

OUR Children's Voice

Retarded Children Can Be Helped

WORST STATE BUDGET SINCE GREAT DEPRESSION



Senator Thomas Libous, Chairman, Senate Select Committee on the Disabled seen discussing State budget with NYSARC's Executive Director, Marc N. Brandt.

Governor Sends Budget to Legislature

Capping off months of dreaded anticipation, Governor Cuomo realized the worst fears of many by proposing a State budget for the next fiscal years that resolves the largest projected deficit in State history mostly through spending cuts. Only a couple months ago the deficit, now \$6 billion, was projected at about \$3 billion. Many considered that to be catastrophic. But, a deepening recession and diminishing State tax receipts soon made the initial projection obsolete as the size of the projected deficit grew almost daily. And, sources indicate that the downward trend hasn't necessarily ended with the Governor's budget submission. The \$6 billion gap could grow even more and the Governor can continue to cut his budget for 30 days following its formal submission to the Legislature on February 1.

Commenting on his proposal, the Governor said "The stunning reductions proposed in this budget would cut deeper than any reductions so far proposed by the most ardent budget cutters... I propose them because I believe the devastating effects of the recession leave us no better alternative."

The unprecedented spending cuts include:

- \$965 million in State operations, including \$572 million in personal service costs from a massive work force reduction of approximately 18,000 workers including as many as 7,000 layoffs;
- \$891 million in State aid for public schools in the coming year;
- \$875 million in Medicaid through cost containment and other measures;
- \$530 million in local assistance for criminal justice, arts and other purposes; and
- \$468 million, or 50 percent of what local governments now receive, in revenue sharing.

While the size of the \$6 billion deficit is unprecedented, its composition attests to the unpredictability of the State's fiscal problems which seem to materialize out of thin air. After last fall's election the State announced that its budget was quickly plummeting into the red. Then, just two months ago, the Legislature met in a special session to enact \$1 billion in spending reductions to eliminate, it thought, the entire deficit. But, as soon as the Legislature completed its work, the deficit soared by another \$900 million. Now, the Governor proposes to borrow \$900 million to finally close the current year gap and pay the entire amount back next year. This expense, added to a pro-

jected \$5.1 billion revenue shortfall for the next fiscal year, yields the \$6 billion deficit which the Legislature has begun to grapple with.

However, the Governor did not choose to eliminate next year's deficit completely through spending cuts. While cutting \$4.5 billion, his proposal includes \$1.5 billion raised through a combination of new taxes, fees and deferring a planned decrease in personal income taxes. The largest new tax is a 10 cent a gallon rise in the State gasoline tax.

By recommending a combination of new revenues and spending cuts, the Governor was able to proclaim that his budget recommendation, while tough, is not harsh. He stated "The record cuts notwithstanding, I believe the approach I have chosen is the wisest and fairest way to preserve our strengths and our mission... This plan provides fiscal balance. It also will help strengthen the economy for the future, not only by keeping our tax code competitive, but by reinforcing the building blocks of growth.

Even after these cuts, my proposed budget will leave New York a national leader in providing opportunity to the able and protection to the defenseless."

Restructuring and Local Relief

The Governor also proposes to save money by "restructuring State" government. This would save \$175 million and include, among other initiatives:

- the gradual consolidation of the Division of Alcoholism and Alcohol Abuse and the Division of Substance Abuse Services;
- merging the Office of Advocate for the Disabled, the Advisory Committee for Black Affairs, the Office of Hispanic Affairs, the Division of Women and the Office of Volunteer Services into a new Office of Advocacy Services within the Division of Human Rights;
- merging the Department of Civil Services and the Office of Employee Relations into a single Department of Human Resource Management.

As part of his budget, the Governor also proposed a package of measures which would relieve local governments of some of the burden of State imposed mandates.

In announcing the package, the Governor stated, "As the demand for essential services outstrips State and local governments' ability to pay for them, it is critical that we ease the financial and regulatory burden of State-mandated programs on local

governments and school districts. This package of initiatives expands on the Omnibus Mandate Relief Bill I submitted during the special legislative session in December and produces substantial savings in such high-cost areas as Medicaid, public assistance and preschool special education."

Of special interest to NYSARC, the Governor's mandate relief package includes an elimination of Medicaid funding for adult dentistry, podiatry, audiology and clinical psychology services rendered by private practitioners. Many chapters rely heavily on Medicaid funding to pay for these services. This proposal was first introduced by the Governor during last December's special legislative session but, after intensive opposition by NYSARC, was rejected.

In education, as in Medicaid, the Governor resubmitted local mandate relief measures which were rejected by the Legislature in December. One measure for preschool requires that evaluations of children be conducted by independent evaluators. This would limit parent choice by eliminating the option of using providers to conduct such evaluations.

The Governor will soon submit legislation detailing other education mandate relief proposals. However, initial press release descriptions appear ominous. For preschool, the Governor proposes to "tighten control and eligibility standards for participation in special education programs for preschool." For school-age special education, the Governor proposes to:

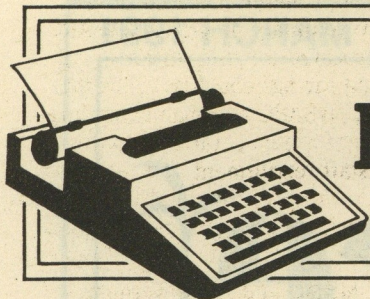
- Change the definition of related services to make these services a support for special education. This would lead to more mainstreaming of students with physical disabilities and speech impairments. It would also facilitate greater access to health insurance reimbursement.
- Change the appeals process to eliminate the appeal at the local level thereby relieving school districts of the cost of those hearings.
- Amend the education law to make psychological evaluations optional for school-age children.

Again, clarification of the true nature of these proposals must await the submission of detailed legislation soon to be submitted by the Governor.

OMRDD Cuts

In his State-of-the-State message, the Governor promised that his budget proposal

(continued on page 3)



EDITORIALS

Family Support Services: More Complicated Than It Looks

If our survival instincts are intact a crises forces us to look more deeply into things. This year's State budget crisis is a case in point

About seven years ago, a line in OMRDD's budget emerged called "Family Support Services." Since then, that line, initially around \$2 million, has grown exponentially. Next year, it would have been at least \$28 million had the Governor not elected to cut it by 50% as part of his FY 91-92 budget request.

The program's astounding growth attests to its intrinsic value: Families with a child with mental retardation need help if they are to offer the care that only a family can give. Otherwise the sometimes crushing responsibility of providing in-home care will force that family to seek out-of-home care, perhaps institutionalization: an alternative which is not only inferior but also enormously expensive.

So, funding for Family Support Services soared. It was as if government discovered that the light bulb had just been invented and could not buy them fast enough.

But, "Family Support Services" is not a new invention; rather it's simply a new appropriations line in the budget. An appropriations line has a few words describing what is being funded followed by the dollar amount being appropriated. As evidenced by its amazing growth, the decision to add a new line clearly labelled "Family Support Services" was a revolution in marketing. And, predictably, the Governor's decision to cut it by 50% set off justifiable outrage.

The trouble was that some people claimed, and others began to think, that the "Family Support Services" line was the only line that supported families. It was not. Other lines do the same thing; they have for years. But, there has hardly been a peep about; the devastation wrought to these lines by the Governor's budget request. And, it is no wonder. Who knows for example what "for Community Services... pursuant to subdivision (d) of Section 41.15 and Section 41.18 of the Mental Hygiene Law" means?

In fact, that line and others like it fund day services, much of it full time and much of it for adult children who live at home with their families. If the Governor's cuts against these lines stand, many of these adult children will be sent home to aged parents whose ability to now become full-time caregivers has long been lost. It will be a disaster.

But, the impending tragedy has been largely ignored not for lack of zeal, but for lack of understanding as to what else is in the budget. Some lines, not clearly labelled Family Support Services, support families. Protecting families — perhaps the most vulnerable families — is a complex

undertaking that must consider that many of the lines and cuts in the budget enmesh the needs of families in a complicated inter-related structure.

Some providers, who understand the budget, can afford to ignore this if their Family Support money comes from the one line clearly labelled "Family Support Services." Their programs won't lose if the other lines that also help families get cut. So, they can jump on the bandwagon. They can help harness the emotional energy released by the one cut that everyone clearly understands, forgetting about the other programs across the State that lack the good fortune of getting their Family Support money from a line with the right label on it. They know that labels are as important in the State budget as they are in advertising. So their choice is simple.

But, in this State budget, the choices are not simple if your aim is to consider the best interests of all persons with mental retardation and developmental disabilities in this State. Because with virtually no money to restore valuable services, the choices become hard, very hard.

We, of course, hope that the State is the beneficiary of some fiscal miracle. Our ideal choice would be that everything cut by the Governor, especially Family Support Services, is restored. But, in lieu of having to make that easy choice, which is to say having to make no choice, we hope that the hard choice, which it appears is the one that must be made, considers the needs of all families, not just those fortunate enough to have their family support services actually labelled "Family Support Services." ■

A Missed Opportunity

"Necessity is the mother of invention" goes the saying. And, for New York State, the necessity of dealing with the largest budget deficit in State history seemed to foretell a silver lining to an otherwise dark cloud. Much rhetoric came out of the Governor's office about how the State would seize the opportunity to do business differently. And, before the Governor released his budget, there was considerable discussion from OMRDD and within the Division of the Budget about how the time had come to terminate the development of State-operated community-based programs and move toward a community system totally operated by voluntary agencies.

Certainly, the pall cast by the State deficit made the logic behind such a move more compelling than ever. State-operated programs cost 25% to 35% more than voluntary-operated programs. Further, the high wages paid by State-operated programs only drive up the cost of doing business for neighboring voluntary programs which are forced to compete for employees from the same labor pool. Nor was the high expense of the State work

force ignored outside of the mental retardation field. Quite the contrary, the New York State Business Council in a major policy statement entitled, "The Zero Option," called for a total wage freeze for the entire State work force for the next two years. The Council maintained that now is the worst time to have the second highest paid state work force in the nation and expect a business as usual approach to renegotiating State union contracts; a process that has produced a 100% increase in wages since 1980 plus exceptionally lucrative fringe benefit packages.

And, when the budget came out, the Governor seemed to seize the opportunity. He requested nothing for State salary increases and asked that the State work force be downsized by 10%, a reduction of 18,000 workers. But, despite the overall trend, State-operated mental retardation programs seemed to float effortlessly upstream. The development of new State-operated residences didn't decline, rather it doubled, from about 22% to better than 40% of all new residential programs. The reason: the Governor's policy of accelerated deinstitutionalization would result in more State layoffs without new alternative work opportunities.

Voluntary providers were flabbergasted. Many had already become mere farm clubs for new State programs, training workers only to have them leave at the first opportunity for a higher paying job opening in the new State residence down the block. More State programs will only make this worse. And, gone was the opportunity to use savings that would have materialized from less costly voluntary programs for additional needed services.

A State official said that the problem was "contracting out," referring to a provision in the union contract that forbids using non-State services which result in the layoff of State employees. This provision

becomes important if, for example, institutional employees are laid off as a result of institutional closure. In such instance, a "contracting out" violation could be claimed if voluntary-operated residences are built when the construction of State-operated residences would have prevented layoffs by providing alternative work opportunities. Obviously, with plans to close the entire institutional system, recently proclaimed by the Governor, "contracting out" becomes a major consideration with thousands of State jobs on the line.

But, for now, the FY 91-92 budget request and the contracting out provision seem to have nothing to do with each other. The FY 91-92 budget request, which recommends expanded State development, is legally effective on April 1, while the union contract, containing the ominous "contracting out" provision, expires the day before — on March 31. And, next year's budget request is still only a request, subject to substantial modifications prior to its final passage by the Legislature. Undoubtedly, the level of State development, contracting out and a million other odds and ends are still on the table, the subject of negotiation for the next three-year union contract.

But, State development is an emotional subject for the practical operational difficulties it poses to voluntary operators and because of the expense it entails in these austere times when programs such as Family Support Services are being slashed by 50%. And, there is also the union's side of the story. Job security for workers who have dedicated their lives to caring for persons with developmental disabilities can't be lightly dismissed. Yet, stories abound wherein new State-operated programs, ostensibly built to prevent institutional layoffs, open only to hire staff from neighboring voluntary programs or from off the street.

(continued on page 3)

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

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

EDITOR:

Marc N. Brandt
Executive Director

STAFF COORDINATOR:

Susan A. Lyons
Director of Public Information
and Special Projects

ADVERTISING MANAGER:

John J. Sherman
Associate Executive Director
for Fiscal Management

PRESIDENT:

Blanche Fierstein

SENIOR VICE PRESIDENT:

John Schuppenhauer, Esq., Western

VICE PRESIDENTS:

Mary L. Caniano, Northeast
Dr. Irving Caminsky, Southeast
David Keymer, Ph.D., Central

TREASURER:

George G. Hirsch

ASSISTANT TREASURER:

Carroll F. Stowell

SECRETARY:

Dallas Boyle

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

Please address all inquiries to:

New York State Association for Retarded Children, Inc.

393 Delaware Avenue
Delmar, New York 12054
(518) 439-8311
FAX: (518) 439-1893

Advertisement Notice

"Our Children's Voice" is now accepting paid advertisements. Although we are appreciative of the companies who support this publication through the purchasing of an advertisement, this does not necessarily mean endorsement by NYSARC, Inc. ■

Letters To The Editor

Dear Editor:

I am writing in response to the Welfare League Chapter's Testimony regarding closure of developmental centers which appeared in the December, 1990 issue of *Our Children's Voice*.

My name is Myra A. Sincoff and I am President of a parent advocacy organization called Rights Equality Always at Letchworth (REAL). I am also a member of the Developmental Center Committee of the New York State Association for Retarded Children. I am writing this in response to Mrs. Kapsack's testimony because I believe that all persons who are mentally retarded or developmentally disabled have a right to live in the least restrictive environment with dignity and respect. I do not believe that institutional living can provide individuals with these essential qualities of life. Isn't this what NYSARC is all about?

Many years ago, parents placed their children in developmental centers because there was no other viable alternatives. It was a decision that was heart wrenching. I realize that it is frightening for parents whose children have lived in a sheltered environment like Letchworth Village Developmental Center (LVDC) for most of their lives to think of placing their family members in a new home. Many feel that this type of care and protection offered by the developmental center will not be afforded to them in the same way if their children were placed in community settings. Some parents have told me that no place will want their adult child and that he or she will be returned to their parent's home or that the facility they select will not be as secure and in close proximity so as to allow for visitations. There is a strong belief that people living in the community have fewer disabling conditions or to a lesser degree than persons residing in developmental centers. It is with great care that parent groups within developmental centers have to explain to these parents that there are people living in the community who have not only the same degree of disability but perhaps are even more severely disabled than those who live in institutions. We just have to ensure that the care and protection will be continued for them when they move to the community.

There is a tremendous difference in living in a house as opposed to an institution. Think about people sharing a bedroom with one or two other individuals, eating in a real dining room, using a bathroom with a door which ensures individual privacy. We take these everyday situations for granted but persons living in a developmental center have not experienced them. A smaller setting with more individualized care and attention creates a nurturing environment for them. Many times parents make the mistake of assuming that their child does not know the difference

but that is not true. We all respond to loving and caring surroundings. We should ask parents to think about the sense of dignity and well being that community environments would provide to our adult children.

The community requires more medical and dental services. It is our responsibility as parents and the parent organizations at developmental centers to strongly advocate for these services to be in place before our adult children leave. It is up to us as advocates to make sure that any person who leaves an institution, no matter how disabled, will grow and flourish in the community. In these austere fiscal times, it is even more important than ever that we vigilantly advocate individually as well as organizationally for these services. It is our challenge for the 90's.

To say that deinstitutionalization is not in the best interest for all persons living in developmental centers is no longer a valid fact. We see study after study demonstrating that the quality of life for persons with mental retardation is significantly improved after moving into the community. How many parents do you know who have placed their adult child in a community setting and then want that person to return to an institution?

To encourage using the LVDC campus as a base for community services is outrageous. It does not allow persons with mental retardation or developmental disabilities to live in the least restrictive environment. The forums held at Letchworth had people presenting papers that were for and against closure. At Senator Spano's hearing, the papers were overwhelming in support of closure of developmental centers throughout the state. It was stated throughout many testimonies that closure was the right thing to do.

Persons with mental retardation get bored just like we do. They respond to kindness and a loving environment just like we do. A self-fulfilling prophecy can work both ways. If you provide all individuals with an environment that will nurture, stimulate, and respect their individual differences, then persons with disabilities will be challenged to fulfill their potential and subsequently live more meaningful and productive lives. ■

Sincerely,

Myra A. Sincoff

(Opportunity, continued from page 2)

Asking for a perfectly equitable solution from State government is probably asking for too much, not simply because State government is sometimes unfair, but because of the legal, operational and moral logistics that must be carefully balanced against each other by scores of different bureaucrats with as many different agendas.

Yet, through all of this fog, it appears clear that the Governor missed an opportunity to substantially improve matters. And, it appears doubly distressing that at least where OMRDD is concerned, the Governor took the opportunity to make matters worse. ■

(State Budget, continued from page 1)

would have "no sacrificial lambs and no sacred cows." And sure enough, there were stiff cuts against OMRDD. For voluntary providers, they include:

- a 0% trend factor for community residences;
- a reduction in the Family Support Services appropriation from \$28 million to \$14 million;
- a reduction from \$1,000 per individual to \$500 for the SEP exemption;
- a \$2.5 million cut to eliminate funding for local government administration;
- elimination of Unified Services Funding to be replaced by folding Unified Services Counties into the Local Services (50/50) program; and
- an increase in the annual Medicaid assessment instituted in December, 1990 from .6% to 1.0%

State-operated programs were also hit. OMRDD is expected to lose 2,100 employees over the course of FY 91-92.

However, remarkably, there was also some good news. Residential development for FY 91-92 and FY 92-93 includes new placements for 3,600 individuals. That will increase the pace of development by nearly 20%, largely in order to accommodate the increased pace of deinstitutionalization that will be required to fulfill the Governor's stated goal - and NYSARC's - of closing all institutions. Included in the development numbers are an unspecified number of new residential placements for persons living at home.

State Development

But, the good news of unexpectedly high development levels was dampened by the high level of residential development which the budget allocates to State-operated programs. Prior to the release of the budget, indications were that the State would initiate a significant shift away from

State-operated, community-based programs toward more voluntary programs. NYSARC strongly advocated for this shift arguing that resulting savings could be reinvested into services. NYSARC also maintained that proliferation of State-operated programs aggravates staff recruitment and retention problems experienced by neighboring voluntary providers whose employees leave to take higher paying State jobs.

Indeed, OMRDD and the Governor's office told NYSARC that a shift to voluntary development was being aggressively pushed as part of the budget, but before it could be finalized, a "political" decision had to be made. That political decision concerned the reaction of State unions. With plans to close more developmental centers (J.N. Adam by the end of 1992, Wilton and Long Island by the end of 1993) State employee layoffs would increase unless more State-operated community programs were developed to offer continued employment to ex-developmental center staff.

The "political decision" finally reached was to include no wage increase for State workers in the budget but, at the same time, attempt to minimize layoffs - 7,000 now proposed - by expanding development of State-operated programs.

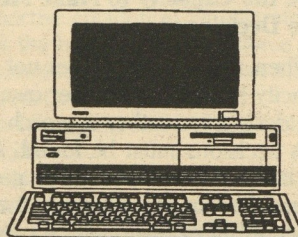
"We're deeply distressed by the decision" said Marc Brandt, NYSARC's Executive Director. "This fiscal crisis was an opportunity for the State to really restructure the way it does business."

But, whether or not it makes sense is beside the point to the unions representing State employees who screamed obscenities at the Governor in front of the Executive Mansion in the grand finale to a giant rally over their budget concerns in Albany.

And, this is only the start of what many have called the worst State budget session since the great depression. ■

Digital / NYSARC Partnership

Special PC pricing available to all NYSARC Chapters. This system and many popular MS/DOS applications are supported by Digital's state-wide support organization.



\$ 2,650*

* Other configurations available at equivalent savings.

Price Includes:

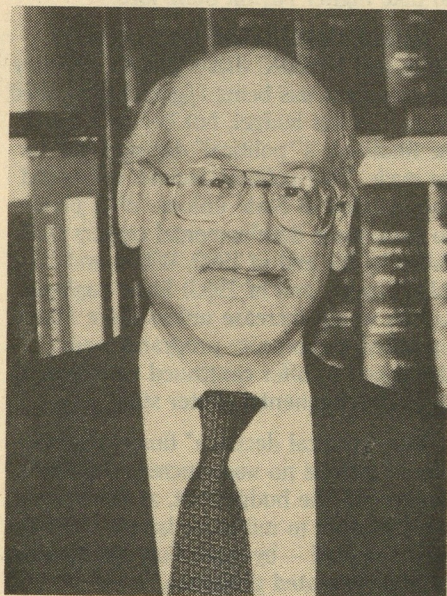
- 80386 sx CPU, 16 MHZ
- 2 Mbyte Memory
- 40 Mbyte Hard Disk
- Color VGA Monitor
- 5 1/4" Disk
- 3 1/2" Disk
- Additional Serial Port
- MS/DOS 3.3
- One-year on-site maintenance

Contact: Digital Equipment Corporation
Corporate Plaza East
Washington Avenue Extension
Albany, NY 12203
(518) 452-7216
Tech Specialist: Jim Alheim

digital

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.)



New York State's Do Not Resuscitate Statute: An Overview

Lawrence R. Faulkner
Deputy General Counsel
New York State Office
of Mental Retardation
and Developmental Disabilities

In order to understand New York's recently enacted Do Not Resuscitate and Health Care Proxy statutes and how they operate, it is necessary to review what the law in New York was concerning medical-care decisions before these two statutes came into effect. They do not resolve all the problems in the area of medical-care decisionmaking for persons unable to make their own care decisions but do fill some very significant gaps that existed prior to their enactment. The Health Care Proxy legislation will be reviewed in the next issue of "Our Children's Voice."

Everyone Has the Right to Make Their Own Health Care Decisions.

The law in New York in the area of medical-care decision making is based on the presumption that all patients have the right to make their own medical-care decisions so long as they have the capacity to make such decisions. The decision itself is not determinative of capacity, we all have the right to make idiosyncratic decisions or decisions others might consider inappropriate. The issue to be determined is whether we have the ability to make a medical-care decision. If we have that capacity, then we have the right to make medical-care decisions for ourselves.

What Constitutes Capacity?

Defining what constitutes capacity to make medical-care decisions is not easy. OMRDD has attempted to define such capacity as: "the ability to adequately understand and appreciate the nature and consequences of such professional medical treatment, including the benefits and significant risks and alternatives to such treatment so as to be capable of making a decision thereto in a knowing and voluntary manner." OMRDD also warns against using the decision itself to judge

the person's decision-making ability: "A person's decision relative to the proposed professional medical treatment shall not, in and of itself, be the exclusive basis for the determination of capacity." These statements can be found in OMRDD's regulations at 14 NYCRR 633.99 (yyy).

The Law Protects Our Right to Make Health-Care Decisions.

The idea that individuals with capacity have the right to make their own medical-care decisions can be found in Department of Health Memoranda (for example see D.O.H. Memoranda 89-84 concerning a patient's right to refuse nutrition and hydration), regulations issued by several New York State agencies, decisions issued by the courts, and New York statutes. Department of Health regulations provide that a patient has the right to refuse medication and treatment (14 NYCRR 414.14). OMRDD regulations provide that, if an individual is over the age of 18 and has the capacity to understand appropriate disclosures regarding a proposed medical treatment, such treatment can only be initiated upon receiving such person's informed consent (14 NYCRR 633.11 (a)(1)(iii)(c)).

The courts in New York have consistently restated this position in cases dating back to at least 1914. In that year the New York Court of Appeals, New York's highest court, held, in a case called *Schloendorff v. Society of New York Hospital* 211 N.Y. 125, that: "Every human being of adult years and sound mind has a right to determine what should be done with his own body..." More recently *In the Matter of O'Connor* 72 N.Y.2d 517 the Court of Appeals ruled that: "It has long been the common law in this state that a person has the right to decline medical treatment, even if life saving, absent an overriding state interest."

What Happens if Someone Does Not Have the Capacity to Make Medical-Care Decisions?

When an individual does not have the capacity to make his or her own medical-care decisions, another approach for making such decisions must be found. Actually the law has developed three general approaches toward resolving the dilemma of delivering needed medical care to those persons incapable of consenting to such care. These three general approaches can be classified as *parens patriae*, legislative design, and previous decisions by the incapacitated person when he/she had capacity. The concept of *parens patriae* reflects the obligation of the state to act in a person's best interest when such individual cannot make decisions for him or herself. It has historically been used by the courts to fashion relief for situations, including those involving medical care, where an individual does not have the ability to care for him or herself and no specific statute exists to govern decisions about such care. It is also the doctrine underlying or justifying those legislatively designed and sanctioned programs providing both voluntary and involuntary care to incapacitated persons.

New York State has developed several legislative approaches to provide medical care to individuals who lack the capacity to make medical-care decisions. Examples of such legislative approaches include provisions of the Public Health Law which permit a parent to give effective medical consent for a child (Public Health Law Section 2504), the surrogate decision-making committees found in Article 80 of the Mental Hygiene Law, Public Health Law provisions allowing for treatment without consent in times where such treatment is considered a medical emergency (Public Health Law Section 2504), Article 17-A of the Surrogate's Court Procedure Act under which a court can authorize a guardian to consent to medical treatment for a incapacitated person who is mentally retarded or developmentally disabled, and the two pieces of legislation discussed more fully later in this article and in the next issue of "Our Children's Voice," the Do Not Resuscitate and Health Care Proxy statutes. In addition, OMRDD has developed regulations which govern who can consent for medical care. These regulations, 14 NYCRR 633.11, provide that a lawfully empowered guardian, an actively involved spouse, parent of adult child, a surrogate decision-making committee, or a court can give effective consent for medical treatment when an individual does not have the capacity to give such consent. However, these regulations do not govern the actions of a doctor or hospital, both of which are governed by regulations of the Department of Health and not those of OMRDD.

Finally, the previously expressed opinions and decisions of an individual can be used to control medical-care decisions after that person loses the ability to make such decisions. In 1988 the Court of Appeals expressed this position in the *O'Connor* decision, restating the position it had taken in 1981 in *Matter of Storar* and *Matter of Eichner* 52 NY2d 363. In *O'Connor* the Court held that a "...hospital or medical facility must respect this right [a person's right to decline medical treatment] even when a patient becomes incompetent, if, while competent, the patient stated that he or she did not want certain procedures to be employed under specified circumstances."

Decisions Concerning Life Sustaining Treatment.

The Court of Appeals in both the 1981 *Storar* case and the 1988 *O'Connor* case held that without clear and convincing proof that a person would decline life prolonging treatment, in the form of statements or written documents executed while the individual had the capacity to make medical care decisions, it would presume that the individual wanted all forms of such treatment. The Court in *O'Connor* said: "Every person has a right to life, and no one should be denied essential medical care unless the evidence clearly and convincingly shows that the patient intended to decline the treatment under some particular circumstances...This is a demanding standard, the most rigorous burden of proof in civil cases. It is appropriate here because if an error occurs it should be made on the side of life."

The court has, in effect, limited the application of the *parens patriae* standard in cases involving the withdrawing or withholding of life-sustaining or death-delaying treatment. Its holdings stand for the proposition that, absent clear and convincing proof that a person, while having the capacity, gave specific instructions

in this area of medical care, and absent specific legislative directives, the doctrine of *parens patriae* will always act to require aggressive treatment. Thus, prior to the passage of the Do Not Resuscitate and Health Care Proxy statutes there was no mechanism in New York State for a surrogate to make the decision to withhold or withdraw critical medical treatment for a person without the capacity to make his or her own medical-care decisions, unless that person once had such capacity and at that time was very specific in his or her instructions.

The Do Not Resuscitate Statute.

The Do Not Resuscitate statute provides a mechanism whereby a surrogate decision maker can direct medical-care givers not to provide cardio-pulmonary resuscitation to an individual under specified circumstances. The statute is applicable to individuals residing in a hospital, psychiatric center, nursing home, developmental center and elsewhere, according to Health Department memoranda, if under the care of a hospice program. Such settings will be referred to as authorized facilities throughout this article. The statute is not applicable to persons at home or in community facilities who are not under hospice care.

DNR: Determining Capacity.

The authorized facility, if considering a DNR order for an individual, must first determine if the individual has the capacity to discuss and decide for him/herself whether or not a DNR order is appropriate. If the individual has capacity, he or she has the sole authority to consent to or refuse such an order. If an individual is determined to have such capacity and consents to the issuance of a DNR order and that person was transferred to the authorized facility from a mental hygiene operated or certified residence, then the director of that residence must be notified. The director can question that capacity decision by having the dispute mediation system (DMS) review the decision.

If the treating physician feels that an individual lacks capacity to decide about a DNR order because of a medical condition, a second opinion must be secured from an authorized physician. However, if the treating physician feels that the individual lacks capacity to decide about a DNR order because of a developmental disability, a second opinion must be secured either from a physician or psychologist employed by a developmental center or from one who has been employed for a minimum of two years in a facility operated or licensed by OMRDD or from one approved by the Commissioner of the OMRDD. If, after such consultation, it is decided that the individual lacks the capacity to make a decision concerning a DNR order and such person was transferred to the authorized facility from a residence licensed or operated by OMRDD, then the director of that residence must be notified of the decision concerning lack of capacity and that director may take the issue to dispute mediation. Notice of a decision indicating lack of capacity must also be given to the patient and the person highest on the patient's surrogate list. It must be remembered that the consultation discussed in this section is only on the issue of capacity and not on the appropriateness of the proposed DNR order.

(continued on page 5)

DNR: Persons with Capacity.

A person with capacity may consent to a DNR order under any circumstances designated by that person and that consent shall be valid if such person later loses capacity. Also, an individual with capacity may designate a surrogate to consent to or to refuse a DNR order if such person later loses capacity.

DNR: Necessary Medical Conditions for Persons Without Capacity.

If an individual is determined to lack capacity and has not formally consented to a DNR order, a DNR order may be considered only if the person is determined to have one of the following four medical conditions: the patient has a terminal condition likely to result in death within one year; the patient is permanently unconscious; resuscitation would be medically futile, (would be unsuccessful or the patient would suffer from repeated arrests and finally a failure to be resuscitated); or resuscitation would impose an extraordinary burden on the patient in light of the patient's medical condition and the expected outcome of the resuscitation of the patient. The last condition does not relate to the level of mental disability of the patient but rather to the medical condition giving rise to the consideration of a DNR order.

DNR: Surrogate Decision Making.

If a DNR order is being considered and the individual is determined to lack capacity and one of the above four medical conditions exists, then a surrogate from the following list, selected in the order of that list, must consent to the issuance of the DNR order: the person designated by the

individual when the person had capacity, the person's Committee or 17-A Guardian, the person's spouse, the person's adult son or daughter (over 18), the person's parent, the person's adult brother or sister, or a close friend of the person. A close friend is defined as someone 18 years of age or older who: "presents an affidavit to the attending physician stating that he is a close friend of the patient and that he has maintained such regular contact with the patient as to be familiar with the patient's activities, health, and religious or moral beliefs and stating the facts and circumstances that demonstrate such familiarity."

DNR: Where no Surrogate is Available.

A DNR order may be issued for a person who lacks capacity to decide about a DNR order and for whom no surrogate from the above list is available if two physicians concur that resuscitation would be medically futile. Under such circumstance, the order can be written without patient or surrogate consent.

DNR: Notice.

Notice of the issuance of a DNR order must be given to the patient in almost all cases and to the director of an OMRDD operated or licensed residence if the patient was transferred to the authorized facility from such a residence. The director of the facility may object to the issuance of the DNR order through the dispute mediation system.

DNR: Minors.

The statute provides that the consent of a parent and the minor, where the minor has capacity, must be secured before a DNR order can be issued for a minor. In addition,

one of the four medical conditions must be documented by two physicians and an effort must be made to reach another parent where the physician has notice of the existence of such parent.

DNR: Revocation, Review and Transfer.

The DNR order is revocable at any time by the party authorizing it or by the patient. It must also be reviewed by a physician every three days for a patient in a hospital or a developmental center. The DNR order may also "travel" with a patient between authorized facilities, for example between a hospital and a developmental center. In such cases, the ambulance transporting the patient should honor the order and the receiving facility may affirm the order during the first 24 hours after the arrival of the patient without going through the entire process.

DNR: Dispute Mediation System.

The Dispute Mediation System has been mentioned on several occasions throughout this discussion. Every facility authorized to issue DNR orders must establish a committee(s) to review objections to decisions concerning capacity or the issuance of a DNR order. If such an objection is filed with DMS, it will serve to delay the application of a DNR order for up to 72 hours. After the 72 hours have elapsed, the covered facility is free to proceed with the imposition of the DNR order and the objecting party must apply to a court for relief.

DNR: Important Issues.

There are several important requirements and themes throughout the law and the interpretations given to it which should be stressed. First, notice of decisions

concerning capacity and the consent to a DNR order by a surrogate, or its issuance without such consent where no surrogate is available and resuscitation would be medically futile, is basic to the protection of the disabled individual. Such notice allows the parent, patient or residential facility director to seek review in the DMS if such review is deemed necessary. Without such notice, the disabled individual loses the protection provided for in the statute. It is essential that all residential facility directors be prepared to respond immediately to such notices. The authorized facility is not required to await a response from a residential facility director before implementing the DNR order. In addition, OMRDD does not have the authority to consent to a DNR order. OMRDD can be called upon to review capacity and may object to a DNR order through the DMS but has no authority to consent to such an order. Finally, the DNR order does not apply to persons in the community unless they are under hospice care.

This information is provided as an overview of the Do Not Resuscitate statute. It must be remembered that every individual's case is distinct and that assistance, including legal counsel, should be secured for the resolution of individual situations. ■

A Message to Supervisors

Why are Safety Meetings so Important?

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

They encourage safety awareness.

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

They get employees actively involved.

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

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

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

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

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

Types of Meetings

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

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

While safety meetings obviously require some planning and forethought, there is a danger in adhering to a set "formula." Employees quickly become blasé about attending meetings that are carbon copies of each other. This is why you, their supervisor, must go one step further and see to it that: (1) their interest is aroused and held; (2) they are not overloaded with information and ideas; (3) they are com-

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

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

Sponsored by



NYSARC Submits FY 91-92 Budget Recommendations

The following is NYSARC's analysis of the Governor's budget proposal and recommendations for dealing with it.

The Blow to Families

The Governor has proclaimed that families are New York State's most precious resource. Certainly, no other statement more accurately describes those families that care for their children with disabilities at home. Yet, the Governor's budget proposal would do the following:

ISSUE #1

The budget eliminates key services to help 10,000 families caring for family members who are developmentally disabled at home.

With the closure of institutions and huge waiting lists for out-of-home placement, the burden of care has increasingly fallen to families.

Families can offer the most cost effective and quality care available but they need help to do it. Family Support Services gives them that help. But, the Governor proposes to slash these services by 50%.

Respite is one of the "hard" Family Support Services that relieves families of some of the enormous burden they assume by caring for their own children, often adult children. These services are devastated by the Governor's proposal.

Recommendation:

Add \$6,000,000 to restore funding for "hard" Family Support Services such as respite.

Language should be added to require that Family Support money only be spent on "hard services" which go the furthest toward helping families maintain a family member at home. Even with this restoration, Family Support will be cut by 28%.

ISSUE #2

The budget will eject up to 4,000 persons with disabilities out of full-time day services such as day training and sheltered workshops and back to families and other residences that lack the resources to cope with them.

Some say that this is acceptable. After all, during a recession, normal people lose work.

But, persons with disabilities have special needs. They can't pound the pavement looking for a new job. Many will simply regress. Some will lapse into self-destructive behaviors. Many will return to families that will collapse under the unbearable strain of providing full-time care to a family member with disabilities. Others will go back to community residences which aren't, in the best of times, staffed to care for them during the day, a task made more difficult since the budget recommends that residences receive no cost of living increase.

And finally, while the Governor's budget will eliminate services to 4,000 persons, it states that 500 more individuals must be placed into these very same programs. This does not make sense.

Recommendations:

Add \$5,600,000 to restore State aid cuts in local assistance based on a reduction in exempt income from the Sheltered Employment Program (SEP).

The Governor recommends a \$5.6 million reduction in State aid as a result of reducing the amount of SEP exempt income from \$1,000 to \$500 per individual. This cut will dramatically reduce total State aid available to Local Assistance programs, especially those programs serving persons with severe disabilities.

Add \$2,300,000 to restore funding for Unified Services Counties.

The Governor's proposal eliminates the Unified Services funding formula and as a result, enacts devastating and disproportionate cuts from five affected counties: Warren, Washington, Rensselaer, Rockland and Westchester. Restoration to this program will help reduce the elimination of vital day services.

Add \$3,500,000 to give community residences a 3% cost of living increase.

The Governor's recommendation that community residences receive no cost of living increase will seriously undermine their ability to function in the face of inflation running 6%. Community residences are the major low cost residential services option. They now operate from an expenditure base already weakened by inadequate past inflationary increases. The absence of an inflationary increase will be a serious threat to the viability of a program which saves State dollars. That doesn't make sense, especially now.

Add \$1,800,000 to restore funding for Local Government Administrative Expenses to those counties that contribute a local share to mental retardation services.

The Governor recommends elimination of funding to counties for administrative expenses they incur in planning and disbursing funds for services. Yet, some counties contribute nothing to local services. Others do. The latter group should continue to receive State aid for administrative expenses otherwise they will likely curtail their financial aid to local programs. In New York City, this loss could total as much as \$9,000,000.

The Danger to Persons in Developmental Centers

The Governor's call for accelerated deinstitutionalization coupled with grave fiscal constraints pose a serious potential danger to individuals who are institutionalized.

ISSUE #1

The budget contains no assurance that adequate institutional staffing levels will be maintained.

With a massive deficit confronting the State, institutional staffing levels are an easy target for cutbacks. Yet, staffing, which has always been precarious, is the foundation to decent care.

Recommendation:

Restore budget language requiring non-Willowbrook class developmental centers to maintain minimal staffing levels.

This language has been added by the Legislature to past budgets to protect

developmental center staffing levels during periods of fiscal crisis. This year, for the first time, it was vetoed by the Governor. Under the circumstances, this is the worst time for the Governor to take such action. The Legislature should restore this language to the FY 91-92 budget.

ISSUE #2

Accelerated deinstitutionalization creates a severe disruption to services and the quality of institutional care.

This was evidenced by the closing of Rome Developmental Center. There, the State's haste to close the facility and make way for a prison severely undermined care, especially to highly vulnerable individuals with special medical and behavioral needs.

Recommendation:

Add language stipulating guidelines for humane closure and deinstitutionalization of developmental centers.

In the face of a massive initiative to close down the State's entire system of developmental centers, the problems which surfaced at Rome Developmental center threaten to reoccur many times over. Language is recommended to help ensure that the mistakes at Rome do not reoccur. The language, taken from NYSARC's "Developmental Center Closure Policy Statement," was developed by parents who have or have had children at developmental centers.

The Failure to Provide Efficient Services

Much has been made of the Governor's goal of saving money by restructuring the way New York State does business. But, the Governor's budget fails to seize the opportunity to do this within OMRDD.

ISSUE #1

First, the budget increases unnecessary reliance on expensive State-operated community programs to close institutions. This strategy will result in tens of millions of dollars of additional, unnecessary State expenditure over the coming years. Ostensibly development of State-operated community programs is done to avoid the layoff of State workers employed in institutions that are about to close. This is a worthy goal. Dedicated public servants have spent their lives serving persons with mental retardation.

But, experience has shown that State-operated community programs, as often as not, hire persons off the street or from neighboring voluntary agencies, rather than employing ex-institutional staff.

Recommendation:

Eliminate State development of those community-based programs which will not contribute to the reduction of State employee layoffs.

This action too will save State funding by relying on lower cost voluntary-operated programs. Precise development levels must be worked out by the Legislature, OMRDD and DOB.

ISSUE #2

Second, the budget starts the process of streamlining OMRDD's system of Developmental Disability Service Offices (DDSO).

But, it doesn't go far enough. Twenty DDSO's were created largely to administer the State's twenty institutions. But, despite the closure of four institutions, the imminent closure of five more, and long-term plans to close the entire institutional system, all original DDSO's remain intact. Not surprisingly, providers note chronic duplication, extensive reporting and paperwork requirements that emanate from an administrative structure that seemingly has little else to do.

Recommendation:

Require the Commissioner to submit a report to the Legislature proposing a plan for consolidating and streamlining the DDSO structure in view of its diminishing responsibilities within OMRDD's changing service system.

Cuts to Medicaid Services

The budget proposes a series of cuts to the Medicaid program that would seriously undermine the ability to care for persons with developmental disabilities.

ISSUE #1

The budget cuts Medicaid funding for audiology, adult dentistry, podiatry and clinical psychology services rendered by private practitioners. This will only force providers to get these services from much more expensive clinics to meet state certification standards.

Recommendation:

Restore Medicaid funding for adult dentistry, audiology, podiatry and clinical psychology.

ISSUE #2

After a bitter struggle, a .6% assessment was enacted by the Legislature in return for a 6.24% trend factor for Medicaid programs. Now, the Governor proposes to increase that assessment thereby decreasing the inflationary increase available to Medicaid providers.

Recommendation:

Maintain the .6% assessment to Medicaid Providers originally enacted by the Legislature.

Includes Fake Savings That Will Devastate Services

ISSUE #1:

In addition to many other reductions, the budget cuts \$7,000,000 by assuming that savings can be generated by pooling all voluntary agencies into a giant, cost effective, liability insurance pool. NYSARC and UCP, representing 50% of all voluntary providers, have already entered into such a pool. It is ridiculous to assume that they can once again effect massive savings on top of the substantial savings already realized.

Further, insurance experts maintain that saving \$7,000,000 in annual liability insurance premiums requires approximately \$280 million in total annual premium payments. It is estimated that the entire mental retardation field now spends less than \$30 million annually on such premiums.

Recommendation:

Savings from economically pooling insurance should be taken advantage of to the extent that they can be realized. The Legislature should modify the Governor's proposed \$7,000,000 offset in view of realistic considerations. ■

OMRDD Commissioner Meets with NYSARC to Preview Budget

In December, 1990, the New York State Office of Mental Retardation Commissioner, Elin Howe and Executive Deputy Commissioner, Thomas Maul, meet with NYSARC chapters for purposes of briefing the Association on the proposed New York State budget. Over one hundred individuals attended the session in Albany, New York.

Commissioner Howe stated that while New York State is facing a deficit and there would be some cuts in OMRDD-funded programs, she pledged that many of the initiatives started during her tenure as Commissioner would be continued. Executive Deputy Commissioner, Thomas Maul, explained to the chapters the various proposed funding changes and talked about ways in which chapters should be addressing these cuts.

The Association is very appreciative of both Commissioner Howe and Deputy Commissioner Maul's presence at the meeting and their open and honest dialogue with the Association. ■



OMRDD Commissioner, Elin Howe addressing the Association.



Paul Nigra (Fulton Chapter) seen in the middle pondering the situation. James Wilson (Schuyler chapter - left) and Linda Smith (Dutchess Chapter - right) comfort Paul.



Executive Deputy Commissioner, Thomas Maul responding to a question as only he can.

State Health Department Supports Efforts to Reduce or Prevent Disabilities

The New York State Department of Health's Disability Prevention Program is working with the Health Science Center of the State University of New York (SUNY) at Syracuse and the New York Office of Mental Retardation and Developmental Disabilities (OMRDD) to reduce the incidence of disabilities through better identification of the causes of disabilities and development of preventive interventions.

The SUNY-Syracuse project, "Scholastic Head and Spine Injury Reporting System" (SHASIRS), identifies factors influencing the occurrence of head, neck and spine injuries in school-aged children (grades K-12) throughout 23 school districts in the Onondaga-Madison-Cortland BOCES District. The data being collected includes the types of injuries, the causes, circumstances, severity, medical care provided and the outcomes. Ultimately, this project will serve as a model surveillance and intervention system that could be implemented by other communities.

The OMRDD project identifies secondary conditions in persons with cerebral palsy who are part of OMRDD's client tracking system, "Developmental Disabilities Profile." This project is collecting demographic information as well as information on clients' residences, health characteristics and behavioral indices. The objective of this project is to extend the findings of a comparable study conducted in California which documented the nature and extent of additional complications occurring in this population.

Both projects were established as part of the Disability Prevention Program's mission to improve surveillance of disabilities. The New York State Strategic Plan for the Prevention of Disabilities, currently under review, calls for statewide and community projects, legislation and public education to reduce the incidence and/or severity of injury-related disabilities, developmental disabilities and secondary disabilities.

Seven additional community projects, focusing on areas outlined in the state strategic plan, have recently received funding. Local health departments in Cattaraugus, Cortland, Monroe, Onondaga, Schenectady, Washington and Westchester counties are implementing projects which address: head and spinal cord injuries; burns; lead poisoning; drug and alcohol use during pregnancy; and, prevention of hearing and visual impairments.

For additional information regarding any of the community projects, or the statewide plan, please contact Fran Stevens of the State Health Department's Disability Prevention Program at (518) 474-2018. ■

The Price

by A. Jean Stark

This was written after a public meeting about a home for citizens who are mentally retarded. The "good people" of Owego's Ridgewood development felt offended to have the home in their neighborhood, and that it would detract from property values...

Two hundred thousand dollars high
Those bigots' fists reached toward the sky.
The meager value of their souls
In words of prejudice and hatred told
Of how little love and friendship meant

When compared to what they had spent
On houses built in neighborhoods
Without the blessings of brotherhood.
I have seen them on Sunday morn
All pious, clean, pristine and shorn
Declare their Christianity and faith
Their love of God — Their sins abate.
In church or temple pew they herd
But fail to heed the sacred words
"As ye have done it unto these,
Ye have done it also unto me."
In dreams I've seen a higher plane

A place of welcome — free from pain.
Those who on earth with minds and bodies torn
Who were not to perfection born
Are sheltered here — are given rest.
While those who thought themselves the best
Are asked to face a final hearing
To answer for their arrogance and jeering.
Then the prophecy will come to pass—
"He who would be first, shall be last."

CHAPTER NEWS

SCHUYLER

Officials Visit

New York State Senator John R. Kuhl, Jr. and New York State Assemblyman for the 126th District George H. Winner, Jr. paid a visit to the Schuyler ARC on Wednesday, October 24, 1990.

Both gentlemen met with Schuyler ARC Executive Director, James E. Wilson, who requested the meeting. The meeting's

agenda covered several issues of concern to persons with handicapping conditions. After the 30-minute meeting, the Government Officials were given a tour of the Schuyler ARC's 25,000 square foot facility. Historically both men have been strong supporters of the Association for Retarded Citizens. ■



Assemblyman George Winner, Jr.; Schuyler ARC Executive Director, James Wilson; Glen Industries Employee, Archie Lewis.

CORTLAND

Chapter Athlete's Compete in State Games

The Cortland County ARC was involved in the Unified Sports Tournament last August at St. Bonaventure University. Unified Sports is a segment of the New York State Special Olympics and has a unique concept of matching up people from the community (who are not disabled) with other people from the community who are diagnosed with a disability, combining to form a team and compete with other "like"-teams.

In order to qualify for the state competition, the team had a "bowl-off" with squads from Dryden, Groton and Ithaca for the right to represent Area 17 (Cayuga, Cortland and Tompkins counties).

The adult team won gold medals, while

the youth team earned the silver.

The idea of Unified sports is very attractive to the Chapter as an enhancement to the healthy relationship it needs with their community. It helps with the seemingly never-ending task of realistically educating community members to know that people in our programs are human, able to laugh, cry, bleed (oh, I hope not, more forms!) just like anyone else. Unified Sports helps take the "dis" out of disabled and see the positive instead of the negative!

The Cortland County ARC will also be entering a unified basketball team in the 1991 competition, which will be held in Ithaca this coming June, the 13th through the 16th. ■



Cortland ARC's Unified Sports Bowling Team brings home the gold!

ORANGE

Allstate Foundation Presents Grant to Orange County Association

The Allstate Foundation, which was formed by the Allstate Insurance Company in 1952, recently presented a \$4,500 grant to the Orange County AHRC. This grant represents the Allstate Foundation's commitment to provide financial support to Civic and Community programs, as well as

Education, Health and Human Services, and Arts and Culture. Specifically, the Foundation Committee has agreed to provide these funds in support of providing dental services to individuals in the chapter's programs. ■



L to R: Doug Scott, Unit Claim Manager, Allstate; Fred Lacorte, Market Claim Manager, Allstate; Dominic Catterson, Sr. Staff Claim Representative, Allstate; Stephen McLaughlin, Executive Director, Orange County AHRC and Henry Vriesema, Associate Executive Director, Orange County AHRC.

MADISON

Alternatives Industry Gives Longevity Awards

Seven participants in Alternatives Industry were given awards December 15, 1990 at the Annual Christmas party. This noteworthy recognition was given for 15 years of continued service at Alternatives Industry.

Executive Director, Raymond Lewandowski, and Jack Campbell, Director of Vocational Rehabilitation, held the rapt attention of all 160 people in attendance as they presented awards.

The afternoon culminated with a surprise presentation. The elected members of the Committee for Habilitation and Recreation Training (CHART) took center stage to present their own Recognition Award. These committee members are elected by their peers and work with the CHART Director to help plan and create recreational opportunities. Addressing Raymond Lewandowski, the committee members thanked him for 15 years of dedicated service. Then, each reading a line individually, they presented Lewandowski with a distinctive wall plaque which read, "For Being Our Leader, For Being Our Advocate, For Being Our Friend." ■



Ray with Recipient of 15-Year Longevity Award, Ms. Bethyl Bruen.

NIAGARA

Janitorial Maintenance Expands to Local Businesses

The Janitorial Maintenance Program at Opportunities Unlimited of Niagara has grown to include 12 off-site contracts in the Niagara County community. Ten to 12 individuals with disabilities are employed through these off-site contracts, at locations as varied as Kimmons Environmental Service Corp., the LaSalle YMCA and the Youngstown Yacht Club.

The Opportunities Unlimited janitorial maintenance crew is responsible for a complete maintenance program which may include carpet cleaning, floor stripping and wall washing at the contract sites. The program competes directly with other janitorial service companies in the community by submitting proposals and qualified bids. Competitive prices and qualified workers have enabled the program to grow

from two contracts in late 1989 to the current 12.

The program is looking forward to expansion in the near future. Plans are to secure a major contract that would employ 15 to 20 workers with disabilities. Based on the successes of the past year, the department expects to gain success on a larger scale. The revenue from business generated in 1990 has allowed for the purchase of professional equipment including carpet extractors used for thorough carpet cleaning and high speed floor buffing machines. These purchases combined with the hard work of the workers and production supervisors will enable the program to expand to provide opportunities for other individuals with disabilities not yet working in our community. ■

Major Corporation Supports "Legacy of Love"

For the third year, McDonalds of Cobleskill has provided the Schoharie County ARC with a valuable means of promoting NYSARC Awareness Week. February 1-14, the trayliners used by McDonalds highlight the "Legacy of Love" and facts about Mental Retardation. Children are encouraged to color the trayliners and deposit them into a special decorated box. One colored trayliner is drawn and the winner receives a \$50 savings bond, a Happy Meal and a package of art supplies. Five-year-old Jessica Bradt was this year's winner. All entries then are displayed in McDonalds.

"Our McDonald family always enjoys being a part of another caring family like the Schoharie County ARC." Brian Hanaburgh, owner McDonalds of Cobleskill. ■



Left to right: McDonald's representative, Jessica Bradt and Tony Alvarez.

Pizza Hut Participates in "Legacy of Love"

In February, the Steuben County Chapter donated 10,000 "Mental Retardation Awareness" placemats to the Southern Tier Pizza Hut restaurants to kick off their "Legacy of Love" campaign.

The placemats were used in all Pizza Hut restaurants throughout the Southern Tier as part of their community education program aimed at heightening the public's awareness of the causes and possible prevention of mental retardation and other developmental disabilities.

Tony Lisi, Director of Property Management for the Southern Tier Pizza Hut,

stated, "We want to help businesses and agencies like the Steuben ARC by being a part of the community and giving back to the community what it has given us. We hope, through the use of these placemats, that the public will become aware of the facts associated with mental retardation and the good Steuben ARC is doing throughout Steuben County with their various programs. We feel that ARC is a vital source to Steuben County and through utilization of these programs, they can be great for area companies." ■



Schoharie Board of Supervisors (left to right): Art Graulick, Chair, Board of Supervisors; John Zamjohn and Tony Alvarez.

"Safety is Prevention"

Accidents and mental retardation/developmental disabilities **can be prevented**. The same attitudes, behaviors and practices which eliminate risks, injury and illness on and off the job are essential in preventing mental disabilities. Mental retardation and accidents limit our enjoyment of life and impose severe costs on the family, the employer, society and the individual.

While knowledge of both the causes and ways to prevent mental retardation/developmental disabilities (whether biomedical or result of an accident) has grown tremendously over the past two decades, every day in the United States alone, 700 children are born mentally retarded or will become so before they reach their first birthday.

Metabolic disorders, parent's genetic makeup, environmental contaminants, disease and infections, social conditions such as poverty, substance abuse and inadequate prenatal care, malnutrition, lead poisoning, abuse and neglect and accidents and injuries may result in a lifetime of disability.

It is estimated that 35-50% of all mental retardation/developmental disabilities could be prevented if we applied the knowledge that exists today.

Comprehensive programs including public education, access to health care and the elimination of environmental and safety hazards which cause mental retardation/developmental disabilities could be prevented if we applied the knowledge that exists today.

Exposure to alcohol, use of drugs during pregnancy, lead poisoning, inadequate prenatal care, metabolic disorders, pediatric AIDS, childhood injuries and accidents, reproductive hazards in the workplace and exposure to environmental toxins are just a few of the ways in which our children can become mentally retarded/developmentally disabled.

Many of the accidents and conditions which are the focus of a Workplace Safety and Health Committee clearly serve to produce more motivated, productive employees and prevent mental retardation. The Safety Committee and Prevention Committee are faced with the same tasks:

- Proactive creation of an environment which eliminates exposure to conditions which risk the health of the workforce and its children;
- Dissemination of information on the causes and prevention of accidents and mental retardation;
- Providing programs which affect the health and safety of the employee both on and off the job and,
- Maintaining the involvement, support and interest of the Committee members and the targeted constituencies.

Both the Safety and Prevention Committees operate in the context where apathy and indifference are rife because the adverse affects of many conditions and acts have a low probability. However, the low probability is accompanied by extremely high costs.

Prevention and safety are naturally complimentary and offer a unique opportunity to **all staff** to use their skills, knowledge and abilities to improve the quality of life and reduce the costs associated with losses from accidents and medical care.

We all must do our share in preventing disabilities in future generations. It is not the job of others. It is **everyone's** job. We must begin today if we are to make a difference in tomorrow's children because **TODAY IS TOMORROW**.

Sponsored by

irwin siegel
agency inc.

Rock Hill, N.Y. 12775
914-796-3400
800-622-8272

ASSOCIATION EXAMINES NAME

The original mission of the New York State Association for Retarded Children, Inc. was:

"To assist the mentally retarded in every manner possible including but not limited to education, training, rehabilitation, recreation, and, to the extent now or hereafter permitted by New York law, guardianship; to foster and conduct study and research of the problems, causes and treatment of mental retardation; to encourage and assist individuals, organizations and agencies, both public and private, working with the mentally retarded; to collect and disseminate to members, parents and the public at large information concerning mental retardation; to advise and assist parents of the mentally retarded; and to do everything necessary or desirable to improve the abilities, skills and resources of the mentally retarded and to develop better understanding and opportunities for the mentally retarded in our society; and to raise the funds necessary to achieve these purposes."

Increasingly, over the past several years, we have discussed whether or not calling ourselves an Association for Retarded Children is appropriate. There are various reasons for this concern. First, we serve more adults than children. But, to some, our name suggests that persons with mental retardation are incapable of becoming adults despite their chronological age. Others note that the term "Retarded Children" is out of step with current terminology intended to emphasize that we are all "people first," even though some of us may have mental retardation.

In response to these kinds of concerns, many of our chapters and many ARC's throughout the nation have changed their names. Are we out of step or behind the times? Or, should we leave our name as it has been for the last 42 years? What do you think?

Please take a minute and assist our Ad Hoc Committee to Review the Name of our Association by completing this form. Thank you for your assistance.

1. Does the name of the New York State Association for Retarded Children, Inc. appropriately reflect the purpose and mission of the Association as you understand it to be?

_____ Yes _____ No

2. Should the name of the Association remain the same or do you think there is a need to change the name?

_____ Should remain NYSARC

_____ Should be changed

3. Any other comments you wish to make concerning the name of the Association?

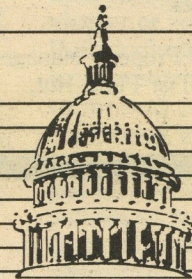
Please return this survey by May 10, 1991 to:
Committee to Review the Name of the Association

NYSARC, Inc.

393 Delaware Avenue
Delmar, New York 12054

GOVERNMENT

In Brief



Published by the New York State Association for Retarded Children, Inc. • (518) 439-8311

Do You Want to Know What's Going On In Developmental Disabilities?

Then subscribe to Government in Brief. It gives you:

- Compelling insight into the event's in Albany. From meetings with top State officials to the inner workings of the Legislature.
- Succinct summaries of news from the nation's Capital, the courts and from around the nation. From the Supreme Court decisions, the Congressional actions on key bills to important developments in other states.

The field of developmental disabilities is remarkably complex. You can't afford not to know what's going on. Nobody else has tried to capture all of the pertinent governmental events in one publication. We have.

Government in Brief is an invaluable means of tracking news of importance to every parent, advocate, provider and interested person.

Government in Brief
Subscription Request Form
Subscription Rate: \$35.00 Annually/12 Issues

Name: _____

Address: _____

Please return with your check for \$35.00 to:

NYSARC, Inc.
393 Delaware Avenue
Delmar, New York 12054
ATTN: Barbara J. Demick

Budget Alert!

NYSARC Reporting...

MARCH 7, 1991

A PUBLICATION OF THE NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

FAMILY SUPPORT SERVICES CUTS ARE WORSE THAN YOU THINK! Our information indicates that most people think that the Governor's proposed \$14 million reduction in the Family Support Services line item was the only cut to services to families. **NOT TRUE.** There are other line items in the budget that support families. These are being cut also, to the tune of nearly \$10 million more.

These line items fund full-time day services to adults. Among other programs they include day training, supported work, recreation and sheltered workshops. All are lumped under the heading "Local Assistance Programs" or "Net Deficit Programs." Local Assistance also funds many Family Support Services programs throughout the State.

If cuts against Local Assistance stand, up to 4,000 persons will lose services. Many of them will go back home on a full-time basis. Remember, they are adults and they will return to aged parents who have lost their ability to provide intensive, full-time care. This will be a disaster.

WHAT CAN YOU DO? Many of you have already been writing letters to your State Legislators about Family Support cuts. But most of you have probably not mentioned Local Assistance cuts which also severely impact families.

WRITE MORE LETTERS to your State Legislators. Tell them that there are cuts to services like sheltered workshops, supported work, recreation, day training and other family supports funded in Local Assistance Programs that will severely impact families. Tell them to restore these cuts in addition to other Family Support Services cuts.

ALSO, send copies of your letters and make calls to the key Legislators listed below:

Senator Nicholas Spano
Chairman, Senate Mental Health Committee
Room 817, Legislative Office Building
Albany, New York 12247
(518) 455-2231 / (914) 969-5194

Assemblywoman Elizabeth Connelly
Chairwoman, Assembly Mental Health Committee
Room 826, Legislative Office Building
Albany, New York 12248
(518) 455-4677

Senator Tarky Lombardi
Chairman, Senate Finance Committee
Room 913, Legislative Office Building
Albany, New York 12247
(518) 445-3511 / (315) 428-4265

Assemblyman Saul Weprin
Chairman, Ways and Means Committee
Room 526, Legislative Office Building
Albany, New York 12248
(518) 455-3851

FOR MORE INFORMATION call the New York State Association for Retarded Children, Inc. at (518) 439-8311.

Governor Recognized Work of NYSARC Chapters

For the 5th consecutive year, Governor Cuomo, through a gubernatorial proclamation, designated the week of February 7-14, 1991 as "Mental Retardation Awareness Week", better known as "Legacy of Love."

Reaching out to the general public to help them understand and accept citizens with mental retardation has been an important role of the Association for the past 42 years.

This year, "Legacy of Love" activities were planned throughout the State by local chapters. Activities included massive media coverage of chapter programs and services; essay contests for local school children; open houses and agency tours; distribution of information regarding causes and prevention of mental retardation by local merchants; issuance of local county proclamations and special presentations to local dignitaries.

In addition, many chapters sold the 1991 "Legacy of Love" product produced this year by our Cayuga County Chapter. Sales totaled nearly 20,000 bringing in close to \$100,000 to selling chapters who used the money to enhance programs and services such as recreation and family support. ■



Nassau AHRC Garden City auxiliary participate in a public display of the Legacy of Love product.



ASSOCIATION CALENDAR OF EVENTS

APRIL

26-27

Spring Board of
Governors' Meeting
Stouffer Rochester
Plaza Hotel
Rochester, New York

26

Executive Committee
Meeting
Stouffer Rochester
Plaza Hotel
Rochester, New York

Scholarship and
Awards Committee
Stouffer Rochester
Plaza Hotel
Rochester, New York

Adult Services
Committee
Stouffer Rochester
Plaza Hotel
Rochester, New York

MAY

23

Public Information
Committee
Resource Group
Meeting
Syracuse, New York

NEW YORK STATE ASSOCIATION FOR RETARDED CHILDREN, INC.

393 Delaware Avenue
Delmar, New York 12054

Non Profit Org.
U.S. Postage
PAID
Albany, N.Y.
Permit No. 164