to a shortage of funds to pay for this service.
- \$880,000 to increase reimbursement for Article 31 clinic programs from \$42 to \$50 per visit. This rate increase is necessary to pay for the actual cost of providing clinic services.
- Restore legislative budget language requiring minimum staffing standards at upstate developmental centers.

Commission on Quality of Care

- \$250,000 and necessary language to enable the Commission to expand Surrogate Decision-Making Committees (SDMCs). SDMC's have proven invaluable as a mechanism for expediting medical decisions for individuals who are incapable of making such decisions on their own behalf and who lack a parent or guardian to make such decisions for them. Begun in 1985 on a pilot basis in 12 counties, SDMC's have proven themselves and it is time to begin to expand them to the rest of the State.

- \$120,000 to restore the Commission's system of three Commissioners. The Governor's budget recommends elimination of two of the Commission's three Commissioner's. This recommendation makes no sense in light of existing workload. Further, the Commission, faced with sensitive oversight responsibilities, needs to ensure that it is structured to take into account a range of opinions on vital issues.

Law Revision Commission

- \$40,000 and necessary language directing the Commission to study criminal procedures laws pertaining to persons with developmental disabilities who become involved with the Criminal Justice System. Existing laws are antiquated and do not recognize the special needs of these individuals. It is imperative that they be revised in light of current knowledge.
- Language authorizing school districts to continue to claim enriched State aid for pupils with handicaps who are placed in regular classroom settings with consulting teacher supports. Existing aid formulas discourage the placement of such students into least restrictive settings by reducing State aid for pupils transferred into regular education programs.

At the time of the publishing of this edition of OCV, the Governor and Legislature were holding meetings in order to enact a budget by the April 1 deadline.

Parents Challenge Impartial Hearing -Commissioner Reverses Decision

In April, 1989, an "impartial hearing" was conducted by a hearing officer whose impartiality was questionable; who denied the parents in the case access to important information; who refused to discuss his potential conflicts of interest with the parents prior to the case; and who proceeded with the hearing despite the parents' request that it be cancelled.

Ed and Dorothy Heldman originally requested the hearing because of the local CSE's decision to send their son to a segregated school for children with mental illness. The parents wanted a combination of in-home services and programming at the local public school for their son who was diagnosed as having severe dyslexia. As it turned out, the Minisink Valley School District's determination that the child had mental illness was fabricated to expedite the district's placement decision.

Furthermore, the hearing officer in the case, George Kandilakis, was apparently recommended by the attorney representing the school district; was a special education administrator in another district; and had made prior placements into the school selected by the CSE for the Heldman's son

Because of these facts, the Heldman's maintained that the hearing officer was not impartial and that the hearing itself had not been conducted in conformance with federal regulations established under the Education of the Handicapped Act (EHA). Acting to rectify the situation, they appealed Mr. Kandilakis' decision to State Education Commissioner, Thomas Sobol.

The Heldmans also took another step: they filed a suit in federal court maintaining that the SED's "impartial hearing" procedures are not in conformance with federal regulations. While the suit is yet to be heard, State Education Commissioner, Thomas Sobol, citing "procedural irregularities," acted on the Heldman's appeal and reversed the decision of the hearing officer. The Commissioner remanded the case to the local CSE to be reconsidered. But, significantly, the Commissioner maintained that the hearing officer did not violate SED's regulations on impartiality and was therefore, technically, "impartial."

Clearly, this case is significant. NYSARC has always maintained that SED's impartial hearing procedures are not truly impartial and succeeded in obtaining sponsorship of legislation altering the process (S.727 by Kehoe). In a letter to NYSARC's Executive Director, Marc N. Brandt, Mr. Heldman thanked NYSARC for its "sympathetic support" which Mr. Heldman maintained "had its effect" in facilitating the Commissioner's favorable decision.



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Seymour Rubin Presented with NYSARC Merit Award

At the December 9, 1989 meeting of the NYSARC, Inc. Executive Committee, a special NYSARC Merit Award was approved to be given to Seymour Rubin. The award was presented to Mr. Rubin at a special gathering on Saturday, January 27, 1990. The award was given at the Orange County Chapter's facility in Middletown, New York.

Mr. Rubin has been involved with the New York City Chapter and State Association from its earliest beginnings. He has been actively involved for forty years and most recently has served on the State Association's Resolution, and Budget and Finance Committees.

The President of NYSARC, Inc., Mrs. Blanche Fierstein, on behalf of the Association, presented Mr. Rubin with a special plaque acknowledging his many years of dedication in the Association. Attending the gathering were representatives of the New York City Chapter, Orange County Chapter President, Regina Black and Executive Director, Stephen McLaughlin, former New York City President and Board of Governor Representative, Dr. Irving Caminsky and State Association's Executive Director, Marc Brandt. Mr. Rubin's immediate family were also in attendance.

Mr. Rubin, upon receiving the Merit Award, thanked all in the Association for their kindness and friendship throughout these past forty years.



Left: State Association's President, Blanche Fierstein, presenting Seymour Rubin with NYSARC Merit Award.

Below: New York City's Executive Director, Michael Goldfarb (L) and City Chapter President, Charles King (R) congratulating



Cortez and McLane Appointed to Top VESID Positions

The Commissioner of the New York State Education Department, Dr. Thomas Sobol, has appointed Edmund Cortez and Brian McLane to top administrative positions in the Office of Vocational and Educational Services for Individuals with Disabilities (VESID).

Mr. Cortez has been named to the position of Assistant Commissioner for Policy and Program Development. His responsibilities will include the supervision of policy development and coordination, quality assurance, program development, technical assistance and support services. He will also be responsible for monitoring programs that are federally or State funded. Before taking the position with VESID, Mr. Cortez had been working in the Office of Children with Handicapping Conditions.

Mr. McLane has been named to the Position of Assistant Commissioner for Service Delivery. Included in his responsibilities are the overseeing of local operations, business and industry outreach and the managing of VESID service delivery system. He will also be responsible for the initiation of a major outreach program to business and industry. Prior to his appointment with VESID, Mr. McLane was an Assistant Commissioner for Governmental and Community Affairs with the State Office of Parks, Recreation and Historic Preservation. He also has served as a past Chairman of the New York State Developmental Disabilities Planning Council.

WHAT TO DO IN CASE OF AN ACCIDENT

- When conditions and/or regulations permit move on to shoulder or side of roadway to prevent further damage or hazards. Place warning signals promptly.
- 2. Ask someone to summon Police, and Medical assistance if anyone is injured. Repeat after 5 minutes.
- 3. Keep calm. Be courteous. Don't argue. Make no statement concerning the accident to anyone **except** a Police Officer. Get his name and badge number. **MAKE NO SETTLEMENT.**
- 4. Complete this report on the scene. Fill in all information. (OBTAIN FROM AGENT)
- 5. Obtain the names and addresses of witnesses. Ask witnesses to complete the Witness Cards.
- 6. Obtain the names and addresses of all persons injured regardless of how minor the injury. Try to learn where injured are treated.
- 7. Do Not administer First Aid unless qualified to do so.
- 8. If an employee report as soon as possible to your supervisor.

DIAGRAM OF ACCIDENT

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THE ACCIDENT

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DESCRIBE HOW ACCIDENT OCCURRED -

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Mountains Move in Boston

When Barbara Burt and her foster care son, Joseph Campbell travelled to the State House in Massachusetts to see the Governor, they did not have an appointment and she was not even sure if the Governor would be there that day. What she did know was that she was angry over budget cuts which Joseph had become a victim of and the time had come to take matters into their own hands and go directly to the Governor. To underscore the seriousness of the protest, Barbara threatened to leave Joseph in the care of Governor Michael Dukakis.

As Barbara told NYSARC, "when governments have budget problems, I understand it requires difficult decisions, but if budget cuts must be made, they must be done in areas which will not hurt persons who are the most vulnerable. When government cannot be decisive, strong and do the right thing, people must force government to do what is right," she added.

Barbara and Joseph's story serves as an inspiration and tribute to the human spirit and its ability to move mountains. Their story first began last July, the month when the Massachusetts budget for 1990-91 was adopted and when Joseph had his 22nd birthday. Included in the \$12 billion budget was an appropriation of \$38.3 million for a program called "Turning 22", a transitional program for persons with developmental disabilities who "age out" of the educational system and are in need of residential and day services.

Of the total amount appropriated for the program, \$3.3 million was earmarked for new people coming into the program. However, even as the budget was adopted, predictions were being made that it would

lead to a substantial deficit. In an effort to curtail the dire predictions, the Governor withheld monies for a number of programs including "Turning 22".

Prior to July, Joseph had received benefits from the Massachusetts Department of Social Services for his residential and educational needs. These benefits stopped in July when he became 22 years old. Normally, Joseph would have been served by the "Turning 22" program. However, because of the Governor's impoundment of the \$3.3 million, Joseph and 113 others who had recently become 22, were left without any service. Since July, Joseph's residential needs were provided by the Burt family without any assistance from the government and Joseph was left to sit at home because the budget cuts also prevented him from attending any habilitation program.

Prior to her trip to the Capitol, Mrs. Burt had appealed to the Governor's office, and numerous legislators about the devastating effect which the cuts were having on Joseph's life. His situation was even more troubling because Joseph has no family or legal guardian. When Mrs. Burt raised this with people and asked what would happen to Joseph if she could no longer care for him, no one would answer her question.

Mrs. Burt told NYSARC, that at first her frustration over what was happening to Joseph left her feeling depressed, but that soon changed to anger. Mrs. Burt who has a thirty-nine year old sister with mental retardation, said she witnessed the service system evolve over the years into one that reflects the many hard won gains that had been made by persons who cared enough to fight for persons with developmental disabilities. She said, "while there have been many gains, there is still a long way to go, and I became angered to see what had been achieved after such a long struggle

being torn apart by budget cuts. People like Joey cannot afford nor do they deserve to have that happen to them".

Although she has been an advocate for persons with mental and physical disabilities, Mrs. Burt explained she is not by nature a person given to dramatic protest. "As a girl growing up in Kansas, I was so shy I was afraid to even raise my hand in class to speak", she said. But she said the effect of the program's cuts on Joseph's life and the inaction of persons Barbara had appealed to within government to correct the injustice seemed to leave no other choice but to protest, "to make Joseph's situation become real to the public and to the people who had made a wrong budget decision." She said she was compelled to make the dramatic appeal to the Governor, "to make him understand that people like Joseph were suffering because of the Governor's decision. The budget cuts did not affect 'numbers' but real people. Meeting Joey was the best way for the Governor to come to really understand this," she added.

Prior to their trip to the Statehouse, Barbara contacted several reporters in Boston to let them know of Joseph's plight and her plan to protest directly to the Governor. When she and Joseph arrived at the Capitol, reporters were there and waiting.

She and Joseph met not only with the Governor but also with the Commissioners of the Departments of Mental Retardation and Human Services about the cuts made in the "Turning 22" program. At the meeting the Governor expressed his sympathy and concern about the cuts, but said that unless the Legislature was willing to raise new taxes there was no money to restore funding for the program. He added that should new revenue become available, "Turning 22" would be the first program restored. Although discouraged, she and

Joseph returned home that evening not knowing that in two days their appeal would be answered.

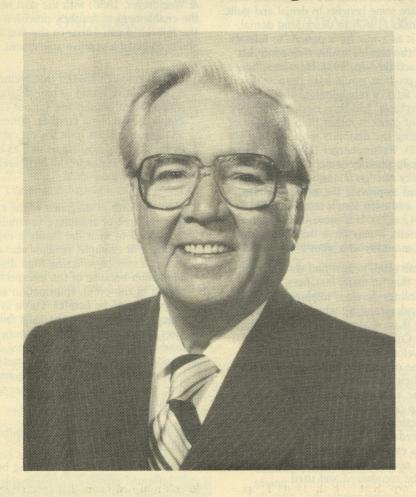
On February 15th Barbara received a phone call saying that the Governor had restored the funds for the "Turning 22" program and that Joseph could begin attending a day habilitation program the following week. The Governor's action came from a Probate Court decision rendered that day which determined that the State's withholding of funds for the program was illegal. A spokesperson for the Governor stated that while Dukakis and his counsel did not agree with the court's conclusion, the Governor had decided to restore the funds for the program "because it was the right thing to do."

A spokesperson for the Department of Mental Retardation said that while the court decision helped to spur the restoration of funds, Barbara and Joseph's personal appeal to the Governor clearly contributed to the change.

On February 21, less than a week after this victory, a public forum was held at the Statehouse to bring public attention to the impact which the budget cuts are having upon human service programs and individuals. Mrs. Burt told NYSARC that the organizers of the forum had named the event, "Joe Campbell Day' in honor and celebration of Joey."

While Massachusetts is still faced with a \$500 million deficit which appears to be continually growing, the outcome of Barbara Burt and Joseph Campbell's trip to the Statehouse serves a poignant reminder that individuals can make a difference. As individuals they reminded Massachusetts that budgets must have both a head and a heart in bad times as well as good.

Senator W.T. Conklin Passes Away



In February of this year, former State Senator William T. Conklin passed away after a brief illness. Mr. Conklin, who spent 22 years as a Republican member of the Senate, retired in 1978 at the age of 70. For many years, the Senator was the deputy leader for the Republican majority in the State Senate.

The Senator was close to many in the New York State Association for Retarded Children, Inc. and attended many of the Association's annual conventions. His career began out of his work as a lobbyist for persons who are mentally retarded after his son, Billy, was born with mental retardation. Senator Conklin and his wife, the former Jessie Hanrahan, helped organize the Guild for Exceptional Children in Brooklyn, New York.

During Senator Conklin's 22 years in the State Senate, he worked closely with NYSARC, initiating and sponsoring many bills protecting and enhancing the quality of life for individuals who are mentally retarded and developmentally disabled. Among his many accomplishments while in Albany, he was successful in gaining employment for individuals who are mentally retarded as messengers and clerks. He pushed successfully for legislation requiring birth tests for Phenylketonuria or PKU, the brain-damaging genetic disorder. He was also the major sponsor of the legislation that ultimately separated the Office of Mental Retardation and Developmental Disabilities from the Department of Mental Hygiene.

Commenting on the passing of Senator Conklin, Marc N. Brandt, Executive Director stated, "Senator Conklin will be long remembered for his accomplishments, humor and compassion. Those of us who had the good fortune to know the Senator will always remember his deeds and his strong advocacy on behalf of persons who are mentally retarded and developmentally disabled."

In Support of Families

NYSARC is proud to announce that on Friday, July 27 and Saturday, July 28, 1990 it will be sponsoring, "IN SUPPORT OF FAMILIES", a dynamic statewide conference on family support. The purpose of the two-day forum is to provide an opportunity for families, professionals, and State policy-makers to work together to improve family supports policy in New York State and design a policy direction and system that is flexible and responsive to the needs and visions of families of individuals with developmental disabilities.

The conference which will be held in Albany, will be co-sponsored by the New York State Commission on Quality of Care for the Mentally Disabled and the New York State Developmental Disabilities Planning Council, DDPC. Featured speakers will include parents and officials from model states across the nation who will explain their exemplary family support programs and how they became part of their state's public policy. Conference plans include setting new horizons, strategies and initiatives for policy and system change, networking, strengthening families, accessing resources, family to family support and personal futures planning. Child care will be available to enable families to participate.

Plans for this conference culminated out of a roundtable forum which NYSARC held in May of 1988. At the forum it became apparent that both families and family support professionals believed that there was no clear State policy for this program and as such there was a need to examine the current system. Participants also believed there were limited opportunities for networking as well as a need to explore innovative resources for families.

Among the recommendations at the forum was that a statewide conference should be held to provide an opportunity to discuss and explore future directions for family support in New York. This interest in examining New York's family support policy can best be explained by looking at how this program began and where it is today.

New York State's Family Support Services Program under the Office of Mental Retardation and Developmental Disabilities, OMRDD, was formally created in 1984 as a demonstration program with a modest appropriation of \$1.15 million. The law creating this program stated that its purpose was "to enhance a family's ability to provide in-home care to their disabled family members." The law goes on to state that services to be provided "shall include but not be limited to outreach services, family member training, counseling, respite, and transportation."

In the six years since it was first established, this program has experienced tremendous growth; it is now offered statewide and in 1989 had a budget of \$20.5

million. In spite of this expansion, there has been a growing frustration that services are often fragmented and limited and do not meet families varied and individualized needs.

NYSARC and its Committee on Family Support and Outreach Services have been increasingly concerned about New York's policy for a number of reasons. The first is "Family Support Services" is presently a vague term that lacks a consensus definition. As a result it encourages a misconception that family support services can take the place of other existing programs and is often viewed as providing services to the individual with a disability rather than their family as a whole. Consequently, this allows family support monies to be diverted for use in programs that do not primarily serve families.

Secondly, while the overall budget of \$20-plus million may seem impressive, the monies are given to so many programs that, of those which do primarily serve families, few receive adequate funding to effectively address the needs of families. As an example, many of the NYSARC chapters which receive funding for family support services have to raise additional funds on their own in order to cover the true costs of their family support programs.

Additionally, program development has been sporadic and inconsistent throughout the state. Statewide funding priorities do not necessarily reflect local needs and regional planning groups have not been established to determine or set priorities for family support. Because of this, services vary county by county so that what services a family receives depends upon where they live within the state.

As a result of these concerns, two Resolutions on family support were adopted at the NYSARC Annual Convention in October 1989. The first calls for a systemmatic state and regional process for family support development to allow for active and meaningful participation of families. This resolution recognizes that if this program is to truly meet the needs of families then families should be involved in decisions about its further development. The second resolution calls for a statewide definition of family support which clarifies that the supports provided are primarily for the family rather than the individual with the disability.

As we have learned over NYSARC's 40 year history, changes in State programs and policy only happen with a united and strong advocacy effort. NYSARC is hopeful that, "IN SUPPORT OF FAMILIES" will serve as the catalyst in developing a future policy direction on family support for which to advocate in New York State.

For further information and registration contact the NYSARC State Office at (518) 439-8311. ■

GUEST COMMENTARY

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

A Parent Speaks...

Professional Perceptions of Parental Adaptation to a Child with Special Needs

By: Dorothy Stone

The author is Project Coordinator of the New Born and Family Support Services Network, North Central Bronx Hospital, Bronx, New York. Mrs. Stone, a parent/advocate, is the mother of Howie, a 28 year-old who is mentally retarded and has cerebral palsy. The author's husband, I. William Stone, is a Vice President of the New York City Chapter and a Board of Governor Representative.

(The following article is reprinted with permission. The article appeared in *Children's Health Care*, a journal published by the Association for the Care of Children's Health, Summer, 1989, Vol. 18, No. 3.)

The professional literature that has dominated the field of mental retardation and developmental disability has often concentrated on the crisis reaction of the birth of a child with special needs and the negative impact of the birth or diagnosis on the parents and the entire family. According to Sieffert (1978), models of coping with mental retardation may vary from three to six stages and "perhaps only a minority of parents get through the normal coping process" (p. 38). Stone (1971) described the "inevitable feelings of guilt, denial, rage and despair" (p. 225) and Olshansky (1962) referred to parental reactions as "chronic sorrow" with the certainty of a lifetime of woes and misery for parents until the welcome solution of either the death of parents or the child.

Jaffe-Ruiz (1984) stated that the "early conceptualizations of parental response to the developmentally disabled were psychoanalytically oriented... focused on guilt, denial, projection and rejection" (p. 65). As an example of this approach, Michaels and Schucman (1962) characterized parents of children with mental retardation as suffering from emotional disorders with their only hope being "that we can appeal to the healthy core of the patient" (p. 568). They described some parents as "grossly psychotic" and depicted husband and wife as "blaming each other," with "constructive mutual support between parents... relatively rare" (p. 570).

In addition to the negative emphasis in defining the stages of parental reaction to the birth and/or diagnosis of a child with special needs, much of the professional literature has failed to take into account the situational rather than the inherent nature of coping mechanisms and to highlight some potential benefits. For example, Solnit and Stark (1961) detailed the failure of a physician to inform a parent of the child's disability until many months after the child's birth and only after another doctor told the parent. The authors then criticized the parent for a denial reaction. Too often the parents' angry reaction has been attributed to a stage of coping, a maladaptive response, rather than a rational response to an insulting remark.

Many professionals have viewed shopping around for other opinions as a form of denial when in fact this behavior could be interpreted as adaptive. For example, Waskowitz (1959) found that the parents

sometimes were unable to obtain answers to their questions and what they were really seeking was "not just a diagnosis, but total handling of the problem" (p. 322). Indeed, the need to actively search for services "because of the fragmentation of treatment facilities [is] one form of mastery in a crisis that parents are powerless to reverse (Irvin, Kennell, & Klaus, 1976, p. 177).

Historically, when parents attempted to discuss their strengths and the benefits they derived from caring for a child with special needs, professionals viewed these statements as evidence of "denial, sublimation, or overcompensation" (Wikler, Wasow, & Hatfield, 1983, p. 313). Even though the less pessimistic views tend to be obscured by the emphasis on the negative approach, there are some changes in more recent professional conceptualizations of parental reactions. For example, in an unprecedented reappraisal of their earlier findings, Wikler, Wasow, and Hatfield (1983) acknowledged that they had discounted data that showed that in spite of feelings of chronic sorrow, "being the parent of a retarded child had been a strengthening rather than a debilitating experience" (p. 313). Dane (1985) urged professionals to make use of the "experiential knowledge that the family has collected over the years" as they monitor their child's development progress and work in partnership with parents to benefit the child (p. 508). Farber (1972) stated that the "existence of a family crisis depends on the extent to which the family members regard an event as disrupting to... future family life... only when the parents perceived their roles an inadequate does the crisis develop" (p. 227). In another study, Gath (1978) failed to find any evidence among the 31 families of infants with Down syndrome that she interviewed to suggest that these families had more psychiatric problems or were more likely to experience family or general dysfunction than were the control families. The only striking finding was that the birth of an infant with special needs "appeared to magnify preexisting weaknesses thus turning stresses into obvious rifts" (p. 112-113), resulting in several marital breakdowns. In contrast, many couples who had a strong bond found themselves drawn together by their shared sorrow. Wolfensberger (1967) also questioned the validity of a negative approach to the study of parental/familial reactions. He noted that many of the

studies of families' reactions in the early 1950's were poorly controlled and impressionistic. He also criticized the selection of parents studied as being unrepresentative of the vast majority of parents of children with special needs.

Many professionals are recognizing that there are some benefits to denial and guilt. Olshansky (1967) in describing denial, views it as a way for a parent "to tolerate better the terrible reality that confronts him each day" (p. 191). He notes "how much progress would have been achieved in the field of rehabilitation if the issues of 'acceptance' had been made the primary focus of concern rather than the issue of managing the disability most efficiently" (p. 192). Wolfensberger (1967) suggested that guilt, whether or not it has any basis in reality can "go a long way in motivating a parent to provide the extra attention, effort, and even love a retarded child may need" (p. 331). If it prevents premature placement, it may serve the child, family, and community as a whole.

Begab (1967) identified research indicating that, in many instances, parents and siblings develop "tolerance, patience, and understanding which strengthens rather than weakens family relationships" (p. 3). Cohen (1962) built on that idea by developing a theory that parents, because of their need to constantly interpret their child's handicap to others, become actively involved in leadership to develop facilities for the handicapped, and as a result, may become more sensitive to the needs of others. Parents certainly possess expertise, knowledge, and sensitivity to the needs of their own children that must be recognized and used.

Implications for Care

In reviewing the various interpretations of stages of parental reaction to developmental disability, Drotar, Baskiewicz, Irvin, Kennell, and Klaus (1975) presented a model for intervention which appears to be a useful approach to acknowledging the potential positive adaptations by parents. They identified five recognizable stages that can be useful in helping parents: (1) shock, (2) disbelief with varying stages of denial, (3) sadness, anger, and anxiety, (4) adaptation and attachment with subsequent lessening of intense emotions, and (5) reorganization with possible long-term acceptance. The merit in the following interpretation is that, if used flexibly and tailored to the individual family, it provides the professional who communicates with parents guidelines for anticipating their needs and adopting an approach that will be helpful in raising their child and identifying and utilizing services. For example, initial shock and disbelief may seriously impair the parents' ability to absorb information about their child's disability. The professional who imparts the initial diagnosis must understand what a profound effect it will have on the family and "that no matter how well he explains the situation the first time, parents must always have a second chance to discuss the nature of the problem" (Kugel, 1976, p. 341). The factors of timing, who tells the parents, how the information is presented to parents, and what follow-up is provided can have a beneficial or detrimental effect in terms of the initial and subsequent reaction of parents to the birth or diagnosis of a child with special needs.

Many of the reactions and problems associated with the birth of a child with special needs are not inevitable, either because of the inherent pre-existing strengths of the family and/or because of

the provision of comprehensive support services. The key to the improvement of intervention with families of children with special needs may well be in a complete overhauling of the way society views the parents of these children. Starting from a proactive approach (Dunst, Trivette, Davis & Weeldreyer, 1988) with the goal being the enablement of families, provision of the following can enhance the family's ability to make a positive adjustment.

- 1. Initiate research studies that include a representative group of parents (i.e., single-parent households, various ethnic groups, low-income families, fathers) and where parents have the opportunity to speak to the positive as well as the negative responses to the birth and/or diagnosis of their child.
- 2. With the birth or diagnosis of the child, gear the type of assistance to families to respond to what the family is experiencing. For example, families who are in shock may be suffering from disorganization because of the unexpected nature of the event. Information and support would be helpful. Those in a "value crisis," in which the child fails to meet parent expectations may benefit from counseling. Where physical demands for care are too great, practical help in management, home care, respite care, day programs, and other services would be helpful.
- 3. At the time of diagnosis, the family is entitled to:
 - a) Skillful and sensitive handling by an informed professional, preferably someone who is familiar with them;
 - b) Early access to information about their child's diagnosis as soon as the diagnosis is made;
 - c) Emphasis on the positive aspects and strengths of the child; and
 - d) Having both parents and other family members present if so desired.
- 4. The person who counsels or imparts the diagnosis should not attempt to influence a parental decision to keep or place the child, but rather provide the information necessary for that kind of judgment, in accordance with the family's values. This kind of assistance can only be given by someone who is knowledgeable about available community resources and realizes the awesomeness of the responsibility.
- 5. Parents should be referred to parent support groups, parent organizations, and/or agencies for follow-up assistance and services.
- 6. Finally, re-examine professional training and qualifications for those who inform parents. Although written over 20 years ago and referring to the qualifications of a professional who counsels parents of a child with mental retardation, Wolfensberger's (1967) description is as timely today as it was then and includes the following:
 - a) Knowledge of the broader medical, social, educational, habilitational, and behavioral aspects of retardation;
 - b) Knowledge of resources in the broadest sense, including agencies, services, long range local prospects, reading materials, and "gadgets" useful in home management;
 - c) Competency, acquired through training, in counseling principles and techniques in general;

- d) Experience in the applied clinical area of retardation;
- e) Freedom from stereotypes about retardation;
- f) Possession of genuinely positive attitudes toward retardation, the handicapped, and their parents;
- g) An orientation to the current community centered management approach;
- h) A sensitivity to the reality needs of the family;
- i) Willingness to go beyond traditional approaches to help parents, even at the cost of personal convenience; and
- j) Great patience (p. 355).

Conclusion

Many of the reactions and problems associated with the birth of a handicapped child are not inevitable and through proper intervention may be preventable. The key to the improvement of intervention with families of the handicapped may be in a complete overhauling of the way society views the parents of these children. If we

start from the premise that a positive attitude will be helpful in: (a) pointing out the strengths and normal aspects of the child, (b) assuring them that there will always be "someone that cares," (c) giving them the support of kind and knowledgeable professionals who make themselves available with assistance, making use of the stages of reactions of parents only as they relate to positive adaptation, (d) encouraging the use of support groups or individuals who can share their experiences and listen, (e) providing financial supports and entitlements for necessities so that they can concentrate on keeping their families together, (f) providing homemakers and nurses for assisting in supervision and management of their child, (g) thinking in terms of a coordinator or case manager for every severely handicapped child as someone to whom families can turn in solving their day-to-day problems - if we give them early interventions, the supports, the programs, and the therapies for their children, only then do we have the right to analyze their psyches and see if they are better adjusted.

New Directions for Senior Citizens

Representatives from Columbia, Delaware, Dutchess, Greene, Orange, Putnam, Rockland, Sullivan, Ulster and Westchester Counties, which comprise the Hudson Valley and Catskill Regional Network on the Aging, have been meeting now for two years, to dialogue new directions for seniors.

Over 50 leading experts in the field gathered at Rose Valley Senior Citizen Center in Monticello recently to discuss new directions for senior citizens. The meeting was attended by professionals working with seniors from the Hudson Valley and Catskill regions.

The day's dialogue began with an overview given by Dr. Alvah Canfield. Matt Janicki, Ph.D., Director of Bureau of Aging Services, Office of Mental Retardation and Developmental Disabilities, spoke on new approaches to providing day services for senior citizens. Janicki recently published New Directions for Seniors and studied new program models for senior citizens being demonstrated by OMRDD.

Paul Vanas of the State Office for Aging has recently published the new State Standards for Social Adult Day Care. He gave a presentation on new developments and new procedures in Social Adult Day Care that will be a part of the new State program for frail, elder people. The morning session was concluded by a roundtable discussion of similarities and differences among the various day programmings.

According to Canfield, over 200 people

at the Sullivan County ARC are senior citizens. Some are fully or partially retiring within the next several years. "Everyone will be looking at the Rose Valley model as we have one of the first programs to serve the retired developmentally disabled person." Canfield explained that this is a program developed under the auspices of the agency and it is suggested by the State according to Canfield, as a model for people over 55 years of age. "The 100% state funded grant for \$375,000 which provides retirement activity for older people who are developmentally disabled and who wish to retire whether permanently or on a part-time basis and in their senior years want to enjoy some of the activities and services offered at Rose Valley." Some of those activities and services are: counseling and referral day programming; health, wellbeing and physical fitness; arts and crafts; recreation and leisure; socializing and social events; maintenance of skills; involvement in community activities and service to the community.

According to Canfield, until recently the problem had never before been addressed; there had been no provisions for senior citizens before; no recognition of the different stages of life and therefore, programs were not specifically designed for seniors who are developmentally disabled.

Anyone interested in learning more about the Rose Valley Senior Citizen Center or the Sullivan County Association for Retarded Citizens may do so by calling (914) 434-3415.

Have you subscribed to "Government in Brief"?

Please see page 4 for details.

Advertisement

The Board's Role in Strategic Planning

This discussion is excerpted from a larger article on the Board's Role in Strategic Planning published in the April issue of Marvin & Co.'s News 'N Views.

One of the most important, but least understood, responsibilities of board members today, especially those of not-for-profit health care organizations, is their role in the organization's planning process. Most board members know that their organization, like others, must clearly define the nature of their business, have a guiding strategy for fulfilling their objectives, and follow an orderly plan for future business development. But questions often arise: What constitutes a sound planning process? What should a strategic business plan encompass? How does strategy development relate to the budgeting process? What should the respective roles and responsibilities of board members and management be in the overall planning process?

Although many organizations in the past assigned much of the responsibility for organizational planning to staff planners, the relative importance of the planning function and the consequences of poor planning decisions are so great today that neither board members nor top management can afford to fully delegate the planning process. In particular, board members must realize that health care organizations are exposed to considerable business risk in today's environment and that the board has a fiduciary responsibility to ensure that a sound planning discipline is in place.

Organizational planning can no longer be a sporadic, adhoc activity, undertaken in response to specific project initiatives or to immediate threats or matters of concern. Planning must be a continuous and on-going process that ensures an orderly assessment of needs, opportunities, and risks and establishes business direction and resource allocation priorities within an economically sound framework.

The organizational planning process must provide a framework for guiding virtually all of the decisions made by the board and management regarding strategic priorities, capital and operating budgets, and organizational development. This framework is, in effect, an evolving blue print of the organization's agenda for change.

Because the strategic business planning process is critical to the future direction and economic well-being of the organization, it is by its nature, the joint responsibility of the organization's board members and senior managers. In the broadest sense, the board's responsibility in the planning process is to:

- ensure that sound planning policies and processes are in place
- make policy decisions regarding overall strategic directions and corporate objectives
- ensure that the strategic direction is consistent with the organization's overall mission
- review and approve specific project initiatives and action plans to ensure consistency with the strategic direction.
- make sure the organization's financial and human resources are available and invested in a manner that will support the strategic direction
- monitor implementation and performance relative to the strategic business plan

In many respects, the planning process itself is more important than the planning project. Those responsible for plan development and execution must reach a consensus regarding the organization's position, strategic initiatives and priorities. This consensus, or "buy in," is achievable only through direct involvement to board members and top-level management in the planning process.

To facilitate this process, Marvin & Co. has developed a consensus building approach to help the board and management identify and prioritize strategic initiatives in an expeditious, unemotional and easily understood manner. For more information regarding our Strategic Assessment Process, please contact any Marvin & Co. executive.

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Welfare League Celebrates 50th Anniversary

This year's Annual Luncheon on November 18, 1989 at the Sheraton Centre hotel held special significance, marking 50 years of continued advocacy and service to the residents of Letchworth Village and its community residences.

Newsman Rich Lamb of WCBS News Radio once again served as the Master of Ceremonies. Before introducing the distinguished guests to a packed Imperial Ballroom, Mr. Lamb spoke of the Welfare League's long-term commitment to improving the quality of life of all the children at Letchworth Village.

This year's seating arrangements called for a special dais, where nine past presidents were seated as Special Guests. In gratitude for their past service in helping The Welfare League reach its 50th year, each was presented with a silver bookmark.

The presentation to this year's Guest of Honor, Jean Kennedy Smith, was made by Arlene Francis. Miss Francis, star of radio, television, film and the stage is probably best remembered as a regular panelist of the long-running TV show "What's My Line?".

Mrs. Smith was chosen as the Honoree in recognition for her outstanding work with the Very Special Arts program, whose New York headquarters are located on the grounds of Letchworth Village.

An additional presentation was made by Welfare League president David Kapsack, who gave Mrs. Smith a check to be used for the Letchworth Village Very Special Arts program.

In her remarks Jean Kennedy Smith noted the special relationship the Kennedy family has with the retarded, and she praised the work the Welfare League has done over the years.

Long-time friend of the Welfare League and advocate for individuals with mental

retardation, State Senator Eugene Levy recalled the early days of the organization. He spoke of his parent's restaurant in Spring Valley, where he grew up seeing so many of the parents bringing their children from Letchworth Village. He also noted how we all fought for legislation to improve conditions for all those who are mentally retarded and urged us to continue the fight for improvement in legislation and the attitudes of governmental agencies.

A surprise speaker at this year's luncheon was John Mackey, a former resident of Letchworth Village. Mr. Mackey, who is now married and living in Rockland County, spoke about his life as a child at Letchworth Village. His reminiscences about a little truck The Welfare League gave him as a child, which he still has and cherishes today, left hardly a dry eye in the house.

Mr. Mackey presented The Welfare League with a plaque on behalf of all the "children" at Letchworth Village.

In appreciation for making the annual luncheons such successful affairs, the Luncheon Committee gave Richard Pizzuto a special plaque, and it was obvious to all in attendance that this year Mr. Pizzuto got the hotel to go all out for our Fiftieth.

The high point of the luncheon once again was the entertainment by Letchworth Village residents. The Recreation Department did another outstanding job in putting it all together. As an added touch, the backdrop this year listed all the previous shows presented at past luncheons.

Welfare League is indeed fortunate to have such dedicated and talented staff and volunteers to care for and work with our children and adults. We thank them all for their patience and understanding, and for their personal time they give so freely.

Down Syndrome Doesn't Deter Bar Mitzvah

Ian Fairclough is 13 years old. Like other young men his age, Ian anticipated that he would achieve his Bar Mitzvah, an important milestone in Judaism.

Ian was born with Down syndrome. The following article was written by Ian following his Bar Mitzvah on October 21, 1989:

"My Bar Mitzvah"

I am Ian Alfred Fairclough. My birthday is July 6, 1976. I am 13 years old. I was born in Albany, N.Y. Now I live in Lake George and I go to Lake George High School. My brother's name is Daniel. He is 11 years old. I live with my parents and my brother. My mother's name is Lois. I love my mother. My father's name is Martin. They are special because they have love and kindness in their hearts.

Jewish boys have a Bar Mitzvah at the age of 13 years old. The date of my Bar Mitzvah was 10/21/89. I had my Bar Mitzvah at Temple Beth El in Glens Falls.

A Bar Mitzvah is having a conversation with God. When you accept the responsibilities of being an adult in the Jewish congregation. My Bar Mitzvah means to me I can help the Rabbi conduct the services, and take part in the life of the Jewish temple. My Torah potion was in Genesis when God created man and woman in his image it does not matter if they are white or black or smart or dumb or cool or silly or rich or poor, they are all God's children. I read from the Torah and the translations in English and I led the Havdalah service. At the Hilander we had a reception with a big band and I was lifted up in the chair and I was carried around and we danced the Horrah. These are the names of the girls I danced with: Robin, Danielle, Jessica. Kristine, Kara and my family. We did the limbo contest and the hula hoop contest. Then I gave a speech and my grandma gave a speech too. I liked the party a lot. I like the band a lot. I really appreciate it a lot.

Reach for the Stars Telethon Big Success



Peter Pierri with Debble & Jason MacConnell, Mid-Hudson ARC's 1989 Telethon Child.

The third annual "Reach for the Stars" telethon was held on October 29, 1989 at the Granit Hotel in Kerhonkson, New York. Six chapters of NYSARC participated in this year's event which raised over \$140,000. The chapters participating in the event were Ulster, Orange, Sullivan, Putnam, Dutchess and Columbia Counties.

Each of the chapters that participated formulated their own fund-raising campaign.

Local radio celebrity Ms. Nancy Cozean co-hosted the event with Ulster County Chapter's Executive Director, Peter Pierri. Major corporations such as Empire Blue Cross/Blue Shield, Norstar Bank, Pyramid Corporation, Cellular One, Chatham Steel, J.C. Penney and many others made major contributions.

Steuben ARC Receives Gannett Foundation Grant

Steuben Association for Retarded Citizens (ARC) of Bath, New York, has become the recipient of a \$2,000 grant from the Gannett Foundation of Rochester, New York.

The Gannett Foundation awards monies to non-profit educational, charitable, civic, cultural, health and social service institutions and organizations in areas served by daily newspapers, broadcast stations and outdoor advertising companies operated by Gannett Company.

This grant money, along with money raised by an ARC raffle, will be used by Steuben ARC to purchase a new specialty camera for its expanding micrographics division. This Kodak Planetary camera will be used at Steuben Services, Steuben ARC's day training division, to microfilm documents for outside businesses.

Any business interested in contracting for the use of ARC's microfilming services should contact Shelia Meese at Steuben ARC at (607) 776-4146.

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Monroe ARC Awarded State Grant

The Association for Retarded Citizens has received a one-year grant for \$66 thousand from the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD). The grant is designed to transition 22 adults from ARC sheltered workshops into support work programs in the community.

Under the direction of ARC Job Coach Tom Tillson, workers in groups of three to eight will be working in industrial settings at various manufacturing and service companies. Under the grant, transportation, training, and on-going job coaching will be provided.

According to Katie O'Donnell, director of ARC's Sigl Center workshop. "transitioning workers with developmental disabilities from sheltered workshop settings to the general workplace allows our workers to achieve their highest level of independence." Tillson, Job Coach, noted that community placement such as work enclaves allows the business community to see individuals with mental retardation as being competent, reliable workers.

The Association for Retarded Citizens, a private, non-profit rehabilitation agency headquartered at the Al Sigl Center, serves over 600 individuals with mental retardation adults in Monroe County. The agency operates two Day Training Centers, a dozen Community Residences, and three Sheltered Workshops.

Celebrating Arts With a Difference

In May 1990, The Multi Media Arts Gallery, in cooperation with The Association for the Help of Retarded Children, The Young Adult Institute and Very Special Arts will present its First Annual Exhibition of Differently Abled Artists. CELEBRATING ARTS WITH A DIFFERENCE, a monthlong series of exhibits, performances and media presentations will feature works by artists whose lives have been touched by disability

CELEBRATING ARTS WITH A DIF-FERENCE will begin on May 5 with the opening of "People in New York", a group photography exhibit, curated by Joseph Caputo and Chana Benjamin. All the photographers in the show are members of Rehabilitation Through Photography, which is a group affiliated with AHRC. The group is composed of mildly retarded adults who are presumed to be unable to either create art or use sophisticated camera equipment. "People in New York" will be the group's first extended exhibit in a New York City commercial gallery, and will run until May 29.

Concurrent with the exhibit, media and performance events will take place throughout the month. May 11 and 12 will feature works exploring the effects of institutionalization on family members, particularly siblings. On May 19, there will be a video screening of differently abled performance groups, and on May 20 special live performances will be given by Choral, Dance and Theater groups who are differently abled.

For further information, please call Chana Benjamin (212) 966-4080. ■

Self-Advocacy

Beginning with this issue of OCV, a column will be devoted to Self-Advocacy. The following article was furnished to OCV by the Self-Advocacy Association of New York State, Inc. The article was written by Bernard J. Carabello, Executive Director and Amy Bittinger, M.P.H., Project Coordinator.

What is the Self-Advocacy Movement?

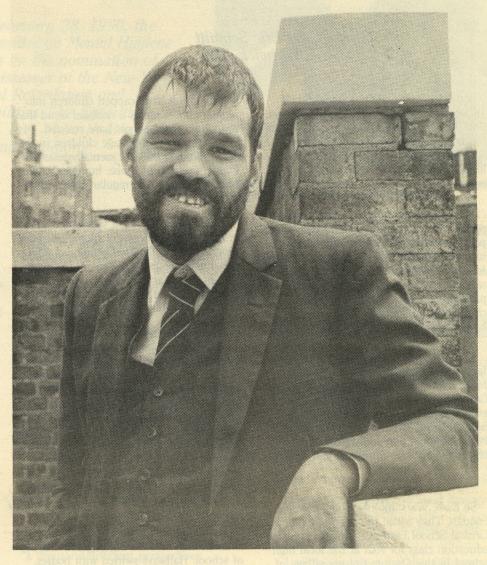
The daily lives of most people with developmental disabilities are controlled by others - institutions, sheltered workshops, residences or families. Basic decisions such as what to eat, what to wear, how to spend leisure time, when to go to sleep, to have and see friends, and working conditions are not theirs to make. In short, people with developmental disabilities are at the mercy of caregivers to get what they want and need in life. But most people with developmental disabilities can and want to make these decisions and more for themselves. They want to be active consumers, not passive "clients."

Through the self-advocacy movement, people with developmental disabilities strive to achieve basic human rights and responsibilities. Self-advocacy means deciding what is best for you and taking charge of getting it. It is a movement of and by people with disabilities for themselves - and thus is the means for the most far reaching and lasting impact on their lives and the lives of all around them. Self-advocacy (also referred to as self-determination, self-empowerment and personal advocacy) provides enormous opportunity to people who have traditionally been given very few choices or input in their lives.

Many service providers, bureaucrats and family members are so accustomed to providing total care for people with developmental disabilities that they are unable to see potential for growth and self determination. Well intended and caring parents were told when their children were young that they would never lead a "normal" life so parents naturally learned to expect very little. Too many agency personnel have received inadequate training and unfortunately have not been encouraged to give consumers choices and opportunities for risk taking. Because of these attitudes and beliefs, many parents and agency personnel are threatened by the goals of self-advocacy. The attitude of lets keep people dependent so that we don't have to change the way we do things prevails in many agencies. People with developmental disabilities nationwide have learned that the best way to achieve more independence and participation in their lives is by working together in self-advocacy groups.

The self-advocacy movement dates back to 1974 with the formation of the organization PEOPLE FIRST in Salem, Oregon. There are approximately 20 states with self-advocacy organizations including the surrounding states of Connecticut, New Jersey, Pennsylvania and Massachusetts. Until the recent incorporation of The Self-Advocacy Association of New York State, New York lagged behind the nation without a formalized self-advocacy network. Presently there are seven local self-advocacy groups in New York City and 13 groups meeting in other areas of the State.

The vitality and importance of self-advocacy groups can be seen in the successful effort of the Warren-Washington Self-Advocacy Group, in existence only two years, to get their agency Warren-Washington Association of Retarded Children to change the name to Warren-Washington



Bernard J. Carabello; Executive Director, Self-Advocacy Association of New York State, Inc.

Advocacy Respite and Community Living.

Labels are very important to all minority groups. That such a traditionally powerless and voiceless group of people would be able to organize, articulate and successfully advocate for this change in an established agency is a remarkable accomplishment. For many of the self-advocates, it was their first experience of being taken seriously by someone in authority.

In New York City, The New York League Work Center has been supportive of self-advocacy activities by providing space for numerous Association activities over the past three years. Other chapters that are initiating self-advocacy activities include: Erie ARC, Herkimer ARC, Monroe ARC, Rensselaer ARC and Saratoga ARC.

Through self-advocacy groups, people with developmental disabilities meet with their peers to share common concerns, experiences and solutions. They support each other for individual achievements such as learning how to speak up, to listen to others and make decisions, as well as work towards group goals such as making their communities more hospitable and accessible. Although run at first with the assistance of an "Advisor," self-advocates work to organize and run their own meetings through elected officers. Self-advocacy groups develop leaders who serve as role models for other persons with developmental disabilities as well as parents and professionals

Some of the goals for the Association for 1990 include: to provide continued outreach; to break down resistance in agencies and residences serving people with disabilities; to support on-going groups and nurture new groups; to conduct "client" rights training; and to provide opportunities for self-advocates to communicate with each other and to share strategies on what's working.

People with developmental disabilities have begun to take control over their lives through the Self-Advocacy Movement. It is a long, slow process very similar to the struggle of the civil rights movement. People with developmental disabilities are only now beginning to enter fully into community life. They deserve support in their efforts to achieve basic rights, courtesies and responsibilities so often taken for granted. Self-advocacy is the opportunity for persons with developmental disabilities to become first-class citizens - a right they have been long denied.

Please feel free to contact the Association at (212) 627-2104 to receive assistance with promoting self-advocacy activities where you live. The film: "OUR VOICES COUNT: SELF-ADVOCACY NOW" is a 25-minute tape, narrated by Geraldo Rivera, highlighting the self-advocacy movement. It is available to be shown to your group or you can receive a copy by sending \$10.00 to: The Self-Advocacy Association of New York State, Inc., 111 8th Avenue, Suite 302, New York, New York 10011.

Jodi's in School and, You See? **Not So Different**

By Eric Schmitt Warwick, N.Y.

Jodi Goodline is like a lot of other 16-year-old girls. She's interested in boys. She likes sports (especially jogging and baseball). She's into heavy-metal music (Bon Jovi! Bon Jovi!). She's bubbly and gregarious. In short, she's a very outgoing

School is usually a place where outgoing people thrive, what with all the other young people around. But for as long as Jodi has been going to school, it's been different. Jodi is mildly mentally retarded - she reads at second-grade level - and in most parts of New York mentally retarded children go to special schools for the handicapped.

That bothered Jodi's parents, Terry and James Goodline. It bothered them that Jodi's school was 10 miles away, in Goshen, and that her friends there lived even farther from her home, while the neighborhood children were strangers. It bothered them that Jodi rarely met children who were different from her.

So three years ago the Goodlines said enough. They asked the Warwick Valley Central School District to create a specialeducation class for Jodi at the local high school in this Orange County village of 4,500 people, 50 miles northwest of New York City. And they asked that she be integrated into nonacademic activities like music, art, gym and lunch. No, the district said, Jodi wasn't ready for that, and besides, mean children might make fun of her. "It's more important to deal with those things than to avoid them," Mrs. Goodline

On the first day, nine students in Room 19 have normal cases of the jitters.

The Goodlines appealed all the way to the State Education Commissioner, Dr. Thomas Sobol, who upheld the district's decision. So the Goodlines sued the school district and the state in Federal District Court in White Plains, contending that the district violated Jodi's rights under the Federal education act by denying her a chance to be educated with children who are not handicapped.

Faced with a long and costly legal battle, the district backed down. It agreed earlier this summer to create a special-education class at Warwick Valley High School for Jodi and eight other mildly retarded teenagers in Orange and Ulster Counties. The children will attend homeroom, gym and lunch with the rest of the school's 735 students.

Integrating handicapped children into regular classrooms is a national trend that most New York schools have resisted. Of the 3.1 million school-age children in the state, about 25,000 are mentally retarded. Only a fraction of those, however, have been integrated into regular public school

"New York is the most segregated state in the country in terms of special-education programs," said Dr. Jay Gottlieb, an educational psychologist at New York University who helped Warwick Valley create its new program. "There's no reason these kids should not be in a public high school."

School officials here have been working hard to prepare for Jodi and her classmates. Over the summer, district officials and Dr. Gottlieb met with the high school's teachers, administrators and staff for "sensitivity sessions" intended to dispel stereotypes about the handicapped and replace them with information about their actual capabilities and limitations. Students volunteered to serve as "buddies" to help the new students around. "It's a school-wide effort," said Brad Gibson, the district's director of pupil personnel services.

Wednesday was the big day, the first day of school. Hallways swirled with bodies. Friends showed off new clothes and new shoes. Freshmen looked like freshmen: totally lost. In Room 19, Medie Ann Close, the special-education teacher, dealt with first-day jitters by having Jodie and her classmates describe their feelings. "Happy, said Jodi, who is tall with glasses and whose brown hair is tied in a ponytail.

'Nervous and confused," said Amy. "Hyped up," said Colleen "Worried," said John

For these students, the toughest part of school isn't mastering algebra or French verb conjugations. It's little things like remembering the combination to a hall locker, choosing between the salad bar and the hamburger line in the cafeteria, and dealing with money instead of a ticket to pay for lunch.

"It's O.K. to be confused. It's O.K. to be nervous. You're going to be just fine," said Ms. Close, a teacher who knows just when to coax and just when to calm.

The first day did go fine. In gym, they found out where the swimming pool was. At lunch, they discovered there is a north cafeteria and a south cafeteria. They also discovered something about themselves. "I like the atmosphere her," Amy said. "I'm not scared anymore."

Reprinted with Permission The New York Times September 8, 1989

Important Court Decision Expands Medicaid

NYSARC an Amicus

Most everyone agrees that, to the detriment of persons with developmental disabilities, Medicaid encourages more restrictive over least restrictive forms of care.

Joining, at least in part in this consensus, the United States Court of Appeals for the Second Circuit in Detsel v. Sullivan, reversed a lower court ruling denying Medicaid payment for services to a girl with severe handicaps. The reversal supports the claim that the child is entitled to receive Medicaid-covered nursing services while attending public school.

Melissa Detsel is an 11-year-old girl suffering from multiple physical impairments involving her heart, lungs, digestive system, back and feet. She requires 24-hour-a-day nursing coverage. However, according to affidavits submitted by school administrators, "Melissa has benefited greatly from her school programs. She has advanced academically and socially... Her determination and participation in classroom activities provides a very positive example for any underachievers; her teachers report that Melissa is magic to have in the classroom. She is competitive and independent and thrives on learning."

Melissa's physician further maintained that full-time school was essential to her physical and emotional well-being.

Nevertheless, the Department of Health and Human Services (HHS) sought to deny payment for any nursing coverage rendered outside of Melissa's home, effectively foreclosing her ability to participate in a regular public school setting. The HHS decision was based on a definition of Medicaid-funded private duty nursing services that was published in 1966 - long before the beneficial impacts of least restrictive placement for children with handicaps were appreciated or widely understood. That definition stated that private duty nursing could be made available only in an individuals home, a hospital or a skilled nursing facility.

But the Court found no evidence to suggest that Congress ever intended to place the limitations on private duty nursing that are contained in the regulation. Further, the Court found that the HHS decision included no "rational connection between the facts found and the choices made": a linkage that the Court stated must be established if the administrative discretion of HHS in this case is to be recognized as legitimate.

Instead, the Court reached a conclusion that is striking - at least in this case - by acknowledging the primacy of current knowledge as the determining factor in the use of Medicaid.

The Court Stated:

In view of advances in the care of severely handicapped individuals over the past twenty-five years, we do not believe that the medical assumptions of the mid-1960's offer a valid basis for the Secretary's interpretation. Two and a half decades ago it may have been widely accepted that a person needing the services of a private duty nurse would be confined to a hospital, a skilled nursing facility, or the four corners of her home, but fortunately these assumptions no longer hold true today. The professional literature cited in the record convincingly demonstrates that private duty nursing is now commonly understood to be "setting independent"; that is, it refers to a level of care rather than to specific locations where the care can be provided.

Concluding that the lower court and HHS had no reasonable basis for their decision, the higher court overturned the decision denying nursing services. Melissa will now be provided the nursing care necessary to enable her to attend school

NYSARC was an amicus in Detsel v. Sullivan case. Commenting on the outcome, Marc Brandt, NYSARC's Executive Director stated "We all know that Medicaid is antiquated in light of our current understanding of developmental disabilities. That's what the Medicaid reform movement, the Chafee and Waxman legislation and the OMRDD proposed 1115 Waiver is all

Brandt added, "But while it's good to see the courts acknowledge this, and while we are delighted with its decision, this issue represents only a very small portion of what remains to be accomplished."

Still, the Detsel v. Sullivan decision is extremely important. It shows that, given aggressive legal advocacy, Medicaid need not remain impervious to the facts about what is best for persons with developmental disabilities.

Remember: **NYSARC 41st Annual Convention**

October 31 - November 4

Angela Z. Van Derhoof Presented Emily Oliver Award

Benevolence is the distinguishing characteristic of man. As embodied in man's conduct, it is called duty. Mencius (372?-289BC) "Discourses"

Angela Z. VanDerhoof, Executive Director of the Association for Retarded Citizens, has been following this duty in her service to the community, her work and her every day life.

Over the past few years, she has been recognized for her accomplishments as 1977-78 Beta Sigma Phi - "Woman of the Year," 1988 - Recipient of the Mohawk Valley Women's Award as the Women of Merit (Human Services Field) and most recently as the recipient of the First Annual Emily Oliver Award.

The criteria for the Emily Oliver Award, presented by the Oneida County Elderly Mentally Retarded/Developmentally Disabled (MR/DD) Task Force, stated it was to be given to a person in the community who has demonstrated achievement of the goals set forth by the Task Force - to identify, integrate and promote community awareness of the elderly MR/DD individuals in our community.

The award is named in honor of Emily Oliver, a former Oneida County Office for the Aging staff member. Emily, through her membership on the Elderly MR/DD Task Force, was instrumental in bringing the Aging and MR/DD service fields together, learning and working collaboratively to enhance the lives of elderly individuals who are developmentally disabled. The award was given posthumously.

The search committee for the award did not have to ponder long on their decision. In 1987, the Task Force was convened under the auspices of the Association for Retarded Citizens and its Executive Director, Angela Z. VanDerhoof.

In her fifteen years as an Executive Director in the field of developmental disabilities, with both the Epilepsy Foundation of America and the ARC, Angela's demonstrated commitment to the unserved and underserved has seen the realization of a variety of programs and services.

Her keen awareness of the growing number of aging individuals within the MR/DD population resulted in the first meeting of an illustrious group of professionals from the fields of Education, Government and Community Services for the elderly MR/DD. This meeting led to many others and the group became known as the Oneida County Elderly MR/DD Task Force.

Angela's vision and her "none of us is as smart as all of us" attitude provided the basis and the bond which has caused the Task Force to flourish. The goals identified in the 1988 Task Force Report - The Newest Minority - The Aging MR/DD Population in Oneida County - are well on the way to fruition. The Task Force and its many subcommittees continue to make great inroads in the areas of education and integration.

Perhaps Angela's greatest contribution to the Task Force is her sense of commitment. She is an individual, who like Emily Oliver, takes stumbling blocks and turns them into stepping stones.

One such stepping stone is the new "Shared Activities" program initiated between the ARC and the Cornhill Senior Center. Through this program, members of the Center take part in activities at the ARC and elderly program participants from the ARC attend the Cornhill Senior Center events. This program has helped foster an awareness of the common ground both populations share.

Angela is a true jewel in the community and her work with the elderly is but one facet.

On the State level, she serves on several committees of the New York State Association for Retarded Children and was a member of the Commissioner of the Office of Mental Retardation and Developmental Disabilities' Task Force on rewriting regulations governing Community Residences (Part 686).

As an active mother of three, she has never lost sight of the true nature of the family. It is this concept and the duty of benevolence, she has brought to everything she has accomplished.

A Daughter's Praise of Her Mother

On September 10, 1989, the Sullivan County Chapter honored its founder, Ruth Bennett, at their 40th anniversary celebration. One of the speakers, Deborah Berlove, the daughter of Ruth Bennett, gave the following remarks. We thought her remarks would serve as an inspiration to others within our Association.

Reprinted with permission, New York Times, 9889.

Most people volunteer their time and effort. My mother volunteers her life. Over the years, she has belonged to at least 11 charitable organizations. Not only has she participated herself, but encouraged others to do so as well, often transporting a car full of people to and from meetings and fund-raisers. And when the drive was too much for her, she'd offer the use of her car.

Her main devotion has been to the ARC. It took strength and courage to turn a personal misfortune into an opportunity to do good. At a time when most people tried to hide children with handicaps, my mother and father went public. Finding little help available for their son, my brother, they established what today helps hundreds and hundreds.

I was not around when the ARC started, but the 1st stories I heard were of my mom standing on the street corner, collection box in hand. But she was asking for more than money, she was asking for understanding and concern for those less fortunate.

As the ARC grew, my mother continued to be a driving force on both the State and local level. I cannot count the numerous trips she has made to conventions, public speaking engagements and to the Legislature trying to get laws passed to help the retarded and other handicapped. My mother has always pushed for better salary and benefits for those who work with the retarded, saying that they were doing the work of angels.



Mrs. Ruth Bennett, founder of the Sullivan County Chapter seen here addressing the Board of Governors.

From infancy, visits to my brother were a way of life for me. My parents brought me up to understand and not be ashamed, to care and never turn my back.

This reflects the inner essence of my mother. She believes that each individual is responsible for the next. And her true, caring heart feels the pain of others. This has always been her motivation.

I am sad that my father and grand-parents are not here to share in the occasion but I am thankful for those of our family who were able to come, many from great distances. I thank all of you who are here today to honor my mother. But I am especially thankful that I have this opportunity to say "Mom, you deserve this honor, I am proud of you and I hope that I can come close to doing in my lifetime what you have accomplished in yours."

Deborah Berlove

Don't Forget to Mark Your Calendars to Attend the Following NYSARC Conferences!

"NYSARC Recreational Staff Retreat"

May 10-11, 1990
Hidden Valley Resort and Conference Center
Lake Luzerne, New York

"Meeting the Needs of Persons Who are Elderly and Mentally Retarded"

June 6, 1990 Desmond Americana Hotel Albany, New York

"In Support of Families"

July 27-28, 1990 Marriott Hotel Albany, New York

"Light Up the Network for Prevention"

September 10-11, 1990 Sheraton Inn and Conference Center Utica, New York

For more information, please see page 26.

Executive Director Vacancy

Small Agency offering job placement, training, and residential services for people with disabilities, seeks applicants for Executive Director.

REQUIREMENTS:

- BSW (MSW Preferred).
- Experience in supportive employment and residential services.
- Ability to negotiate with Government Agencies regarding

funding for services provided to disabled persons.

- Proven experience in securing Grants from State and Federal Agencies.
- Strong Managerial, Budgetary, and Public Relations experience necessary.

BENEFITS:

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- · Paid Vacation

Send Resume in confidence to:

Search Committee c/o Pioneer Agency, Inc. 2516 Lodi Street Syracuse, New York 13208

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

PROCLAMATION

For more than four decades the New York State Association for Retarded Children has been helping New York State citizens with mental retardation to realize lives filled with dignity, opportunity and hope.

As the result of this continuing commitment, today thousands of persons with disabilities are leading fulfilling and productive lives as full and valued members of the family of New York.

Because of the leadership and vision of the more than 50,000 member families and countless professionals affiliated with the Association's chapters throughout the State, the future of New York citizens with mental retardation is now brighter than ever before.

One of the longstanding initiatives conducted by the Association, helping to improve the general public's understanding and acceptance of persons with mental retardation, has been its unsurpassed efforts in the areas of public education.

It is fitting that, in this its 41st year of service, we recognize the Association's initiative and express our support for its past accomplishments and future endeavors in this regard.

NOW, THEREFORE, I, Mario M. Cuomo, Governor of the State of New York, do hereby proclaim February 7-14, 1990, as

MENTAL RETARDATION AWARENESS WEEK

in New York State.

FIVEN under my hand and the Privy Seal of the State at the Capitol in the City of Albany this eighth day of January in the year one thousand nine hundred and ninety.

BY THE GOVERNOR:

Mario Me. Denoms

Secretary to the Governor

1990 NYSARC AWARENESS WEEK FEBRUARY 7-14

According to the control of the cont



NYSARC Chapters Mark Annual Legacy of Love

The period before Valentine's Day was designated by NYSARC as the Fourth Annual Legacy of Love Week.

A Gubernatorial Proclamation marked February 7th through February 14th as Mental Retardation Awareness Week and specially cited the NYSARC chapters for leadership and vision in making the future of people with mental retardation brighter than ever before. Programs offered by the chapters were described by the Governor as filled with dignity, opportunity and hope.

Matilda Cuomo joined in the observance by again accepting a presentation of the Legacy of Love product, which this year was a hurricane lamp with a rose motif, produced by the Oneida chapter.

The selling effort for the Legacy of Love product was organized in many locations throughout the state, including village and town halls, supermarkets, beauty salons, transportation terminals, bowling alleys and banks. Some chapters distributed the product to restaurants for display as centerpieces and subsequent sale.

Using the Legacy of Love Week as a focal point, over thirty chapters engaged in public information and awareness activities. These included street banners, open houses at program facilities, and several hundred press and broadcast releases.

Legacy of Love is one of the activities sponsored by the NYSARC Public Information Committee and the selection process for the 1991 product is now underway. That selection will be made by chapters attending the Public Information Committee's Resource Group meeting set for May 17th in Syracuse.



Matilda Cuomo is presented with this year's Legacy of Love product; a hurricane lamp with a real preserved rose bud produced by the Oneida Chapter. Presenting this year's product is Nancy Witchiey, an employee of Oneida ARC's sheltered workshop. (Photo by Joe Elario)

NYSARC Chapters Participate in Legacy of Love

Broome-Tioga ARC Holds Legacy of Love Balloon Release Celebration

On Valentine's Day, Wednesday, February 14, 1990, the cold, grey skies above the Broome-Tioga ARC Main Facility were filled with over 300 red and white balloons during the Broome-Tioga ARC's first Legacy of Love Balloon Release Celebration. This very special event was held in conjunction with the 4th Annual New York State Association for Retarded Children Legacy of Love Awareness Week, February 7-14th, 1990

This annual state-wide event, recognized in a gubernatorial proclamation issued by New York State Governor Mario M. Cuomo, is observed by the sixty-two Chapters of the State Association through various activities, celebrations, and ceremonies in an effort to heighten the public's awareness and understanding of individuals who are mentally retarded and developmentally disabled.

Locally, government officials, other dignataries, ARC Board Members, parents, friends, program participants, and staff gathered at the Broome-Tioga ARC to acknowledge the contributions and capabilities of persons with disabilities in the community.

Following opening remarks by ARC Board President Robert Shrader, 300 balloons, each with a fact about mental retardation attached, were released into the air. Formal ceremonies were then held in the Day Treatment Lobby. Robert Shrader introduced ARC Executive Director Matthew Guokos who opened the ceremonies with a brief legislative history of the ARC and welcomed Mrs. Susan A. Lyons, Director of Public Information and Special Projects, NYSARC. Mrs. Lyons spoke regarding the

importance of the Awareness Week as well as the necessity for a pro-active approach to the prevention of mental retardation.

The festivities continued with the presentation of Legacy of Love Hurricane Lamps to local and state dignataries in recognition of their support of Broome-Tioga ARC programs and services. The lamps were assembled and packaged by sheltered workshop employees at the Oneida County ARC in Utica, New York.

On hand to receive these recognition awards were Juanita Crabb, Mayor of the City of Binghamton; Mr. Richard Thamasett, Director, Broome Developmental Services; Mr. Fred Alexander, Developmental Disabilities Program Specialist; Mr. Don D'Angelo, Tioga County Representative; and Mr. Timothy Grippen, Broome County Executive. Mr. Grippen also announced that he had issued a proclamation designating

the week of February 7-14, 1990, as "Legacy of Love and Mental Retardation Awareness Week" in Broome County, and called upon the citizens of our community to support the efforts of the New York State Association for Retarded Children, Inc. Also receiving the Legacy of Love Hurricane Lamp were Ms. Nadine Battaglini, Representative of Assemblyman Richard Miller's office, and Mr. Thomas Libous, New York State Senator representing the 51st District, who has clearly demonstrated his strong support and interest in our agency programs.

Following the ceremonies, refreshments were served.

The Broome-Tioga ARC would like to thank all of those who attended the Balloon Release Celebration and also the ARC staff and program participants who helped to make this special event such a success.



Oneida ARC Legacy of Love Valentine Rose Arrangements Ready to Go



Valentine's Day is for lovers, and Governor Cuomo has designated February 7-14 as a "Legacy of Love" celebration for those citizens in our county with mental retardation. In Oneida County we have gone one step further and have had the entire month of February proclaimed ARC Awareness Month.

Each year, a special "Legacy of Love" Valentine Rose Arrangement is produced by one of the NYSARC sheltered workshops, and sold state wide. This year's exclusive contract has been awarded to Progress Industries-Oneida County Association for Retarded Citizens' sheltered workshop. These arrangements are lovingly hand assembled by workers with mental retardation.

All proceeds from the sales of the "Legacy of Love" Valentine Rose Arrangements will help support the programs and services we provide to individuals with mental retardation. Just as importantly, they will remind the public of the love and care we provide to over 750 developmentally disabled individuals every day of the year.

The 1990 "Legacy of Love" product features a real red rose, that has been preserved to capture its beauty for all time, in a hurricane vase, and is surrounded by white Victorian lace and rose leaves. Inserted in the top of the vase is a tempered votive cup and candle, enhanced with a bright red ribbon and bow. The vase is attractively packaged in a gold foil box imprinted with the "Legacy of Love" emblem. You can show the world you care by giving your special someone a "Legacy of Love" Valentine Rose Arrangement.



Nassau ARC



The Town Hall in Hempstead, Long Island, was one of the many sites in New York State for the public sale of this year's Legacy of Love product. Volunteers from the Nassau AHRC chalked up another sale as they helped to mark the NYSARC Legacy of Love Week.

Herkimer ARC

Sharon Hughes, second from left, a Herkimer County legislator and chairwoman of the human resources committee, presents Sam Geloso, Herkimer Association of Retarded Citizens board president, with an official proclamation of HARC Week. Other officials are shown with Valentine hurricane lamps which will be sold as part of the HARC "Legacy of Love" campaign. From left are Doug Brewer, County Administrator; Josie Detore, HARC receptionist and Dominic Frank, HARC public relations director.





Nominee Elin Howe listens to testimony given by NYSARC Executive Director, Marc N. Brandt.

NYSARC Testimony on the Nomination of Elin Howe to be Commissioner of OMRDD

On Wednesday, February 28, 1990, the Senate Standing Committee on Mental Hygiene held a public hearing on the nomination of Elin Howe as Commissioner of the New York State Office of Mental Retardation and Developmental Disabilities. The Executive Director of NYSARC, Inc., Marc N. Brandt, presented the following testimony:



NYSARC Executive Director, Marc N. Brandt, testifying before Senate Committee on Mental Hygiene.

Good morning.

My name is Marc Brandt. I am the Executive Director of the New York State Association for Retarded Children, Inc. With 60,000 members and 62 chapters serving 25,000 individuals on a daily basis, our Association is the State's largest voluntary provider of services for persons with mental retardation and developmental disabilities.

I want to thank you for allowing me to testify on the Governor's nomination of Elin Howe to be the next Commissioner of the Office of Mental Retardation and Developmental Disabilities.

Obviously, Ms. Howe's nomination is of enormous significance to our Association, the many parents and volunteers who belong to it, and, of course, the people we serve.

So far, OMRDD has had four Commissioners. Each has had his unique traits; each has been competent; and, fortunately, each has made a positive and significant contribution to services for persons with mental retardation and developmental disabilities.

Elin Howe, I strongly believe, will enable the office to continue a tradition of fine leadership. And, like each of her predecessors, I believe that Ms. Howe will make her own unique and very positive contribution to this field.

By the way of background, it is important to point out that the Office of Mental Retardation and Developmental Disabilities is unique amongst State agencies. It was started in response to a grass roots effort by parents of persons with developmental disabilities who believed that the needs of their children were sufficiently unique to justify a specialized agency dedicated to serving them.

OMRDD's constituents conceived of it, advocated for its establishment and have always sought to be part of it. And I believe, the relative success of the office is a direct outgrowth of this kind of unprecedented level of grass roots participation.

In short, we are accustomed to being involved; we expect to be involved. That is the essence of participatory democracy; but it does not necessarily make life easy.

As you know Senator Spano, the relationship between OMRDD and its constituents, though close, has not always been smooth. And as I have said on other occasions, the duty of the office to manage does not always dovetail with the responsibility of advocates to strive for what they believe is in the best interests of persons with mental retardation and developmental disabilities.

Yet, these differences can work for the people we serve; they should not become an occasion for unnecessary conflict. A Commissioner that can understand and appreciate this, can do a lot for this field.

Elin Howe is that person. She is honest. She is deeply respected and she is deeply trusted by parents and advocates. Her sensitivity to the needs of persons with mental retardation and developmental disabilities is beyond question. After watching her serve for 20 years, we know how knowledgeable and competent she is. She has and as Commissioner will undoubtedly be required to make decisions with which we may not agree. But, it is far better to disagree with someone you trust; someone with whom you agree about where you are going, though you may have differences on how to get there.

Yet, there are other compelling reasons to confirm Elin Howe.

Our field isn't what it used to be. The small providers have all become much larger and the larger providers have become bigger still.

As this has occurred, our funding streams have become increasingly complex and the task of management has correspondingly become even more imposing.

Each provider must manage hundreds of employees who must be entrusted to look after vulnerable individuals often with severe disabilities and complex physical and emotional needs. New programs are continually being constructed at a cost of millions of dollars annually to State and federal taxpayers; new individuals are entering these programs; and new regulatory requirements for them are constantly being promulgated.

And finally a new trend is emerging.

The people we serve and their families want

more self-determination and greater choice; they want program alternatives that make them a legitimate and working part of everyday society. Senator, the status quo that our field has become accustomed to is no longer adequate. It must change.

The demands on us are enormous. We must be caring; we must be competent; we must be efficient; and, of course, we must be accountable.

Yet, none of this happens in an inert environment. As if we already didn't have enough to do, our field is constantly changing. And the issues seem endless.

Words like staff recruitment and retention, supported work, self-advocacy, Local Assistance reform, Medicaid reform, least restrictive environment, medical consent, site selection, family support, deinstitutionalization and many others each represent an important concern viewed from a thousand different perspectives.

And though I do not know how we will ultimately decide to resolve all of these issues, I know this: it is not enough for all of us in this field to be technocrats led by other technocrats.

Nor is it enough for all of us to be purely advocates led by other advocates.

It is essential to be both of these and be led by leaders combining both of these characteristics.

Does Elin Howe measure up to this standard? I believe she does.

For almost 20 years as a manager in this field, she has struggled with the most complex issues we have ever faced. As the former director of Staten Island Developmental Center - formerly Willowbrook - she saw the infamous facility through its worst times. I do not need to remind anyone about the legal, moral and philosophical issues here.

For almost the last six years, she has been OMRDD's first deputy presiding during a period of unprecedented sophistication in areas from Quality Assurance, to Revenue Management to the operation of developmental centers and establishment of community facilities.

Her credentials and reputation as a manager need no further explanation than

this. And if all we needed was a technocrat, I could stop here. But I won't because there is the other part of Elin Howe that I want to tell you about.

Ten years ago, I was the Executive Director of the Sullivan County ARC. One day Elin came to visit our chapter. I think that at the time she was the head of OMRDD's Southeastern County Services Group; it was shortly after she had been the director of Willowbrook.

As Elin moved amongst the persons with mental retardation and developmental disabilities that our chapter served, some 500 persons, I noticed what at first I could hardly believe; she personally knew every individual that ever lived at Willowbrook.

And as she continued to move amongst them, I noticed something else: they knew her personally. I kept hearing people shout, "Elin, Elin."

I will never forget that day. Moreover, to this day, I do not know how one person could be so aware of so many others.

But I do know this: you have before you an individual whose experience and abilities make her uniquely qualified to be the next Commissioner of OMRDD.

Someone who will sit down and work with us on the many complex issues of our time. Issues such as continued closure of developmental centers, Medicaid Reform, staff recruitment and retention and the rest. Issues of urgency and great difficulty; issues that cannot be forgotten about, glossed over or soft pedaled. Issues that may require a Commissioner to confront the system, Governor, the Division of Budget, the unions and even the Legislature and say "this is what is right for persons with mental retardation and developmental disabilities. This is what must be done for their sake and the sake of their families.

Sometimes I wonder why anyone wants to be Commissioner and preside over a field where there are so few easy answers to so many complex questions.

Yet, the Governor made the perfect choice.

Elin Howe's credentials speak for themselves. I urge the State Senate to confirm her at its earliest convenience.

CHAPITE

BROOME-TIOGA

ARC Annual Banquet

On Saturday, September 16, 1989, nearly 375 persons, including program participants and their families, Board Members, staff, and other special guests attended the 1989 Broome-Tioga ARC Annual Banquet held at St. John's Memorial Center in Johnson City, New York.

The theme for this year's banquet was "An Exceptional Year - People, Talents, and Events," in recognition of the truly special events and initiatives of the Broome-Tioga Chapter during the past year, including NYSARC Lobby Day, Exceptional Artworks, and the establishment of the ARC Transportation and Family Support Programs.

Following program participants, staff, community, and special recognition awards, the ARC Day Treatment Bell Choir performed "Morning Has Broken" and "Edelweiss," which was one of the highlights of the evening.

Our chapter was again honored to have as guests a long and distinguished list of dignitaries including New York State Senator Thomas W. Libous, Assemblymen James Tallon and Richard Miller, New York State Association for Retarded Children Executive Director Marc Brandt and New York State Association for Retarded Children President Blanche Fierstein.



New York State Association for Retarded Children President, Blanche Fierstein, speaks at the Broome-Tioga ARC Annual Banquet.

ROME

A New Name: Rome Tri-County Chapter

As of the end of October 1989, when Rome Developmental Center closed its doors, our Chapter will no longer be known as Rome Developmental Center Chapter but the Rome Tri-County Chapter.

Our main focus will continue to be advocacy for individuals served by the Rome DDSO now living in the community and most of whom were former residents of the developmental center. These people live in about 79 different houses and apartments throughout Lewis, Herkimer and Oneida Counties.

The Chapter continues to seek relatives and friends from these homes who would serve as liaisons between the residences and the Chapter.

DUTCHESS



After a fire which destroyed the Dutchess ARC building, workers now enjoy their new "office" space.

After a great deal of hard work by staff clean-up crews, a \$15,000 contribution from The Pyramid Management Group, approximately \$8,000 in contributions from Dutchess County residence and members and a great deal of patience on the workers part, the chapter's light line and mail room can claim recovery from a fire that took place two years ago.

During the reconstruction time, workers had to use make-shift conveyors moving product by hand for assembly and packaging. The workers remained in rather cramped working areas since a disastrous fire in 1988. Contracts had to be maintained, production schedules met and customers satisfied during the great ordeal of reconstruction. Today, the assembly line area is fully reconstructed.

"A lot of good came out of the reconstruction," said Todd Virgilao, Group Supervisor for the light line. He referred to the staff unity that working through a crisis had brought. He also spoke about the tremendous support Dutchess County residents had given the agency over the past two years.

ALBANY

The True Spirit of the Holidays

On December 21, 1989, Sean Curran and Patricia Kelly, two trainees from the Albany ARC Day Training Program, were accompanied by staff to the Albany Medical Center Burn Unit where they presented a gift of three hundred seventy-five dollars (\$375.00) to Ms. Donna Beeke, Assistant Director of Development/Telethon Coordinator and to Ms. Jeanne Barriere, Development Coordinator.

This project was initiated in an effort to assist the trainees in recognizing that the "true spirit of the holidays" is not in the receiving but in the giving.

In recognition of this donation, "Albany ARC Day Training Workers" will be inscribed on a plaque displayed at Albany Medical Center to indicate that the trainees are now considered to be charter members.

This project was strongly supported by the families and advocates of the trainees and is anticipated that this activity will become an annual event.

The chapter is truly proud of the effort put forth by their trainees during this project; they exemplified the true meaning of the holidays.

DELAWARE

Bus Ports, Garages and Air Conditioning Projects Near Completion Supportive Apartments on the Way

Delaware County is very close to completing a joint project with OMRDD on behalf of our local Chapter. The County will finance and manage the construction of a bus garage and three bus ports to maintain and house the ever growing fleet of ARC buses and vans and will install air conditioning at one of the ARC facilities. OMRDD will fund the project through a multi-year lease.

The repair garage will enable the Chapter to start performing preventative maintenance, routine repairs and regular washings while the ports will facilitate preservice vehicle checks. These new facilities should greatly enhance passenger and driver safety.

The final aspect of the project is the installation of air conditioning in the

County owned and ARC leased Hamden facility with houses a Vocational Rehabilitation/Sheltered Workshop program, Early Intervention Center, and Administrative and Business Offices.

In other news...

The much anticipated opening date of the Chapter's first three Supportive Apartments is projected for March 1, 1990. The opening of these apartments will enable six individuals to move closer towards independence. Two of the apartments are located in the village of Sidney; one apartment is in Walton. Four of these individuals currently reside in the Chapter's Supervised Apartments. The remaining two are on the community waiting list. Each apartment will serve two individuals.

PUTNAM

Putnam Chapter Celebrates "Legacy of Love"

This year the Putnam Chapter has approached the concept of the "Legacy of Love" campaign from a different vantage point.

In keeping with the chapter's now imaging campaign which highlights "PARC Gives Back to Its Community," the agency has fostered networking amongst its clients, staff and the Putnam County Hospital Center towards a "grand day of bake sales" in each of the agency's three day program sites, with proceeds going to fund a designated article for the hospital's pediatric center.

A special client committee of advisors will be working toward coordinating the sale, collection of proceeds and purchase of the article which will, according to the public relations director of PCHC, "enhance the stay for countless children."

The chapter is committed to the concept that without affording agency client workers and program participants the opportunity to give, they must necessarily be seen by others and, more importantly, by themselves, as second-class citizens in a perennial position of dependence.

PARC's imaging campaign, of which 1990's "Legacy of Love" is one component, seeks to more firmly establish the agency's attendees as productive and aware citizens of the Putnam Community. Presentation of the gift will be made to the children at the hospital on Valentine's Day.

As a kick-off to the campaign, PARC's attendees collected food, assembled baskets as well as wreaths and, in cooperation with the local Department of Social Services, Office for the Aging and Putnam County's Housing Authority, delivered those welcomed and spirit-raising articles to seventeen grateful Putnam County families who would have otherwise gone without during the 1989 holiday season.

The gesture of "giving back" was echoed, as well, in the practiced tones of PARC's carollers who entertained the community on the steps of of the County Building, braving weather conditions below freezing.

No one complained of the cold.

What better speaks to the concept of a reciprocal "Legacy of Love"? ■



Mary Hutcoe, Tony Crupi, Richard Rodriguez presenting basket of food to Putnem County Senior Citizens.

RIFINS

ROCKLAND

Special Artists Honored

On Sunday, October 15th artists from the Rockland Association for Retarded Citizens were honored at a reception at the Lougheed Library at St. Thomas Aquinas College by family, friends and members of the Association. The art exhibit entitled "Exploration in Painting and Pottery Exhibit" featured works that were created in special art classes that were held on Saturdays to provide intensive instruction and individual encouragement to twelve people who evidenced artistic talent in these media. Funding for this program was provided by the New York State Council on the Arts' Decentralization Program which is administered by the Arts Council of Rockland and the Rockland ARC.

The art classes enabled these adults to learn to explore their talent and to learn the skills that are specific to pottery and painting. Pottery teacher and artist, Susan Shaw, refers to one young man as having both creative ability and the skill to learn the craft itself. Another man in the program

created beautiful works and now defines himself as an "artist." He has shown a new sense of pride and inner dignity as a result of the program. Artist Peter Schuerholz, teacher of the painting class, saw students' confidence grow as they learned to believe in their ability to create. One person realized that he could draw and paint freehand as well as trace the works of others, an important first step toward unleashing his creative abilities.

Photographs of the artists at work accompany the exhibit and are exquisite reflections of the "creative process at work." Trish Schroer, a gifted amateur photographer graciously donated her talents so that these photographs could be a part of the display.

After exhibits at two local libraries and the college library the art work will be on display at the Clarkstown Town Hall. Rockland ARC is proud of its artist and has immensely enjoyed the results of these "Explorations."

Becky Uliman and her artwork at October 15th exhibit.

SUFFOLK

ICF Goes to Frost Valley

Residents and staff of Suffolk AHRC's Robert Sansone Intermediate Care Facility (ICF) in Shoreham proudly announce the success of their recent trip to the Frost Valley YMCA camp in Oliverea, NY. After much planning and coordinating, the ICF's first trip ever involving overnight accommodations was made possible. The trip involved twenty-two residents (including five from the Westhampton ICF) and fifteen staff members.

Frost Valley is located on 4,500 beautiful wooded acres in the Catskill Mountains. While it is best known as a YMCA summer camp, it also has a year round weekend program open to those who seek out the healthy fun of this self described "wellness" camp. The counselors and other staff at Frost Valley are very accommodating, allowing every camper to achieve individual potentials.



A YMCA Frost Valley instructor teaches one of the Suffolk AHRC's Shoreham ICF residents special techniques in archery. The staff and clients at the Westhampton and Shoreham ICF's enjoyed their first ever weekend excursion to Oliverea, New York.

SARATOGA

Family Support Services

Family Support Services provides inhome respite care, home care, home habilitation services, outreach and referral, Saturday and summer camp, an adult social club and guardianship services.

Referrals from families caring for a child or family member at home continues to increase, with the majority being residential referrals. The Saratoga ARC has been taking an active role in advocating for parents seeking residential services. We hope their word is heard by those who plan residential development in our community. So often parents must wait several years before an opportunity for residential placement occurs.

Saratoga ARC Horse Bandage Patented

Saratoga ARC has been granted a patent for The Saratoga Bandage™. The bandage is an equine leg wrap and support manufactured by The Saratoga Horseworks, a division of Saratoga ARC. The Saratoga Horseworks produces a line of equine softgoods sold through retailers throughout the U.S. and Canada.

Other News...

Alpha Industries' supported work program grants were increased to \$70,000. A new supported work program has been set up with Shop n Save... and

construction has been completed on a 5,000 square foot warehouse for Alpha Industries. Production materials were moved from Alpha to the warehouse freeing up space on the production floor. Workdays were re-designed to allow more space for new workers and higher efficiency.

STEUBEN

Chapter Offers Resource Book to Parents and Caretakers

The Steuben ARC has acquired a new, updated booklet for parents and caretakers of persons with developmental disabilities. Entitled "How to Provide for Their Future", this 46-page booklet explains guardianship, wills, trusts, insurance and government benefits.

Also known as "Everything You Need to Know to Provide for Your Developmentally Disabled Family Member's Future", the book is geared toward families who are concerned with providing lifetime support for a family member with a developmental disability.

Other News...

After two and a half years in the planning stages, the chapter has completed construction of its transportation facility for the repair and maintenance of the 37 vehicle fleet used daily throughout Steuben County. Construction of the facility, which includes bus lifts, began in June and is now complete. A ribbon cutting ceremony was held recently to officially open the transportation facility.



L-R James Gilbert, Mechanic; Richard Eddy, Mechanic Supervisor, are ready to "go to work" at the Steuben ARC's new transportation facility.

GI-APIN

MONROE

DeliWorks

Freshness is the key to DeliWorks, the Association for Retarded Citizens' new food service program at the Al Sigl Center. Fresh directions, fresh faces, fresh paint, and of course, fresh bread.

DeliWorks is more than a place for clients and employees to purchase meals and snacks. It is a training site to prepare adults with developmental disabilities for jobs in the growing food service industry.

"This is what the Al Sigl Center is all about," says executive director Dan Meyers. "In keeping with our mission of freeing agencies for program and service, the Center is providing a fully equipped kitchen and a ready-made customer base to the Association for Retarded Citizens. The Center has foregone its own food service to support a new client training opportunity for our largest member agency."

DeliWorks will be run as a competitive business. Explains Jim Mroczek, executive director of the Association for Retarded Citizens, "If people with mental retardation are going to thrive in business situations, they need real, not sheltered, work experiences.

To provide that experience, DeliWorks intends to be a top quality, service oriented delicatessen-style restaurant that offers fresh, tasty food at competitive prices for the staff and clients of the Al Sigl Center agencies.

An advisory committee of food service industry and business representatives helped ARC develop the business plan for this new venture. The committee, which has identified 2,500 likely job placement opportunities in the community, will continue to advise DeliWorks to assure that the training program meets the needs of potential employers.

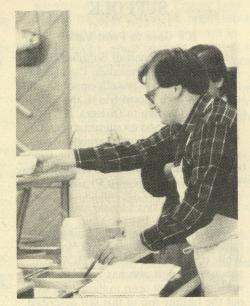
Three staff members operate the food service with the help of a transitional employee and four food service trainees. Job Path, ARC's employment service, helps select trainees and will work to place them in transitional or full time jobs upon completion of the 12-week training program. Job Path also provides a job coach for DeliWorks' first transitional employee,

NASSAU

Demonstration Project Approved

The winter was particularly busy for the Nassau AHRC

A demonstration project received approval from OMRDD which would provide for a minimum of fifty six additional residential placements annually for the next five years. Architectural work also proceeded to develop two previously approved community residences located in Glen Cove and Bayville with preliminary design activity underway for two additional sites in Syosset and Hicksville tentatively planned as new intermediate care facilities. In addition, the state is making funding available for AHRC to lease a house for the Respite Program. This is in addition to operating funds previously approved for an overnight weekend respite facility.



"DeliWorks"

a recent graduate of ARC's food service training program in conjunction with Strong Memorial Hospital. At that more limited site, 12 clients were trained last year.

Steve Lovi, manager of DeliWorks, combines just the right skills and background to run a successful food service training program. A graduate of RIT's National Technical Institute for the Deaf with a bachelors degree in social work, he grew up in his family's Chicago restaurant and deli operations. For the past year he has worked as a production supervisor in ARC's sheltered workshop program, where he set up a production group for hearing impaired workers.

Steve expects to create a pleasant working atmosphere in which adults with developmental disabilities can acquire marketable skills in food and sandwich preparation, bussing tables, and clean up. At the same time, he plans to satisfy the desire of long-time cafeteria customers for freshly made, healthful fare with made-to-order sandwiches, soups, and salad specials."

"Freshness is key," says Steve, "especially the fresh faces of clients eager to learn and grow into a real job." ■

During the winter months a Boy Scout and Girl Scout troop was formed at the AHRC Educational Center, with about twenty-five children enrolled.

The holidays were marked at the Nassau AHRC by a special holiday greeting card which listed end-of-the-year Angel contributors. Over nine hundred Nassau Angels participated in that effort.

The chapter is presently at work in the gathering of ad contributions for its 1990 Journal. That publication, which runs just under six hundred pages and raises close to \$300,000 is the keystone together with the AHRC Rose Ball of the chapter's community fund raising. This year Glenn McCarthy, who chaired AHRC's Annual Labor's Gift To Its Special Children, will be the recipient at the Rose Ball of the chapter's Humanitarian Award.

FULTON

Mountainview ICF - A Success



Fulton County ARC Executive Director Paul Nigra, left, Director Care Coordinator Tracy Murphy and Resident Manager Martin Wadsworth of Mountainview Facility examine a gastrostomy feeding system, an example of the skilled care available at Mountainview. Photo by Lisa Major, from Amsterdam Recorder

Fulton County ARC has successfully completed the first year of operation of its specialty ICF for elderly people who are medically fragile and/or frail. Located minutes away from the local hospital and Fulton ARC's Day Treatment Center, the residence looks out to the foothills of the Adirondack Mountains from which it derives its name - Mountainview.

Mountainview is home for 25 elderly men and women. Unique to this ICF is an inhouse day treatment component for people who for medical reasons are unable to

STEUBEN

February 7-14 Declared Mental Retardation Awareness Week

Mario M. Cuomo, Governor of the State of New York has declared February 7-14, 1990 as "MENTAL RETARDATION AWARENESS WEEK" in New York State.

This proclamation marks the "Legacy of Love" activity which many ARC chapters are participating in the week before Valentine's Day, and especially commends the ARC Association for its initiatives in public awareness.

Steuben Association for Retarded Citizens (ARC), headquartered in Bath, New York, is the local chapter of the New York State ARC. Steuben ARC currently provides vocational, residential, and transportation services to a broad range of the adult handicapped population throughout Steuben County.

Through the numerous programs provided by Steuben ARC, many mentally handicapped and developmentally disabled individuals throughout Steuben County are housed, taught health and habilitative services and trained to be productive

attend the off-site day treatment center.

Most recently, the staff at Mountainview have been trained in the use of a gastrostomy feeding system which is required for one of the residents who underwent esophageal surgery last summer.

Mountainview, through innovative programming and specialized training, is closing one of the gaps in the service system - the care of our aging men and women who are developmentally disabled and who are in failing health and/or are frail.

members of society.

Steuben ARC's many programs include a vocational training and employment center in Bath, several group homes, supportive apartments, a county-wide transportation network, and numerous other programs for the developmentally disabled throughout Steuben County.

Currently vocational programs comprised of initial assessment, job training and placement, and sheltered employment are offered to over 170 participants enrolled in Steuben ARC's programs. Specific skill training in micrographics, screen printing, offset printing, food services, shipping and receiving, and custodial services is available. Program emphasizing general work socialization and individual adjustment and adaptation attempt to provide a wellrounded approach. Steuben ARC's vocational programs also receive strong local support with contractors often recommending the client-provided services to other firms.

The goal of ARC is to provide the supports and the programs necessary for each handicapped person to obtain their highest level of independence possible.

RIVIAVIS

ONONDAGA

O.A.R.C. Fishing Club

In April the O.A.R.C. Fishing Club will kick off its second season of sport-fishing in the lakes and rivers around New York State. The club is made up of 14 adults who have an interest in sportfishing. The focus of the club is to promote fishing education, angling skills, travel, friendships and enjoyment of the outdoors.

Under the direction of the O.A.R.C. Community Recreation Specialist, John Hamel, the club members go on fishing outings twice a month from April - November. Club members also participate in a season long fishing contest and at the end of the season enjoy a fish dinner at a local restaurant where prizes are awarded to the contest winners.

This year the fishing club has worked with the Cornell Cooperative Extension and the New York State Department of Environmental Conservation to receive fishing education and training for the staff and volunteers.

The club will be attending some special activities this summer as: the Crappiethon U.S.A. fishing derby, a chartered boat trip and a weekend fishing trip.



Onondaga chapter fishing club members

SCHENECTADY

A Schenectady ARC/Catholic Family Services Partnership

"Ridge Service," the transportation department of the Schenectady ARC, entered into a mutually advantageous contract with Schenectady Catholic Family Services on October 1, 1989.

Both agencies provide transportation services: Ridge has a fleet of buses and vans available to transport the Maple Ridge Day Treatment Program clients and Catholic Family has 10 vans that are used for their "Meals on Wheels Program" and senior citizen recreational activities.

This cooperative arrangement has afforded a wealth of benefits to the Schenectady ARC:

- The availability of shared staff and vehicles has provided a much-needed backup network for Ridge and Catholic Family.
- The Schenectady ARC's part-time drivers have an opportunity to increase the number of hours they work each week, thus making their jobs more stable and appealing and reducing staff turnover.
- Ridge Service mechanics are repairing Catholic Family vehicles, a great costsaving benefit through the spreading of parts and salaries between the two agencies.
- Shared office space and equipment has resulted in a reduction of overhead costs for both agencies.

Two other direct benefits to the ARC derived from this venture are the ability of Schenectady ARC to buy gas for its vehicles at county prices (60 cents a gallon!), and the award to the Schenectady ARC of a federal grant to purchase two new buses under the Urban Mass Transit Program will pay 80 percent of the cost of each vehicle.

It is also anticipated that the door has been opened to obtain further federal grants for coordinated county-wide transportation services.

HERKIMER

Herkimer Honors Program Participants, Residents and Staff

Herkimer ARC celebrated the tenth anniversary of its Mohawk and John Street residences and its Lifestyle Day Treatment Program at a luncheon on December 1, 1989. The luncheon honored residents, program participants and staff who have been with the programs for the past 10 years.

Sam Geloso, President of HARC was the

Master of Ceremonies. The guest speaker was James Connell. Mr. Connell worked in both the HARC programs as a clinician, house manager and as director of the residential services program.

Seventy-three people attended the luncheon. Gifts of appreciation were awarded to people for their 10 years of participation as original members of HARC's programs. The gifts were presented by Susan Streeter, Lifestyle Program Director and by Karen Peterson, Residential Services Program Director.



From Left to Right: Susan Streeter, Program Director Lifestyle Day Treatment Pregram; Karen Peterson, Program Director Residential Services Program; Philip Catchpole, Director Rome DDSO; and Ralph Eannace, New York State Assemblyman 116th District.

SENECA

Twenty-Six Receive the Commander's Award

During a ceremony at the Seneca Army Depot on December 14, 1989, 22 dining facility attendants and four staff members were presented the Commander's Award for meritorious service. During the recent renovation of the dining facility from April to November, 1989, workers persevered adverse conditions while operating out of temporary shelter, yet still maintained the rigid standards required by the Army.

The Commander's Award is now proudly displayed with several awards and certifi-

cates the workers have received, including the Philip A. Connelly Award, recognizing excellence in food service in the Armed Services.

The Food Service Support Program, one of several employment opportunities available through Seneca ARC, provides off-site supported work and training for 22 disabled employees in the food service area.

Seneca ARC has operated the program since 1984 under a contract with the Department of the Army, administered through the National Industries for the Handicapped. For more information on this program, please contact Tom Hicks, Vocational Services Director, (315) 539-8600. ■

MONROE Jack Decker Retires from Monroe ARC Jack Decker former talouision station ideas were read ideas were

Jack Decker, former television station manager and more recently Public Relations Coordinator for Monroe ARC, was honored on January 11, 1990 at a retirement party at Logan's Party House. Jack's wife, Mary, and his daughters, Penny, Polly and Patty, many members of the Board of Directors, staff, friends and media colleagues gathered together to wish Jack well.

Jim Mroczek, Executive Director of the Monroe County Chapter of NYSARC, Inc., introduced the speakers and presented Jack with an overnight stay at an historic inn in Clarence, New York. He also received from the agency an engraved album of memories, put together by Linda Morrow and Annie Kearney. Congratulatory telegrams sent by Marc Brandt, Executive Director of NYSARC, Inc., and from mem-

bers of the state's Public Information Committee (of which Jack was a member) were read to those present. Many of Jack's ideas were adopted for special campaigns by the local chapter and also the state organization, among them the "Legacy of Love" campaign and the "We are Your Neighbors" campaign.

Warren Doremus, Channel 10 personality, entertained everyone with quips about well-known persons. For example, he said that Dan Quayle thinks that "Roe vs. Wade are two ways to cross the Potomac."

Paul Hanson, former ARC Board President, talked about Jack's time at ARC as a growing experience. Gail Ferguson, Sigl Center Campaign Manager, presented Jack with luggage on behalf of the center.

Jerry Fedele, Coordinator Production Manager, videotaped the evening's festivities, which showed that we all cared — plus! ■



Staff members and dining facility attendants from Seneca ARC pose with 1st Lt. J. Ann Scott, Commander of Hq & Hq Co. of the Seneca Army Depot, Romulus, NY, to proudly display the Commander's Award bestowed upon them recently.

ALLEGANY

Allegany County ARC Secures Funding for Building Projects

The Allegany County ARC has secured funding for three major building projects scheduled for completion in 1990.

The Farnum II facility, the largest project, involves construction of a 15,000 square foot building that will house the Day Training Program. A total of 60 severely disabled individuals are expected to be served at this new site. The program provides living skills training such as food preparation, hygiene, survival skills, etc.; pre-vocational training in food service, light hand assembly and janitorial/maintenance. Productive work is offered through the programs' frame shop, DTP frames. The two level structure will also house the administration department.

Monies for the project will come from HUD (Housing and Urban Development); OMRDD (Office of Mental Retardation and Developmental Disabilities): RARP (Rural Area Revitalization Program through the

CHEMUNG

Recreation Rates A+ at Chemung ARC

the schedule available to clients who take

part in recreation programs at Chemung

vised swimming, bowling, basketball and

Big hits during February? The annual

semi-formal Sweethearts Dance held Feb-

ruary 12 at a local high school, followed

by a casual Valentine's Dance at the Elmira

March always includes a St. Patrick's Day

Swimming for children and adults takes

place weekly in separate sessions at the

party, as well as a Mardi Gras event.

Monday night social events.

Heights VFW.

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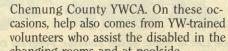
The Spring Schedule offers staff super-

Division of Housing and Community Renewal); and UDC (Urban Development Corporation). Construction is scheduled for this spring.

The second project involves the spring construction of a 12-bed community residence. It too will be located in Wellsville, across from the Farnum II facility. Funding will be provided through a program development grant and a state aid construction grant. Both grants are from OMRDD.

Renovating the Belmont community residence will be the agency's third construction project. Monies have been committed from RARP. These funds will be utilized for structural improvements and repairs, safety improvements, energy conservation measures and some equipment and furnishings. This project is also scheduled to begin in the spring.

The Allegany County ARC serves 135 individuals on a daily basis. It currently operates three day program facilities, three community residences, two supported apartments, a respite program and a supported work program.

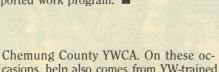


ketball games, while Rossi Lanes of Elmira is the chapter's long-time bowling site.

ings to tourist sites and state parks on day and overnight trips.

The bottom line, always, is fun.

Legacy of Love sale to offset some of the costs for the Recreation Program.



changing rooms and at poolside. The YW also plays host to the ARC bas-

Come summer, staff will supervise out-

ARC earmarked proceeds from our 1990

In other chapter news, we plan an early spring opening for our adult ICF being built on Liberty Street in Elmira. The ICF will be home to 12 adults, 10 of whom are transferring from New York City.



Dodge Pond News

Dodge pond will be the sight of the St. Lawrence County A.R.C.'s summer camp program again this year. The agency owns and operates the 180 acre recreational sight in the Adirondack Park with a 17 acre private lake.

The 1990 camp program will begin on June 18 and run for eight, one-week sessions, concluding on August 11, 1990.

The camping program is exclusively utiized for the recreational enjoyment of mentally and physically handicapped individuals. The campers that attend the structured program must have the skills necessary to function in groups of 2 to 4 people.

Campers participate in such programs as art, crafts, nature, recreation, aquatics, boating, follies, olympics, dances, structured camp fires, scavenger hunts and more.

Each one week session runs from Monday afternoon through Saturday morning.

Our summer camp staff consists of thirtysix trained and dedicated individuals with a full time resident medication coordinator on staff. Our camp staff ratio to campers is approximately 1 to 3.

In 1989 the camping program served 471 campers with 171 campers from outside of the St. Lawrence County. The program's average weekly attendance is 60

The 1990 summer camp program is gearing up for another successful and memorable experience for a great number of individuals. For additional information regarding our program, please contact Richard L. Laurin or Dennis G. Durant at The St. Lawrence Chapter, NYSARC, Inc., 6 Commerce Lane, Canton, NY, or by calling (315) 379-9531. ■



Madison Employee Awards (Back L-R) Jack Campbell, Director of Vocational Rehabilitation; Raymond Lewandowski, Executive Director; Mr. Ronald Caswell and Mr. Conrad Penna. (Front L-R) Lois Jones, Board President; Janice Wagner, Martha Smith and Susan

Employee Awards' Presented

Amid the festive celebration of Christmas, the assembled employees and staff of Alternatives Industry paused to give special recognition to Ronald Caswell, Susan Noffsinger, Conrad Penna, Martha Smith and Janice Wagner.

Raymond Lewandowski, Executive Director; Jack Campbell, Director of Vocational Rehabilitation; and Lois Jones, Board President presented the awards in appreciation for 15 years of consecutive service at

Alternative Industry.

Mr. Lewandowski stated, "We have known each other for nearly two decades working together through good times and through hardship. It gives me great pleasure to recognize these dear friends in this way." Conrad Penna summarized the feelings of the recipients best by stating, "Thank you very, very much for the opportunity to work and to learn." It was a very fitting culmination of this year's Christmas celebration.

CHAUTAUQUA

Disability Awareness Awards and **Recognition Dinner**

Cummins Engine Company of Jamestown, Chautauqua County Special Olympics and Robert Houston of The Post-Journal were among seven recipients recognized by the Resource Center at its first annual Disability Awareness Awards and Recognition Dinner, held December 4, 1989 in the Crystal Ballroom of the Hotel Jamestown. The dinner, which also celebrated the Center's 30th anniversary, paid tribute to and recognized individuals and organizations who have made strides over the past year toward independence for and integration of individuals with disabilities in Chautauqua County.

Awards were received by Cummins Engine Company for Employer of the Year; Chautauqua County Special Olympics for Humanitarian of the Year; Robert Houston

for Journalist of the Year; Mary Andrews for Employee of the Year; George Benton for Allied Industries Client Employee of the Year; Claudia Kelley for Success of the Year and Eunice Hedges for Volunteer of the Year.

Awards were presented by Board of Directors' President Michael Felice and Board Vice-President and Awards Committee Chairperson Merrill Rosen. Executive Director Paul Cesana stated that recipients were chosen based on nominations received from Chautauqua County human service providers, area schools, Resource Center staff and membership, and the community at large. Mr. Cesana added that the evening provided an opportunity to celebrate the accomplishments of program participants, staff, benefactors and community members who have fulfilled The Resource Center's mission of independence for an integration of individuals with disabilities in Chautauqua County.



Award Recipients (left to right): Robert Houston, Eunice Hedges, James Kelley, Helen Bryner, Mary Andrews, George Benton, and (in front) Claudia Kelley.

Governor Appoints Ralph D. Farkas to Chair DDPC

Mr. Ralph D. Farkas of New York City has been appointed by Governor Cuomo to serve as the new Chairperson of the New York State Developmental Disabilities Planning Council (DDPC). He is succeeding Mr. Michael E. Reif.

The DDPC is a statewide planning and advocacy body. It is composed of individuals with developmental disabilities, their parents or guardians, representatives of principal state agencies and others concerned with services to people with developmental disabilities. The responsibilities of the DDPC include developing and implementing a state plan for promoting the independence, integration and productivity of people with developmental disabilities as well as reviewing and commenting on other state agencies' service plans.

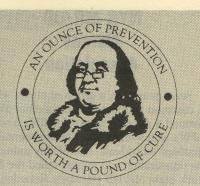
Ralph D. Farkas is presently the Executive Director of Professional Service Centers for the Handicapped, Inc. (PSCH), a ten-year-old, non-profit agency, based in New York City serving persons who are developmentally disabled and persons who are mentally disabled. The agency which Mr. Farkas co-founded in 1979, provides residential, rehabilitative and professional support in Brooklyn and Queens to over 500 persons who are handicapped and their families each year. In 1989, Professional Service Centers for the Handicapped, Inc. was the recipient of the United Way's Joseph Weber Award for best managed social service agency in New York City.

Before founding PSCH in 1979, Mr. Farkas worked as a Residential Administrator for Catholic Charities of Brooklyn in a residence serving adults who were deaf and developmentally disabled, and for Helen Keller National Center supervising a residence for 50 adults who were blind and deaf.

A decade of building services at PSCH has furthered his stated career objectives, "to continue to bring to the public's attention the value of persons who are developmentally disabled. I feel that the value of a society should be based on how that society takes care of and supports the people that are unable without assistance to take care of themselves."

Along with holding the position of Chairperson of the New York State Developmental Disabilities Planning Council, Mr. Farkas is involved in other professional affiliations including being the New York City Vice-President for the New York State Community Residence Association (NYSACRA). He is on the Board of Directors of Inter-Agency Council, past Treasurer of the Association of Community Mental Health Agencies, Chairman of the Legislative Committee for the New York State Commission on Quality of Care Surrogate Decision-Making Program and an Arbitrator for the American Arbitration Association.

NYSARC Prevention Corner



PRENATAL EXPOSURES TO COCAINE ARE HARMFUL TO THE HUMAN FETUS

Cocaine and its metabolites are concentrated on the fetal side of the placenta and causes vasoconstriction and hypertension. In addition placental blood flow also is decreased. Therefore, one might expect to observe an increased frequency of birth defects and developmental disabilities due to alternations in fetal blood flow. These kinds of defects have been referred to as "disruptions" and might include such central nervous system (CNS) problems as infarcts, hemorrhages (Chasnoff et al., 1986), porencephaly and hydranencephly, gastrointestinal defects as non-duodenal intestinal atresia, or skin defects such as aplasia cutis. Hoyme et al., (personal communication) have preliminary data to suggest that these types of defects may in fact be associated with prenatal exposures to cocaine. The investigator cautions. however, that the magnitude of risk for congenital defects following prenatal cocaine exposure is not known. Therefore, accurate determination of fetal risk assessment following prenatal cocaine exposure is not possible at this time.

In summary, prenatal exposures to cocaine are harmful to the developing fetus, but the magnitude of this risk is not known. Whereas, the incidence and severity of major birth defects following cocaine exposure might not be as remarkable as those after exposures to retinoic acid or thalidomide, its wide-spread use and the findings of low birth weight and abnormalities in CNS function make cocaine an agent with substantial potential for increasing the risks for developmental disabilities. As in most cases of so-called recreation exposure, avoidance of cocaine, especially during pregnancy, is advised. (Prevention Education Project)

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TERATOGEN UPDATE: COCAINE

By Luther Robinson, M.D.

Prenatal exposures to cocaine are harmful to the human fetus. Though the history and magnitude of cocaine use in the United States is beyond the scope of this review, one should recognize that abuse of this substance has reached incredible proportions in this country. For example, it has been estimated that 5 million Americans use the drug regularly, and its relatively low cost, easy availability, and high purity make cocaine a substance with tremendous potential for abuse not only among the affluent but also among the poor (Cregler and Mark, 1986). There is considerable information regarding the teratogenic effects of cocaine on laboratory animals, but only recently have data accumulated that show this agent also is teratogenic in man (Chasnoff et al., 1985, Bingol et al., 1987).

One of the early reports on the morbidity of cocaine was a brief report on two

women whose pregnancies were complicated by abruptio placentae (premature separation of the placenta from the uterus), premature delivery, and in one case, emergency Caesarean birth (Acker, et al., 1983). As one might expect, these complications were associated with considerable problems for the exposed fetuses; one infant was stillborn, and the other was delivered at 33-34 weeks gestation. Development outcome on that infant is not known.

More recently, Chasnoff et al., (1985) have published data on a prospectively ascertained cohort of 38 infants who were prenatally exposed to cocaine alone or in combination with opiates, or to opiates alone. A control group of 15 infants were not exposed to these agents. In that study the investigators demonstrated that pregnancies in which there were exposures to cocaine showed an increased risk for spontaneous abortion and abruptio placenta with its attendant complications. In addition, the data showed that prenatally exposed neonates had statistically significant rates of jitteriness and abnormal neurodevelopmental scores as measured by the Brazelton Neonatal Behavioral Assessment Scale. However, the score returned to normal in subsequent assessments. These infants are being followed longitudinally to determine whether the exposed group has an increased risk for such problems as developmental disabilities in comparison with controls. Two other studies of more than 600 pregnancies (Bingol, et al., 1987, Oro and Dixon, 1987) have shown similar results. In addition, the cocaine-exposed groups showed an increased rate of poor fetal growth and complications of pregnancy, further raising concerns about developmental outcomes in this group.

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NYSARC's President Appointed to Vocational Rehabilitation Advisory Group

NYSARC's President, Blanche Fierstein, was appointed by the Governor and State Education Commissioner, Thomas Sobol, to serve on a 12-member advisory group to the Interagency Council on Vocational Rehabilitation. The Council was established last July by the Governor and Board of Regents in order to resolve longstanding disputes over the operation of the State's vocational rehabilitation system.

In announcing the selection of advisory group members, the Governor states: "We are fortunate to bring together a group of people with the knowledge, experience and commitment needed to achieve productive changes in the way we deliver rehabilitation services to New Yorkers with disabilities." The Governor added, "Members of the advisory group will ensure that people with disabilities are given adequate input in the development of new strategies aimed at giving persons with disabilities a greater chance for independent and productive lives."

Some of the additional members of the advisory group include: Roy Susskind, Executive Director of the J.M. Murry Center in Cortland; John Cutterson, a member of Vietnam Veterans of America; Janet Foster, a consumer; Dr. T. Alan Hurwitz, Associate Dean of the National Technical Institute for the Deaf in Rochester; Carol Robertson, of the New York City Mayor's Office for the Handicapped; and Paul Tendler, Executive Director of UCP of Rockland County.

Thomas Sheldon, Executive Deputy Commissioner of the State Education Department and Michael Dowling, Deputy Secretary to the Governor for Human Services are the co-chairs of the advisory group.

To date, meetings have been concerned with existing funding and program issues. For example: what should be the role of the Sheltered Employment Program (SEP), what purpose does the Purchase of Service System (POSS) serve, how can the State best maximize federal funds? Also discussed is the need to eliminate gaps in service, to involve consumers in decision making, to enhance access to services and to cut down on unnecessary red tape. Finally, the future role of sheltered workshops and supported work is a top priority for the Council and its advisory group.

NYS MR/DD Nurses Association

Seven years ago, a group of nurses with a common purpose, came together and formed a support group for RN's and LPN's who worked with developmentally disabled individuals. Out of this union, an organization was formed called the New York State MR/DD (Mentally Retarded - Developmentally Disabled) Nurses Association. Their goal was to network with one another because they were in a field with little information from traditional sources and few in-services.

Mrs. Mary Gage, President, who is also the supervisory RN at Saratoga ARC's Day Treatment facility, feels that most medical personnel as well as the general public, are not familiar enough with mental retardation and other health concerns relating to the developmentally disabled. Because of this factor, the NYS MR/DD Nurses Association is committed to educating people about the mentally retarded. In fact, its members speak to nursing colleges and other health agencies on a regular basis, often conducting one day experientials for student nurses in schools that do not offer courses in the field. One of Mrs. Gage's major goals for the MR/DD Nurses Association is that it will eventually see the field of nursing for the developmentally disabled become a recognized nursing specialty.

Besides educating the public about mental retardation, the NYS MR/DD Nurses Association offers an annual seminar for nurses working in the field. The seminar, which is usually a two-day event, has a format consisting of a plenary session and concurrent workshops that address challenging, informative issues. They are conducted by members of the NYS MR/DD Nurses Association, as well as other medical personnel, and CEU's (Continuing Education Units) are offered to those people attending them. This year's seminar will be offered in October in conjunction with the Albany Medical Center Department of Continuing Education.

With the ever-increasing need to inform the public about our developmentally disabled, it is Mrs. Gage's hope that the NYS MR/DD Nurses Association will become an incorporated entity, perhaps serving as a prototype organization for other states.



Senators Spano & Libous tour the ARC as Broome-Tioga ARC Executive Director Matthew Guokas explains the Prevocational Day Training Program.

Thanks from the Community League

Ken Briggs Has Retired? He Should Be Rehired!

Some of us thought he was the biggest boost to employee morale since New York established the 40-hour work week. Others found him to be a fount of knowledge and trivia. Still others considered him to be the poet laureate of Wassaic.

We all had accolades to shower on Ken Briggs, who recently retired from state service and his position as Director of Public Education. He was, and is, many things to many people. And if we don't see him every day now - as we would like to - he's left us a closet full of memories to draw from.

Ken was responsible for the creation of Wassaic Today, the organization's first

daily newspaper, which quickly became a popular and efficient communications source for staff. He also oversaw production of the Wassaic Horizon and the far-ranging programs and activities of Senior Companions, Volunteer Services and Kids' Project/Mainstreet. Prior to that, he provided Wassaic with dynamic service as Administrator on Duty, Teamleader and Chief of Service.

Wherever he went in the organization, Ken brought along his humanistic viewpoint and a genuine concern for the people he supervised. When you saw him coming, you knew that you were going to hear about something you had done well, even if it was something that no one seemed to notice. More than anyone else, Ken made working fun.

Now it's time to enjoy yourself, Ken. And I hope you get back a little of what you've given us. Best wishes. ■



Fiorence Siegel, Board of Governor Representative from the Community League Chapter with Ken Briggs.

Broome-Tioga Hosts ARC Meeting with Senators Libous and Spano

On Monday, September 18, 1989, New York State Senators Thomas W. Libous and Nicholas Spano, representing the 51st and 35th senatorial districts respectively, visited the Broome-Tioga ARC during a one-day tour of Broome County area MR/DD service providers. Following a tour of the agency programs, the Senators met with executive Directors and Board Presidents from the various NYSARC Chapters, including Broome-Tioga, Cayuga, Chenango, Delaware, Herkimer, Madison, Oswego, Otsego, and Schuyler.

This meeting provided ARC representaives with an opportunity to discuss key issues and concerns facing those agencies providing services to the mentally retarded and developmentally disabled. Such topics of discussion included the need for a cautious approach to any changes in local assistance reform, the need for staff salary enhancements and the Senators' doubt that monies would be available, as well as the necessity for a state funding commitment to simultaneously provide financial support for sheltered workshop and supported work programs.

Both Senator Spano and Senator Libous have demonstrated a genuine concern and interest in services provided to the mentally retarded and developmentally disabled and strongly supported budget legislation this spring which averted major cuts to programs serving the disabled.

Choice Not Chance

Every day across the United States, more than 700 babies are born with mental retardation. Nationwide, 60,000 children a year become mentally retarded due to accidents, illnesses or environmental causes such as lead poisoning, neglect and abuse.

Within the next five years, experts project that AIDS will become the main cause of developmental disabilities in infants. Already 11% of all births in the U.S. are affected by cocaine leading to learning disabilities, attention deficits and behavioral problems in children.

Fetal Alcohol Syndrome (FAS) is considered by some as the most common cause of mental retardation in the U.S. today.

These are just a few of the startling facts that identify factors leading to disabilities that can be prevented.

Becoming aware of such facts, Ulster ARC has made a commitment to go beyond providing services to those individuals with developmental disabilities by undertaking a concerted effort to reduce the number of those births through a comprehensive education program.

The Ulster ARC Board of Directors has proclaimed 1990 as the "Year of Prevention of Disabilities" and announces a new program, "Choice Not Chance," said Peter Pierri, the non-profit agency's Executive Director.

The announcement of "Choice Not Chance" is timed to coincide with MENTAL RETARDATION AWARENESS WEEK which ran from February 7 through February 14.

Responsibility for "Choice Not Chance" falls to Mary Carney, UARC's director of Family Support Services. Carney, a CSW, brings eight years of experience to the program as an expert in the field of mental retardation and developmental disabilities. "As the county's foremost provider of services to people with disabilities," Pierri

said, "we thought we should focus on the fact that up to 50% of all disabilities are preventable. The public is unaware of this and we believe we have an obligation to educate the community we serve."

Preventing disabilities makes sense from an emotional standpoint, but taxpayers cannot overlook the costs involved in caring for long-term disabilities. "And, you can't place a dollar value on the emotional stress and heartbreak that results in families with disabilities," Pierri said.

"Education from a positive standpoint is the approach we are taking," Carney said. "Choice Not Chance" focuses on healthy lifestyle choices that can prevent disabilities either at birth or into adulthood.

"We emphasize prenatal care and abstinence from alcohol and drugs, but it doesn't stop there," Carney said. Emphasis includes providing a safe and loving - nurturing - environment for youngsters that ensures healthy development free from disabilities. Of course for adults, some simple things like buckling up a seatbelt goes a long way toward preventing disabilities," Carney said. "We are also joining with our neighbors in advocating a drug-free Ulster county community."

The program features a slide presentation and seminars offered free of charge to area schools, youth centers and other agencies that serve people who are at highrisk of having children with disabilities or at risk of disabling themselves. This spring, "Choice Not Chance" will offer a free seminar focusing on ways to prevent disabilities.

"Ulster ARC wants our neighbors to have healthy babies. Give you baby a "birth day" present before birth; make choices about your lifestyle to help ensure your infant a healthy life - that's the message," says Carney.

For further information about this program, call Carney or Jo Gallante, Director of Community Relations at (914) 331-4300. ■

Price Chopper Named Saratoga County Chapter Employer of the Year

Every year, NYSARC, Inc. (New York State Association for Retarded Children) asks each county chapter to nominate an "Employer of the Year." This year, Saratoga ARC has chosen PRICE CHOPPER as its' recipient because of the corporation's outstanding example in providing job opportunities for the developmentally disabled people.

Since January 1989, Price Chopper's Super Center in Clifton Park has hired clients from Alpha Industries in Malta. Alpha Industries is the sheltered workshop and vocational training center under the auspices of Saratoga A.R.C. During October of '88, Alpha staff members, Audrey Barrantes, who is presently Director of Saratoga A.R.C.'s Center for Evaluation and Therapy and Bob Berger, former work job coach, met with Tina Graziani, Assistant Store Manager of Price Chopper. Ms. Graziani was interested in hiring five permanent employees from Alpha to work in the new store, as packers, bottle return persons, bakery assistants or cart return

The Alpha Supported Work Staff, along with Price Chopper's assistance, were able to fine tune the details of the client's work

schedules to include a 9 a.m. to 3 p.m. day, Monday through Friday. With this type of schedule, Alpha Industries is able to provide two (2) vans to transport the workers to and from PRICE CHOPPER from Alpha Industries.

Price Chopper was so pleased with the original five interviewees, who were initially screened by Alpha, that they not only hired them but five additional workers as well! Price Chopper has also allowed Alpha the opportunity to use Price Chopper placements as a training program for individuals identified as ready for competitive employment outside of the sheltered workshop environment. For many clients, this is their first working experience.

One of the more interesting aspects of the program is the "job coaching" or training the clients receive from the Alpha staff. Debbie Lapp, an Alpha Industries job coach feels that this is one of the most attractive features for employers, since the onus of training is on A.R.C. Other Alpha personnel responsible for the success of the Supported Work Program are Nancy Cannon, Director of Alpha Industries, Tricia Artlip, Placement Specialist and Lisa Spivey, Vocational Coordinator.

Report Finds Parents Rely More on Lawyers But Often Settle Special Ed Cases

A report recently issued by the General Accounting Office (GAO) found that parents are relying more on attorneys in special education disputes and are also settling these disputes more quickly. The report was based on a study Congress had directed the GAO to undertake to examine the effects of the 1986 Handicapped Children's Protection Act which allowed some parents to win legal fees.

Under the 1986 law, courts can order school districts to pay the legal fees incurred by parents who prevail in special education administrative proceedings and court cases. During the debate on the measure, concerns had been raised that the law would make special education increasingly litigious.

Sure enough, the GAO study revealed that parents are increasingly using attorneys: 54 percent hired lawyers for administrative hearings in 1988, compared to fewer than 41 percent in 1984. But, the study also found that while requests for administrative hearings had risen, a greater percentage of hearings are now settled before a hearing officer issues an opinion. However, William DeSarna, GAO study manager, warned that because these trends began before 1986 "it's hard to draw conclusions based on the law."

The GAO also maintains that data on legal fees awarded to parents is insufficient

to serve as the basis for any conclusions. The few states with information on legal expenses awarded - 12 in 1987 and 13 in 1988 - reported that the total amounts more than doubled from 1987 to 1988: from \$157,000 to \$387,000. Six states, however, reported that no attorney's fees were awarded in either year.

Other findings contained in the report were:

- In cases carried through to a hearing officer's decision, GAO found the success rate of parents has risen. In 1988, parents with attorneys prevailed in 67% of their cases, up from 49% in 1984.
- Parent's success rates in administrative cases varied with the type of disagreement. Parents won in about 55% of the cases involving procedural issues but only 32% in eligibility and identification issues.
- Placement issues are the most common subject of administrative hearings and court cases.

Copies of the GAO report, "Special Education: The Attorney Fees Provision of P.L. 99-372" are free from the General Accounting Office, P.O. Box 6015, Gaithersburg, MD 20877, (202) 275-6241. ■

Chautauqua Chapter Opens Diagnostic and Treatment Out-Patient Center

The process began nearly six years ago when a number of individuals trained or employed at the work center division of the chapter had been identified as being in need of one or more clinical services to enhance their vocational potential or rehabilitative progress and to increase their opportunities of obtaining prospective competitive employment in the community. The Resource Center, which is the only rehabilitation facility serving all individuals in Chautauqua County with any type of disabling condition, had operated for a number of years a Clinic Treatment Program certified by the Office of Mental Retardation and Developmental Disabilities. Under the auspices of this program, available services included nursing assessment and follow-up, psychological assessment and counseling, physical therapy, occupational therapy, speech therapy, audiological services and social services.

A number of limitations existed, however, with the eligibility and funding criteria of this program. Available clinical services could only be provided for the specific purpose of maintaining individuals in sheltered employment and only for people who were developmentally disabled and who met stringent diagnostic criteria. These stringent admission criteria excluded individuals who were participating in other

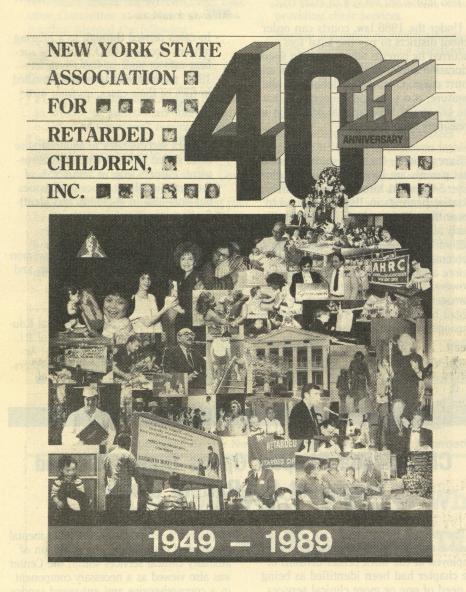
employment settings who had other mental or physical disabilities. The provision of auxiliary clinical services within the Center was also viewed as a necessary component in a comprehensive and enhanced service system that based on any type of individual need could make available diagnostic, evaluation, rehabilitation and clinical treatment interventions and modalities through an effective and comprehensive individual plan. Planning would be carried out with the participation and input of program participants and their families, production supervisors, therapists, counselors and other program personnel as appropriate, to provide a coordinated individual program plan conveniently and effectively accessed within the Resource Center's array of programs.

With certification of the Diagnostic and Treatment Center, all work center employees and other rehabilitation program participants can now readily access any of the needed services with a minimal amount of disruption and with the greatest level of impact on the achievement of their personal and program objectives. These out-patient services are also available to all persons in the community with any type of acquired disability, handicapping condition or age group.

40th Anniversary Commemorative Posters Available

In celebration of the 40th anniversary of the New York State Association for Retarded Children. Inc., an 18" x 24" commemorative poster has been printed and is available for purchase at a cost of \$4.00 each (includes postage and handling).

Those individuals wishing to purchase the poster may do so by completing the form below and mailing it with a check or money order to the NYSARC State Office.



1989 Commemorative Poster ORDER FORM

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NYSARC Sponsors Conferences

"Meeting the Needs of Persons Who are Elderly and Mentally Retarded"

The NYSARC Adult Services Committee is pleased to announce that June 6, 1990 will be the date of a one-day conference on "Meeting the Needs of Persons Who are Elderly and Mentally Retarded".

The conference which will be held at the Americana Hotel in Albany, will focus on issues such as integration, senior day care and day treatment models, medical and health services and long-term care. This forum will be targeted for program personnel, administrators and board members.

For more information, please contact NYSARC at (518) 439-8311. ■

"In Support of Families"

July 27 and 28, 1990

Albany Marriott Albany, New York

A statewide conference for families with members who are developmentally disabled, professionals and policy makers to explore and work together on designing a family support policy direction for New York State which will assist families in whatever manner needed to best provide for their family at home. The conference will be held on July 27-28, 1990 at the Albany Marriott.

Sponsored By:

New York State Association for Retarded Children, Inc.

Co-Sponsored By:

The New York State Commission on Quality of Care for the Mentally Disabled and

The New York State Developmental Disabilities Planning Council

For further information, call (518) 439-8311.

"NYSARC Recreational Staff Retreat"

Need new ideas? Is planning for leisure time becoming a stressful job? Want to meet people with new ideas?

Then this Retreat is for You!

NYSARC, Inc. will be holding its Second Annual Recreational Staff Retreat on Thursday and Friday May 10-11, 1990 at the Hidden Valley Resort and Conference Center located in Lake Luzerne, New York.

This conference will be open to all individuals who are or have an interest in providing quality, innovative and appropriate recreational activities for individuals with developmental disabilities.

For more information regarding the Retreat, please contact Susan A. Lyons, Director of Public Information and Special Projects, at the NYSARC State Office at (518) 439-8311.

"Light Up The Network For Prevention" NYSARC Prevention Conference to be Held

The New York State Association for Retarded Children, Inc. will be sponsoring a two day conference on the prevention of mental retardation/developmental disabilities on Monday and Tuesday, September 10-11, 1990 at the Sheraton Inn and Conference Center in Utica, New York.

Topics to be discussed include: Drug-Related Disabilities; Fetal Alcohol Syndrome; Snow Babies; National, State and Local Activities; AIDS Education; as well as many others.

Please address any questions regarding the conference to Susan A. Lyons, Director of Public Information and Special Projects, at the NYSARC State Office at (518) 439-8311.

Watch for additional information in the next few weeks. ■

Chapter Presidents and Executive Directors Hold Meeting

On Friday and Saturday, March 2-3, 1990, the Presidents and Executive Directors of NYSARC, Inc. chapters held a meeting in Albany, New York. One hundred and twenty-five chapter Presidents and Executive Directors were joined with the Association's Executive Committee and State Office Staff. A variety of issues were discussed and reviewed during the two-day meeting.

The meeting opened with the President of the Association, Mrs. Blanche Fierstein, making some brief remarks. The Executive Director of NYSARC, Marc N. Brandt, then introduced the Acting Commissioner of OMRDD, Ms. Elin Howe, who spoke to the gathering. Ms. Howe summarized the recommended Governor's State budget as it relates to OMRDD. Ms. Howe also stated her priorities and the direction that OMRDD would be taking during her administration. Numerous questions were asked and the forum provided ample opportunity for the chapters to get acquainted with the new Commissioner.

Ms. Howe's remarks were followed by an analysis and discussion of NYSARC's recommendations concerning the 1990 New York State budget. NYSARC's Associate Executive Director for Governmental Affairs, Ben Golden, led the discussion and answered numerous questions.

On Saturday morning, the group convened with a presentation concerning the needs of senior citizens who are developmentally disabled. The Chairperson of the Association's Adult Services Committee, Ms. Bonnie Bowes, led the discussion and introduced the two presenters. Ms. Lee Jamison of the Columbia Chapter and Dr.



Ms. Elin Howe, Acting Commissioner of OMRDD, addresses gathering. Looking on (from left to right) is State ARC Executive Director, Marc N. Brandt; Senior Vice President, John Schuppenhauer and President, Blanche Fierstein.



Dr. Aivah Canfield addressing group. Looking on (left to right) is Ms. Bonnie Bowes and Ms. Lee Jamison.

Alvah Canfield of the Sullivan Chapter gave excellent presentations on the programs and services their respective chapters are offering.

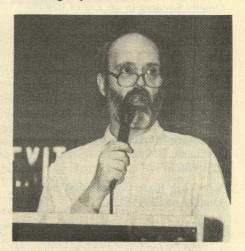
A discussion and review of the Association's strategic planning process then followed. The Chairperson of the Committee, Dr. David Keymer, presented both the process and results of a survey of chapters.

He reviewed with the group the time frames of the Committee.

Following lunch, Hector Dowd, Chairperson of the Association's Ad-Hoc Committee to Review and Study the Issues Pertaining to Persons who are Mentally Retarded and/or Developmentally Disabled at Risk or Within the Criminal Justice System, presented an issue concerning the



Chairperson of NYSARC's Strategic Planning Committee, Dr. David Keymer, seen answering a question.



Mr. Howard Siegel addresses the group concerning the NYSARC insurance program.

death penalty. A good bit of discussion followed concerning this issue.

The meeting ended with a presentation by Howard Siegel of the Irwin Siegel Agency regarding the NYSARC, Inc. insurance program.

New York State Association for Retarded Children, Inc.

SAFETY GROUP MANAGEMENT COMMITTEE

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

Steve Biro Maxine Galarneau

On December 27, 1989, while enroute to the Turin Workshop on a -34° day, the bus driven by Maxine erupted in flames. Maxine assisted the ambulatory and Steve evacuated the wheelchair-bound passengers. Their quick thinking and prior training in emergency evacuation permitted a rapid and composed response which saved the lives of all the passengers.

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UPCOMING CONFERENCES

1. National Industries for the Severely Handicapped (NISH) National Conference

Date:

March 25-28, 1990

Place:

Atlanta Marriott Marquis Atlanta, Georgia

For more information contact: NISH (703) 560-6800

2. Young Adult Institute

Theme:

"Strategies for Survival in the 1990's: How to Meet People's Needs and Ensure Quality Services in an Era of Regulations, Audits, Staff Shortages and Fiscal Constraints"

Date:

April 18-20, 1990

Place: Penta Hotel New York

For more information contact: Stephanie Bowman (212) 563-7474

3. New York State Commission on Quality of Care

Theme:

"1990 Annual Advocacy Conference"

Date:

May 15-16, 1990

Place:

Hilton Hotel Albany, New York

Co-Sponsored by:

New York State Developmental Disabilities Planning Council

For more information contact: Robin Worobey (518) 473-7378 4. American Association of Mental Retardation

Theme:

"A Better Way of Life: Policy Research and Practice"

Date:

May 27-31, 1990

Place:

Atlanta Hilton Atlanta, Georgia

For more information contact:

(800) 424-3688

5. New York State Association for Retarded Children, Inc.

Theme

NYSARC Conference on Family Support Services "In Support of Families"

Date:

July 27-28, 1990

Place:

Albany Marriott Albany, New York

Co-Sponsored by:

New York State Commission on Quality of Care for the Mentally Disabled New York State Developmental Disabilities Planning Council

For more information contact:

Helen R. Hines Assistant Executive Director for Policy Analysis and Training New York State Association for Retarded Children, Inc.

393 Delaware Avenue Delmar, New York 12054 (518) 439-8311



ASSOCIATION CALENDAR OF EVENTS

MARCH

2-3 NYSARC Presidents' and Executive Directors' Meeting Albany Marriott Albany, New York

9 NYSARC MIS Meeting Delmar, New York

30 NYSARC Developmental Center Committee Meeting Delmar, New York

APRIL

6 NYSARC Education Committee Meeting Delmar, New York

20-21 NYSARC Spring Board of Governors' Meeting Sheraton Airport Inn Albany, New York

20 NYSARC Adult Services Committee Meeting Sheraton Airport Inn Albany, New York

20 NYSARC Executive Committee Meeting 3:00 p.m. - 5:00 p.m. Sheraton Airport Inn Albany, New York

> NYSARC Scholarship and Awards Committee Meeting 3:00 p.m. - 5:00 p.m. Sheraton Airport Inn Albany, New York

25 NYSARC Safety Group Management Committee Meeting Delmar, New York

MAY

10-11 NYSARC Recreational
Staff Retreat
Hidden Valley Resort &
Conference Center
Lake Luzerne, New York

16 NYSARC Public
Information Committee
Meeting
Syracuse, New York

17 NYSARC Chapter Public Information Resource Group Meeting Syracuse, New York

JUNE

29 NYSARC Resolutions Committee Meeting Delmar, New York

SEPTEMBER

10-11 NYSARC Prevention Conference Sheraton Inn and Conference Center Utica, New York

OCTOBER

31- NYSARC Annual Convention

Nov. 4 Concord Resort Hotel Kiamesha Lake, New York

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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